

**THE INFLUENCE OF ANTIRETROVIRAL
MEDICATION ON THE LIVES OF CHILDREN IN
BOTSWANA**

by

ESTHER LORATANG MMATLI

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SUPERVISOR: DR CE PRINSLOO

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DECLARATION

I hereby declare that **THE INFLUENCE OF ANTIRETROVIRAL MEDICATION ON THE LIVES OF CHILDREN IN BOTSWANA** is my own work and that all the references that were used or quoted, were indicated and recognised.



30th August 2010

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EL MMATLI

.....
DATE

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ABSTRACT

THE INFLUENCE OF ANTIRETROVIRAL MEDICATION ON THE LIVES OF CHILDREN IN BOTSWANA

Student: EL Mmatli

Supervisor: Dr CE Prinsloo

Department of Social Work and Criminology
University of Pretoria

This study sought to appreciate the influence of antiretroviral medications on the daily lives of children in Botswana. The aim of the study was to explore and gain in-depth understanding of the influence that antiretroviral medications have on the children's lives. The study focused on children receiving services from the Bamalete Lutheran Hospital in Ramotswa, Botswana. It is important to give children an opportunity to have their voices heard as not doing so might present missed opportunities for the various care and support services providers.

The study was qualitative as it sought to come closer to the individual children and get their own personal perspective of the influence of medication on their lives. The phenomenological strategy was applied to derive the description from each participant.

Although the study was mainly applied as hoping to add a dimension of the meaning of antiretroviral medication from the children's perspective which would facilitate improvements on service delivery; it can also be seen to contribute toward the body of knowledge as there are limited literature resources in this area.

The sampling method used in this study was purposive in order to ensure a variety of responses and an enriched understanding of how the participants perceived the influence of these medications. A few broad areas of discussion were developed to facilitate the one-to-one unstructured interview.

The conclusion from this study is that children do have stories to share in terms of how they perceive the influence of antiretroviral medications in their lives. These stories need to be explored and understood to facilitate better targeted care and support services for them. The stories from the sixteen children interviewed in this study are herein reported as well as the conclusions and recommendations that followed them.

The general theme from listening to the stories of the children is that children understand that they have to take the medications and that it helps to improve their health.

KEY WORDS

- HIV
- AIDS
- Children
- Antiretroviral
- Medication
- Influence

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CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) arrived on the world scene without warning. A mere two decades ago it was unknown. Today HIV and AIDS cover Africa in dark clouds of fear, uncertainty and suffering. The virus has destroyed the innocent hopes, desires and plans of countless numbers of people whose lives have been cut short by an unseen enemy. For those living in Africa, it is a human catastrophe from which no single one in the region will be exempt because HIV and AIDS affect all (Van Dyk, 2001:iii).

The global statistical picture as presented by the World Health Organization (WHO) and UNAIDS has over the years indicated the extent of HIV and AIDS. Statistics from 2004 to 2007 indicate as follows: Estimates for people living with HIV as of end of 2004 stood at 39.4 million. The new infections for the same year stood at 4.9 million and the AIDS deaths were 3.1 million. A closer look at what the new infections actually meant is that about 14 000 new infections occurred daily. Amongst these new infections 2 000 were in children under the age of 15 years. Regionally, all these infection rates are not evenly distributed; Sub-Saharan Africa is the hardest hit with 25.4 million of those infected found in the region (Uniting the world against AIDS, 2006). Another look at the latest statistical release still places Sub-Saharan Africa in the same position of being the most affected: "Sub-Saharan Africa has just over 10% of the world's population, but is home to more than 60% of all people living with HIV – 25.8 million" (Uniting the world against AIDS, 2006).

As for the year 2007, the estimated number of people living with HIV stood at 33 million, of which 2 million were said to be children under the age of 15 years. In

terms of new infections for the year 2007, a total of 2.7 million people got the infection, 370 000 of whom were children under the age of 15 years. In terms of regional distributions of the HIV prevalence rate, the trends of earlier years are still maintained; for instance, Sub-Saharan Africa is still the hardest hit. Sub-Saharan Africa has 22 million of the 33 million people living with the virus and 1.9 million of the 2.7 million new infections as well as 1.5 million of the 2 million AIDS related deaths in the year 2007 (UNAIDS, July 2008).

The global HIV and AIDS situation indicates how the epidemic has affected the entire human race and specifically the Sub-Saharan region of which the country of Botswana is a part. Botswana is one of the hardest hit in terms of HIV infection prevalence rates, coming second in the world after Swaziland (HIV/AIDS in Botswana, 2006). In addition, data coming from the 2005 Second Generation HIV/AIDS Surveillance indicates that the prevalence rate among women aged 15-49 years stands at 33.6%. According to Van Dyk (2001:iii), "... never before in the history of the human race has one disease presented so many challenges and brought about so many unanticipated changes." In an attempt to address these challenges the Botswana government has engaged in a number of efforts. Some of these efforts include a national coordinating agency, numerous domestic and international partnerships, efforts on provision of public education and awareness, education for young people, condom distribution, voluntary counselling and testing, antiretroviral therapy, targeting of high mobile populations, reducing stigma, training health workers, and preventing further mother to child transmission (HIV/AIDS in Botswana, 2006).

Part of the efforts indicated above is the provision of antiretroviral medications. The introduction of highly active antiretroviral therapy to qualifying persons in selected public hospitals in January 2002 was another "first" in Sub-Saharan Africa (Ministry of Health Botswana Guidelines on Anti-Retroviral Treatment 2005 Version). This implies that those infected have to depend on antiretroviral medications for as long as they are alive.

According to *Antiretroviral drugs* (2006), antiretroviral drugs are medications for the treatment of infection by retroviruses, primarily HIV. Different classes of antiretroviral drugs act at different stages of the HIV life cycle. A combination of several (typically three or four) antiretroviral drugs is known as Highly Active Antiretroviral Therapy (HAART). These medications are prescribed to control the replication of HIV in the human system, thereby prolonging and enhancing the quality of the infected person's life.

The use of life long medications has often been an issue of interest and challenge for both health service providers and those on such medications (Van Dyk, 2001:68). This research project therefore endeavoured to explore and gain understanding on how children cope with the influence of antiretroviral medications as a life long medication. In addition, an investigation of how they are coping with the medications was carried out.

According to the above statistics children are not bystanders in the epidemic. They are fully involved in a number of different ways: some as care givers to adults who are sick, others as guardians for their younger siblings after the death of parents and some as infected persons themselves (Van Dyk, 2001:265). In addition, the UNAIDS indicates that every minute of every day, a child under the age of 15 becomes infected with HIV. Ninety percent of the more than 5 million children who have been infected were born in Africa (Uniting the world against AIDS, 2006). The outcome of this study will therefore, add the voice of the children themselves as they shared the influence that antiretroviral medications have in their personal lives. *The Circles of Support Manual* (2007:20) stipulates the value of involving children in issues that affect them as follows:

There are many reasons why children and young people should participate in activities that affect them. In many societies however children's voices are rarely heard and they have little opportunity to participate. Adults often take decisions without talking to them. Children and young people may participate at different levels, from being given information to full partnership. Appropriate types of participation will depend on the child's age and circumstances.

The researcher's interest in this subject area stems from her natural interest in working with children. This interest has further been enhanced by fulfilling experiences enjoyed during hospital work experience. During the eight years (1995-2003) of hospital work the researcher has always found children to be fascinating – particularly their sincerity and honesty in terms of relations.

Furthermore, Kgosi (2008) indicates that in her work experience children do have stories to share about their life on antiretroviral medication. She indicated that the children's stories vary and they include the following:

- Some children wonder why they need to take the medications.
- Some children are still young and they fail to appreciate the importance of taking their medication. They will go out playing all day and their guardians will need to be all over looking for them in order to get them to take their medications on time.
- Some of the children are angry at their parents for having them when they knew they were infected with HIV. They feel that their parents should have not fallen pregnant since they were aware that there is a possibility of passing the virus to them.
- Some children believe so much in the medication that they adhere to them and they are not bothered by anything including their diagnosis. Those children tend to do very well on the medications.
- Yet some children wish they could be attended to only as children in their own clinic where they could be given the due attention. They feel this would help since they would not have to miss school the whole day while they come for medical attention.

1.2 RESEARCH PROBLEM

A research problem refers to the identification or focusing of the study in a specific direction. It is about understanding “what” about the topic is one

interested in. In addition, problem formulation is also referred to as the problem-definition phase in a study (Fouché & De Vos, 2005:100).

Mouton (2001:48) describes formulating a research problem as transforming an interesting research idea into a feasible and researchable problem. This research project is therefore interested in transforming the idea of the influence of antiretroviral medication on the lives of people to what the children themselves are saying about life on the medications. The view being followed is influenced by the notion that the one way to find out the impact of a phenomenon is to find out from the person it has affected directly (Leedy & Ormrod, 2001:153).

In addition, UNAIDS (1999:27) says that young people are increasingly being appreciated as a resource for changing the course of the epidemic. Several lessons have been learned over the past years that can be applied to planning effective actions to focus more on young people in the HIV epidemic. Priority actions to be considered in the light of situation and response analysis in various countries, and feedback from youth organisations and young people include:

- Promoting young people's genuine participation in expanding national responses to HIV/AIDS
- Mobilising parents, policy-makers, media, and religious organisations to influence public opinions and policies with regard to HIV/AIDS and young people
- Expanding access to youth-friendly health services including HIV and STD prevention, testing and counselling, and care and support services
- Ensuring care and support of young people living with HIV/AIDS

This study therefore, sought to establish the voice of the children in relation with the influence of ARV in their daily lives. The perspective of the study was that the children, silent as they may be; have their own experiences and interpretation of issues. These experiences and interpretations of issues by the children can add value in the care and support by guardians and health care providers if the

children are given an opportunity to express them. In addition, the lack of research on the area of children and ART (Children's rights, 2006) may result in inefficient adaptation by various health care providers as they treat children with HIV or AIDS. In other words, the presumption may be that whatever mechanisms or systems used for adults would also work for children, which may not necessarily be the case. Finally, since the voices of the children are silent, and we do not know what they are experiencing, care and support services providers could be having a number of missed opportunities in the care and support of children which would otherwise enhance the functioning of our systems.

1.3 GOALS AND OBJECTIVES

The term goal, purpose and aim are often used interchangeably. They convey a broader meaning of what is hoped to be achieved at the end or on a long term basis (Marlow, 2001:65). Objectives on the other hand, are short term and are more concrete, measurable and more speedily attainable (Fouché & De Vos, 2005:104-105). For this study the goal was: **To explore the influence of antiretroviral medications on the lives of children in Botswana.**

The objectives were as follows:

- To do an in-depth exploration into the influence of antiretroviral medications on the lives of children in Botswana.
- To describe the influence of antiretroviral medications on the lives of children.
- To draw conclusions from the in-depth study and the literature review and make recommendations on the basis of patterns that might present themselves in the stories of the children. These recommendations will be made to various stakeholders involved with the care of these children (such as the various professionals and the guardians of the children); as well as any one interested in child welfare issues. This information may help to improve on the services provided for these children.

1.4 RESEARCH QUESTION

According to Leedy and Ormrod (2001:60) research questions provide another means for guiding and directing a researcher's thinking and is more common in qualitative studies. Fouché (2005:117) indicates that: "An exploratory study using qualitative methods usually does not have a precisely delimited problem statement or precise hypothesis. One purpose of qualitative methods is to discover important questions, processes and relationships and not test them". This therefore implies that since this project was clearly intending to explore the influence that the medications have on the children, the issue of having a problem statement or a hypothesis did not arise. A research question was more relevant for this project.

The question generated by this research problem therefore was: **What is the influence of antiretroviral medication on the lives of children in Botswana?**

The methodology to address this question was an unstructured one-to-one interview with the children receiving services from the Bamalete Lutheran Hospital. The choice of methodology in this study was influenced by Karugaba (2006:23) who quotes Fontana and Fray (1994) as well as Brink and Woods (1998) who assert that when the objective is to explore what people feel or think, the easiest and most effective way is to ask the person directly.

1.5 RESEARCH APPROACH

According to Marlow (2001:208), Neuman (2003:16) and Fouché and Delport (2005:73-75) there are basically two main approaches to research, namely the qualitative and the quantitative approach. The qualitative approach is more subjective and comes closer to the subjects since the researcher attempts to gain a first-hand holistic understanding of a phenomenon, whereas the quantitative approach is more remote (in terms of relating with participants) as

the researcher is only an objective observer whose involvement with a phenomenon being studied is limited to what is required to obtain necessary data (Fouché & Delport, 2005:73-74).

This project followed the qualitative research approach, as it was perceived to be the most appropriate. By nature of the title, the aim and objectives of the study, there was a clear intent to focus on interactive processes since the researcher was in direct contact with the children. The researcher's view of this project is in agreement with Fouché and Delport. (2005:80) who indicate that "...it is important that the researcher ignores his bias to the one or the other if the topic does not lend itself to a certain approach." Although a mixture of the qualitative and the quantitative approach is often desirable it may not always be possible since the topic itself may dictate otherwise. This project was therefore qualitative in approach and provides a subjective view as it sought to find out the influence of antiretroviral medication (ARVs) on the lives of each of the participants. Since each respondent was talking from their own perspective it was not easy to make broad generalisations at the end of the study. However, there were patterns and themes that presented themselves and they were noted and reported.

1.6 TYPE OF RESEARCH

The type of research in this study was applied. There are two types of research namely basic and applied research (Neuman, 2003:21-28). Fouché and De Vos (2005:105) differentiate between basic and applied research in the following way:

Basic or pure research seeks empirical observations that can be used to formulate or refine theory. It is not concerned with solving the immediate problems of the discipline, but rather with extending the knowledge base of the discipline. Applied research, on the other hand, most often is the scientific planning of induced change in a troublesome situation.

Although the major aims or focuses of these types seem distinct, they still can have an impact on each other and complement each other. For instance, where

a researcher may intend to address an identified problem the outcomes of their scientific planning may also enhance or refine an existing theory.

For purposes of this project, the inclination is towards applied research. The researcher is hoping to add a dimension of the meaning of life on ARVs for children, although it is not attempting to deal with any specific identified problem in the field. The outcome of this study is also applied research in the sense that it is focusing on a specific service area. It is also not intended to address any already established theory which is typical of basic research. Therefore, this project is mainly applied research in the sense that its outcome may come in handy for various service providers as well as the children in terms of enhancing the quality of service they are provided with at the clinic. The project has given the children an opportunity to express themselves and share their challenges; which will help the service providers to re-look their service provision and see how they may improve.

1.7 DEFINITION OF KEY CONCEPTS

1.7.1 ANTIRETROVIRAL

Antiretroviral is medication/drugs given for controlling the HIV disease (Botswana Guidelines on Anti-Retroviral Treatment, 2005:3). Antiretroviral drug (Wikipedia, 2007) states that; antiretroviral are medications for the treatment of infection by retroviruses, primarily HIV. Antiretroviral in this research project will be used to refer to the drugs given to persons infected with HIV to help with controlling HIV disease progression.

1.7.2 AIDS

AIDS is the Acquired Immune Deficiency Syndrome (Van Dyk, 2001:iii). According to the *Botswana Prevention of Mother to Child transmission (PMTCT)*

of *HIV Programme – Presentation Booklet* (2006:4), AIDS is a syndrome or group of infections that attack the body when the immune system is weak. AIDS in the researcher's view refers to a collection of diseases and conditions that one suffers from due to the fact that they are infected with HIV and are at a point where their immune system is quite compromised and inactive allowing easy access for other infections.

1.7.3 HIV

HIV is the Human Immunodeficiency Virus (Van Dyk, 2001: iii). *The Botswana Prevention of Mother to Child transmission (PMTCT) of HIV Programme – Presentation Booklet* (2006:4) indicates the same definition as above but also states that “HIV is a virus that attacks the immune system of people it infects”. HIV according to the researcher is the virus which only survives within the human body and destroys the infected person's immune system, rendering it helpless against other infections.

1.7.4 CHILD

A child (plural: Children) is primarily a boy or girl who has not reached puberty. However, some youth reach puberty earlier or later than expected. It is because of this, as well as the varying degrees of mental development, that a youth is often defined as a child by either psychological or chronological age rather than biological. The term also refers to offspring of any age; adults remain the children of their parents, no matter what their age (Child – Wikipedia 2007). According to the *Chambers Adult Learners' dictionary* (2005:103), a child is a young human being; a son or a daughter. A child, according to Children's Act No. 38 of 2005, “means a person under the age of 18 years.” A child in this research project will refer to anyone between the ages of nine and eighteen who is receiving HIV care services from the Bamalete Lutheran Hospital ARV Clinic.

1.7.5 INFLUENCE

“Influence is the power to affect, take over control or manipulate something or someone” (Influence – Wikipedia 2008). According to the *Chambers Adult Learner’s Dictionary* (2005:292) influence is the power to affect other people or things, an influence is someone or something that has an effect on other people or things. Influence in this research project will refer to the impact or the effects that antiretroviral medications has on the lives of children at the Bamalete Lutheran Hospital ARV Clinic.

1.8 LIMITATIONS OF THE STUDY

- The process of obtaining permission to conduct this study was lengthy and time consuming.
- The Bamalete Lutheran Hospital (BLH) Paediatric ARV Clinic’s age cut off point is 12 years whereas the study wished also to hear from children up to 18 years. This has therefore led to a situation where some of the ages were under represented as indicated below.

Table 1: Representation of ages of participants

Age in years	Number of Participants
9	3
10	1
11	3
12	1
13	1
14	2
15	1
16	2
17	1
18	1
Total	16

- In addition, this being a qualitative study with only 16 participants interviewed implies that the findings can not really be generalised to the

entire population of children on ARVs in Botswana; due to the small sample size. This is however in accordance with a qualitative study where the aim is not to generalise.

1.9 CHAPTERS OF THE REPORT

This report has four chapters. Each chapter has its own area of focus, the chapters are as follows:

- Chapter 1 is the introduction to the study which provides an overview of what the research study is all about.
- Chapter 2 provides the empirical findings in all its details – in order to ensure clarity to all the readers.
- Chapter 3 focuses on literature review, the reason being that the thorough review was conducted after the data collection to ensure that the biases from literature is avoided during the course of the study (since this is a phenomenological study).
- Chapter 4 discusses the conclusions and recommendations from the study.

CHAPTER TWO

THE EMPIRICAL STUDY

2.1 METHODOLOGY

2.1.1 RESEARCH DESIGN

The research design that was followed in this study amongst the qualitative designs was the phenomenological design. The design implies getting to understand and interpret the meaning of a given phenomenon that subjects attach to their everyday lives. This is the kind of study that describes the meaning and experiences of a phenomenon, topic or concept for various individuals (Fouché, 2005:270). In this research study, the researcher sought to understand and interpret the influence that antiretroviral drugs have on the participants' lives.

2.1.2 METHOD OF DATA COLLECTION

The method of data collection that was put to use in this project was that of an interview. Greeff (2005:287) quotes Seidman (1998) as saying that a researcher interviews due to an interest in other people's stories. This data collection method is the most suitable to this project by virtue of it being a qualitative study: "Interviewing is the predominant mode of data or information collection in qualitative research" (Greeff, 2005:287).

The type of interview that was put to use in this project is the one-on-one unstructured interview. According to Dawson (2002:27) unstructured or in-depth interviews are sometimes called life history interviews. In this type of interview, the researcher attempts to achieve a holistic understanding of the interviewees' point of view or situation. With the unstructured interview the participant is free to talk about what he or she deems important, with little directional influence from the researcher. In addition, Baker (2003:220) states: "The less structured the

interview the more valid the data as the respondent has more and more freedom to express precisely how they think and feel about a topic being discussed.” In the researcher’s view, the unstructured interview was the most appropriate since it allowed each participant the freedom to express the influence the medications have had in their own life without having to fit it in any specified manner.

A few broad themes in question form were used to guide the interview process. The use of these questions was helpful especially in the sense that the participants were children and therefore needed more guidance. During the course of the interviews the researcher also used a tape recorder to record the interview proceedings, and took brief notes both during and after the interviews. The notes were written soon after completing the interview while the data was still fresh in memory (Dawson, 2002:67; Neuman, 2003:384). This also helped work towards the preliminary data analysis process, as in qualitative research it is difficult to treat them as independent and separate processes, since they work hand in hand (De Vos, 2005:335).

2.1.3 POPULATION, SAMPLE AND SAMPLING METHOD

The population for the study is children between the ages of nine and eighteen, receiving services from the Bamalete Lutheran Hospital. These in terms of child development are by virtue of their ages, at an advanced language capacity and can therefore communicate more fluently. According to Joubert, Bauling and Le Roux (2005:13)

Language and vocabulary increase rapidly and emotions can be named. Sentences of increasing length and complexity, as well as more advanced grammar (e.g. passive form) can be used and understood. Metaphor, irony and humour in wordplay can be understood. In addition, rehearsal and other memory strategies are used to transfer information from working memory, a temporary store of information, to long-term memory.

In addition, Karugaba (2006:21) indicates in her study that “During the pilot test phase it was realised that it is children nine years and older who were able to recall and articulate their experiences and also endure a 30 to 35 minutes face to face interview with the investigators.”

In this research project the sample size took into consideration the following; the purpose of the project (a small scale project – mini-dissertation), the limitations of time (project cannot go on indefinitely), the homogeneous nature of participants (children receiving HIV care services from the same health facility and also the fact that the service has only been offered as from 2004 and therefore their experiences are unlikely to be so varied in terms of time). This is also as guided by Neuman (2003:232), who indicates that “a researcher’s decision about the best sample size depends on three things: (1) the degree of accuracy required, (2) the degree of variability or diversity in the population, and (3) the number of different variables examined simultaneously in data analysis”. In addition, by virtue of the research approach to be used (qualitative) where an in-depth consideration of each participant’s situation is sought, as well as the fact that the participants had a choice to participate in the study or not to; it was therefore decided that a sample size of 16 participants was reasonable. Leedy and Ormrod (2001:153) also indicate that in a phenomenological study, a typical sample size is from 5 to 25 individuals, all of whom have had direct experience with the phenomenon being studied.

The sampling technique that was used here was purposive sampling. This sampling technique looks for a sample composing of elements that contain the most characteristic, representative or typical attributes of the population (Strydom, 2005a:202). Leedy and Ormrod (2001:219) indicate that in purposive sampling people or units are chosen, as the name implies for a particular purpose. For instance, people may be chosen because they are typical of a group or they represent diverse perspectives on an issue. The criterion that was

used in this study to ensure a high likelihood of possible diverse stories from the participants was as follows:

- Both males and females,
- The different ages between 9 and 18 years; a participant from all the ages between 9 and 18 was interviewed and only a few ages had more than one participant. These ages were purely on the basis of them consenting to be interviewed.
- Children who have been on the medication for different numbers of years (1, 2, 3 and 4). Those who became participants however did so, on the basis of consent given by their guardians.

2.1.4 PILOT STUDY

According to Leedy and Ormrod (2001:196), a pilot study is carried out to iron out any wrinkles in identifying and classifying the behaviour(s) under investigation. They also perceive conducting a pilot study as a must since embarking on a fully-fledged study without piloting first may result in many hours of wasted time. Greeff (2005:294) mentions that carrying out a piloting exercise enables researchers to get an idea of some of the practical aspects of establishing access, making contact and conducting the interview, as well as becoming alert to their own level of interviewing skills.

A pilot test was carried out to enable the researcher to check for the feasibility of this project in terms of acceptability on the part of participants to participate on the project. This was of significant importance to this project in the sense that the participants are children and therefore someone else has to give consent on their behalf. The resources used during this pilot phase such as time spent with every respondent, and availability and willingness of participants to participate gave the researcher an idea as to whether the research project was feasible or not (Greeff, 2005:294).

The process of getting participants was through seeking permission from the Botswana Ministry of Health Research Division who, after reviewing the University of Pretoria approved research proposal, gave permission for the study to be carried out. Following the letter of permission granted by the ministry the researcher submitted the relevant documents to the Bamalete Lutheran Hospital management who also accepted the request and handed it over to the Antiretroviral Clinic Management where the study was conducted.

In this research project, there was no pilot test of the interview because the data collection method is that of an in-depth interview. According to Collins (1998:3, 5) as quoted by Greeff (2005:293) “interviews are social interactions in which meaning is necessarily negotiated between a number of selves. The relationship between the researcher and the participant is fluid and changing, but is always jointly constructed”. This therefore to the researcher implies that with the use of the unstructured interview each participant will have a unique relationship with the researcher rendering the use of piloting the interview unnecessary. This therefore implies that piloting was carried out only to check for the acceptability to participate in the study by potential participants and their guardians.

2.2 ETHICAL ISSUES

According to Strydom (2005b:57) ethics is:

A set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.

A number of authors, namely Leedy and Ormrod (2001:107) and Strydom, (2005b:56) are in agreement concerning the need for ethical considerations in research involving human subjects. The following ethical issues were viable for consideration in this project.

2.2.1 AVOIDANCE OF HARM

Researchers should not expose respondents or their participants to undue physical or psychological harm. The guidance is that the risk involved in participating in research should not be appreciably greater than the normal day to day living (Leedy & Ormrod, 2001:107). In this research project there was no overt form of physical harm that participants were exposed to. However, since the possibility of evoking some level of emotional discomfort is difficult to predict or rule out (Strydom, 2005b:59), precautions were taken (in the form of avoiding involvement of potential participants who seem emotionally unstable or not sure if they want to participate in the study) to prevent any emotional harm. But in the event that there was evidence of such discomfort to the subjects, given the nature of this study as seeking in-depth experiences from them, participants could have been referred for the psychosocial support available within the clinic.

2.2.2 INFORMED CONSENT

As far as informed consent is concerned, Dawson (2002:148) states as follows:

I believe researchers should be open and honest about who they are and what they are doing. People can then make a choice about whether they take part in a project. It is their prerogative to refuse – no body should be forced, bullied or cajoled into doing something they don't want to do.

Strydom (2005b:59) is of the following opinion: “Nobody should ever be coerced into participating in a research project, because participation must always be voluntary”. He also quotes a number of authors (Babbie, 2001; Neuman, 2003; Thomas & Smith, 2003) who call informed consent “voluntary participation”. Subjects can only be said to be voluntarily participating if they are fully informed of the nature, purposes of the study, possible advantages and disadvantages. In the case of this research project therefore, since the focus is on children, not only were efforts made to facilitate informed consent focusing on the subjects (children) but also on their parents/guardians as they were the ones with the

capacity to consent or descent. Both were therefore provided with information on the intent of the project and given an opportunity to choose either to be or not to be involved. The parents or guardians gave consent and the children gave assent. In addition, the participants could withdraw at any time. Both the children and their guardians were given the consent forms written in both English and Setswana for them to decide if they want to participate in the study or not.

2.2.3 DECEPTION OF SUBJECTS AND OR PARTICIPANTS

Loewenberg and Dolgoff (1988) as quoted by Strydom (2005b:60) describe this situation as “...deliberately misrepresenting facts in order to make another person believe what is not true violating the respect to which every person is entitled”. This may be done in any of the following forms: hiding the real function of the actions of the subjects, hiding the experiences that subjects will go through or disguising the real goal of the study. In this project, participants were provided with the real goal behind undertaking this study, the whole process that followed both orally and in written form. There were consent forms signed by the parents/guardians and children before participation in the study.

2.2.4 VIOLATION OF PRIVACY/ ANONYMITY/CONFIDENTIALITY

Privacy, anonymity and confidentiality are all related concepts that have to do with the individual's personal rights. According to Strydom (2005b:61) individuals normally decide when, to whom and to what extent their attitudes, beliefs and behaviour will be revealed. The practice of social research however mainly survives on some degree of encroachment upon the privacy of subjects. Strydom (2005b:63) therefore feels that there is need to negotiate with participants, respectively request their cooperation and carefully explain the research's importance. The participant's refusal of consent must also be accepted and respected. Walsh (2001:72) also emphasizes the same principle as he indicates that all research participants have a right to privacy. This according to him

includes the right to withdraw from the research investigation at any point if they wish to, the right to refuse to answer any question asked and the right to remain anonymous and to have the confidentiality of their data protected.

For purposes of this research project as an exploratory endeavour on the influence of antiretroviral medication on the lives of individuals, the principle of confidentiality will be jealously upheld. Personal details of the participants are not revealed in this report, although known to the researcher. As part of the consenting process, participants were informed of the researcher's intent to use an audio tape as a medium of data collection and assured that no personal information will be discussed with others not involved in the research study. All particulars are thus handled confidentially.

2.2.5 ACTION AND COMPETENCE OF RESEARCHERS

The concern here is on the researcher's skills and conduct of research work. According to Strydom (2005b:63), "Researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed investigation". In addition, the researcher is ethically bound to be scientific, to report correctly on the analysis of data and the results of the study.

For purposes of this project the researcher adhered to the scientific principles of scientific investigation and also depended on the guidance and skills of the supervisor as a more experienced and skilled resource available to her. The involvement of the supervisor was through consultations. There is also an overt intent on the part of the researcher to be non-judgemental and to uphold all the professional principles of the helping professions, as has been the practice of the researcher as moulded by the training in research methods and direct social work practice experience.

2.2.6 COOPERATION WITH CONTRIBUTORS

The ethical issues here relate to situations where a researcher has a collaborative effort with others whether financially (as sponsors of the project) or colleagues (who may be formally or informally involved) (Strydom, 2005b:64).

For purposes of this project there was no researcher-sponsor relations, since this is only taken on a small scale as an academic requirement. In terms of fellow professionals' involvement, this was at the level of assisting with the selection of participants. These were clinic staff members who are already involved with the care of the research project's potential participants. The expectation for their involvement was explained and they were also provided with copies of the consent form and the interview schedule to facilitate their appreciation of what their clients are going to be exposed to. The researcher also cooperated with the clinic staff by giving them the criteria of participants needed and heeding to their guidance on clinic operational procedures.

2.2.7 RELEASE OF PUBLICATION OF THE FINDINGS

Dane (1990) in Strydom (2005b:65) indicates that report writing is about ensuring that the report is as clear as possible, containing all the information necessary for readers to understand what has been written. The researcher is obliged to ensure that the investigations proceed correctly and that no one is deceived by the findings. In addition, Wagenaar and Babbie (2004:41) indicate that "ethical obligations to colleagues dictate accurate reporting of shortcomings and negative findings in a study. Also social scientists should not identify accidental findings as the product of careful hypothesizing and theorizing."

In terms of this project, the researcher has strived to ensure that the final report is accurate, clear, and objective and contains all essential information. The researcher has also constantly sought assistance from the supervisor. These

findings are published in the form of a mini dissertation according to the requirements of the Department of Social Work and Criminology, University of Pretoria. In addition, copies will be submitted to the Botswana Ministry of Health Research Division and the Bamalete Lutheran Hospital. The participants in this study were informed about the issues pertaining to the final report, as guided by Dawson (2002:152) who states that; it is useful for participants to know what is going to happen with the results.

2.2.8 DEBRIEFING OF PARTICIPANTS

Debriefing is carried out for the following reasons:

- To give subjects the opportunity to work through their experiences and their aftermath, and therefore help to minimize possible harm which may have been done in spite of all the precautions the researcher may have taken against such harm.
- To rectify any misconceptions that may have arisen in the minds of participants after completion of the project.
- To ensure sensitivity in withdrawal of therapy in cases where subjects benefited from therapeutic aspects of the research (Strydom, 2005b:67).

For purposes of this project, the researcher conducted the debriefing for the participants and made plans to refer participants if therapeutic intervention seemed necessary. In view of the type of research project this was, namely by virtue of exploring participant's views, which may have been a first encounter for them to get an opportunity to share the influence of antiretroviral medicine on their lives, the researcher perceived it necessary to liaise with the clinic's staff for purposes of ensuring the continuity of care for the participants.

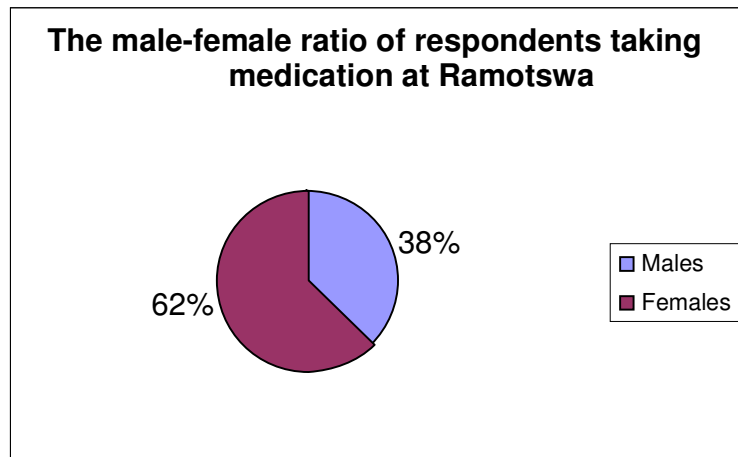
2.3 THE BIO DEMOGRAPHIC DATA OF PARTICIPANTS

Table 2: Bio demographic data of participants (N=16)

Participant	Gender	Age	Educational level	Length of stay on ARV medication
1	Male	16	Form 2	Transferred from Gaborone to Ramotswa in 2004 (more than 4 years)
2	Male	15	Standard 7	Since Standard 5 (2 years)
3	Female	9	Standard 2	Since 2005 (3 years)
4	Male	11	Standard 4	Since 2006 (2 years)
5	Female	11	Standard 6	Around Standard 2 (4 years)
6	Female	10	Standard 3	Since 2007 (1 year)
7	Male	18	Standard 6	Since Standard 2 (4 years)
8	Female	14	Standard 7	Not sure
9	Female	11	Standard 6	Before starting school
10	Female	9	Standard 4	Since Standard 3 (1 year)
11	Female	9	Standard 4	Since standard 1 (3 years)
12	Female	17	Form 3	Not sure
13	Female	14	Form 3	One year
14	Male	13	Standard 7	One year
15	Male	16	Standard 7	Since Standard 4 (3 years)
16	Female	12	Standard 4	Since Standard 2 (2 years)

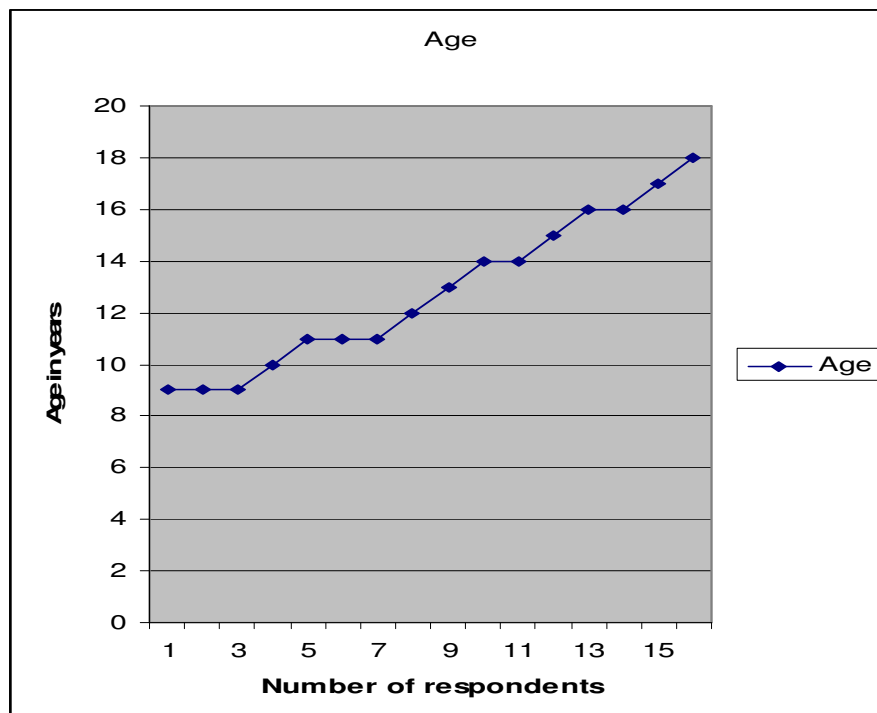
A look at the above table indicates that there were more female than male participants in this study. The ratio of males to females was 6:10. This in percentage form implies that 38% of participants were males while 62% were females. This should not however be understood to mean that there are more females than males receiving services at the Bamalete Lutheran Hospital ARV Paediatric Clinic. It only implies that these, as well as their guardians, responded positively to the request for participation on this study. The male-female ratio is presented below in a pie chart form.

Figure 1: Male-female ratio



In terms of age, all the ages between 9 and 18 years were represented in this study. However, some ages had more than one participant and those were purely on the basis of their availability at the clinic on the days of data collection and their willingness to participate. The chart below summarizes the ages.

Figure 2: Age distribution



As far as the educational level of the participants is concerned, all the participants were schooling at the time of data collection. This the researcher found as a positive point in the sense that the *Ministry of Education's Circles of Support* programme's overall objective is "...to strengthen school/community networks to ensure the provision of basic needs and psychological support to orphans and other vulnerable children (OVC) to enable them to remain in or re-enter the school system, to realize their rights and to fulfil their developmental potential" (Ministry of Education, 2007:6). This therefore, to the researcher, implies that although the participants may be children living with HIV, and therefore vulnerable, they have managed to remain in school. The table below summarizes the level of education for the participants.

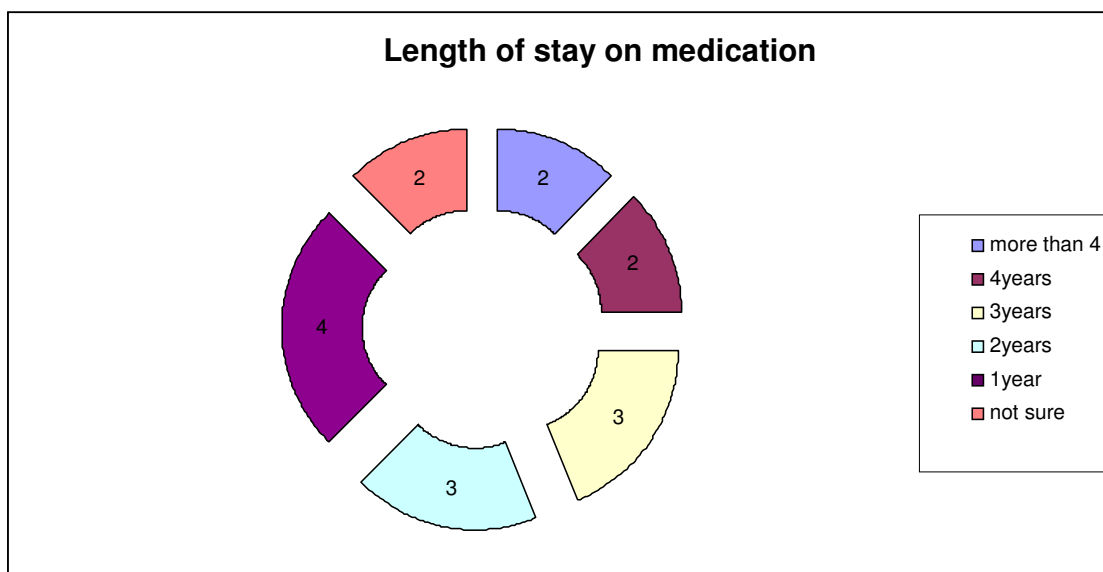
Table 3: Educational level of participants

Education	Number of Participants
Standard 2	1
Standard 3	1
Standard 4	4
Standard 5	0
Standard 6	3
Standard 7	4
Form 2	1
Form 3	2
Total	N=16

The length of stay on the ARV medication also varied amongst the participants. Their length of stay varied between more than four years and one year. Some of the participants had been on the medication for more than four years as they were referred from Gaborone to Ramotswa when the service was initiated at Ramotswa. Most participants remembered when they started taking the medications and they tended to remember that in association with their level of education at the time. Two participants said they were not sure as to how long

they had been on their medication. These participants were however sure that they had been on the medication for more than a year (as the study was intended to cover only those with at least one year of stay on the medication) as stated by both themselves and the hospital staff who assisted the researcher with the selection of the potential participants. The chart below shows the length of stay of participants on the ARV medications.

Figure 3: Length of stay on medication



2.4 QUALITATIVE RESPONSES

The influence of ARV medications on the lives of these children was explored as guided by seven broad areas (as indicated in the interview schedule). The following are therefore the responses to those areas:

2.4.1 QUESTION 1: WHY DO YOU THINK YOU ARE ATTENDING THIS CLINIC?

2.4.1.1 Main theme for question 1: Attending the clinic for health reasons

The participants generally (except for one) had some reason they attached to attending the clinic. The reasoning they had generally, had to do with their health status as some said they were sick or they needed medication or to consult with medical staff. This, in the researcher's view, is positive since if the participants did not have any reason for attending the clinic; it rendered attending the clinic a purposeless activity which can possibly de-motivate them from attending.

The responses to this question were as follows:

- "I am attending so as to consult with medical staff and get some medication"
- "I am taking medication so that I do not get sick"
- "Because I am sick"
- "For check up to prevent opportunistic infections"
- "Because I am sick"
- "I don't know how to respond to this question"
- "Because I am sick"
- "To get medication and advice on the use of such medication"
- "To get help and so we get healthy"
- "To collect medicines and tablets"
- "I come for check up especially that my nose was badly congested/blocked"
- "I am taking medication so that I don't get sick"
- "Because I am seeking help"
- "Because I am sick"
- "My mum sought for help here"

- “I was sick when I was supposed to do standard 1; I had chicken pox”

2.4.2 QUESTION 2: WHAT MEDICATIONS DO YOU GET HERE AT THE CLINIC?

2.4.2.1 Main theme 1 for question 2: No clear idea of type of medication

In terms of the medication that they get at the clinic; participants tended to give a description of the sort of medications they were on and mostly did not give the names of their medication. For instance, of the sixteen participants interviewed, only two said the medication they were on is antiretroviral medication. The implications for this situation could be multiple; for instance, some children may not have an accurate appreciation of their health condition as has been the case in a number of children from the researcher's clinical work experience. In those instances, mostly the guardians were facing skill challenges in terms of how to disclose to the children. This is also evident in that two of the participants said that they were not given an explanation as to why they were taking their medication. One said, “It was not explained to me”, while the other one said, “They did not tell me”.

This matter is also been expounded on by Domek in his view point article published in the *Lancet* (2006:1367-1369) where he states that; the survival of HIV infected children due to ARV treatment has given rise to some concerns, one of these concerns being disclosing to the children that they are HIV infected. He explains that disclosing to the child that they are infected is important because with ARVs they are no longer expected to die in their first few years, and can now reach puberty. He further indicates that as they grow older they now need to know why they are unwell and understand the virus.

To this question the participants gave the following answers:

- “Tax and stock”

- “Tablets”
- “Tablets (3 types), medicines (2 types)”
- “Don’t know the names of the medication”
- “Medication that prevents opportunistic infections”
- “Tablets and medicines”
- “ARV tablets and TB tablets”
- “I have forgotten the names – but my medication is of two types”
- “TB medication, medicines (one in brown bottle, another is white in colour). I also take 3 types of tablets”
- “Brown and white medicines as well as tablets”
- “Brown and white medicines in breakable bottles as well as tablets”
- “2 types of tablets including vitamins”
- “ARV “
- “For the morning and evening”
- “Tablets”
- “Tablets and medicines”

2.4.2.2 Main theme 2 for question 2: Status treated as secret

Some of the implications for this lack of knowledge of the medication by participants could also be due to the fact that some of them treat the whole issue of their health status as a matter of strict secrecy. For instance, during the interviews the following responses were given:

- “My mother told me I should not tell other people about the fact that I take these medications; there is however another girl who lives near our home who is also on the same medication and my mother told us that we could talk about our medication issues together but we should not tell anyone else about it”.

- “There is only one friend who knows about my taking of these medications, and she only came to know because we met here at the clinic when both of us had come for our check up appointments”.
- “One can choose only one friend that they really trust and share with them the fact that they are on these medication”.

2.4.2.3 Sub theme for question 2: Self-protection

Participants who gave such responses as the three stated above could also therefore be acting purely on the basis of self-protection against anybody who appears to be a stranger and seemingly wishing to come too close on this sensitive, private and personal issue. The table below indicates their responses.

Table 4: Type of medication for participants

Type of medication	Number of Participants
Two types of medicines	3
Three types of tablets and two types of medicines	6
tablets	1
For the morning and the evening	1
Helps in preventing ailments	1
I don't know the names	2
ARVs	2
TOTAL	N = 16

2.4.3 QUESTION 3: WHY DO YOU THINK YOU NEED THE MEDICATIONS?

2.4.3.1 Main theme for question 3: Depend on medication for wellness and survival

The responses clearly indicate that the participants generally appreciated their dependence on these medications for both wellness and survival. They generally

thought that they needed the medications for suppressing illnesses and survival. All these responses except for the two, who said it was not explained to them, indicate a central message for all persons once put on ARVs, namely that, with ARVs, adherence to medication is the way to go. Tomeletso (2009:2) indicates that; “the success of the ARV programme is judged based on adherence”. Van Dyk (2007:71) also states:

A patient who wants to take anti-retroviral therapy should be committed and well informed. The patient should be in a position to adhere to a strict medication regimen. This means that they should be able to take two to three tablets two to three times a day (taking some dosages with food and some on an empty stomach).

As for this question, the participants answered as follows:

- “They control viral load/virus”
- “They did not explain why I need this medication”
- “They did not explain why I need this medication”
- “So that I can be treated of my ailments”
- “Because medication helps me not to fall sick”
- “Because I am sick”
- “So that I can survive because currently I am very sick”
- “So that I can be treated of my sickness”
- “I was born with TB infection – information my mother gave me before she passed on”
- “So that I do not get infection. It is said that if one does not take medication, one dies.”
- “To de-congest my nose”
- “To boost my immune system”
- “To suppress sickness”
- “So that I get well”
- “They help me that my sickness will not go up rather it comes down”
- “Because I was sick and my mother took me to the hospital and it is hospital that said I need to take the tablets from this clinic”

2.4.4 QUESTION 4: WHAT DO YOU THINK THESE MEDICATIONS ARE SUPPOSED TO DO?

2.4.4.1 Main themes for question 4: Accurate appreciation that medication cures further illness and helps to cure

Here most participants felt that the medications are supposed to boost their immunity. A number of them directly said that the medications are to boost their immunity. Some also said that the medications are supposed to heal, treat or cure them. There was also a mention of the medications being meant to control the virus and one participant said that they are to help him survive.

The general themes indicated through the responses are:

- The participants have an accurate appreciation of what their medication is supposed to do for them. The researcher regard this as positive since it implies that the service beneficiaries are empowered to look after themselves, as they appear to appreciate what the treatments are supposed to do.
- The participants realise that the medication helps to prevent further illness.
- The participants know that the medication helps to cure/heal them.

Here the responses were as follows:

- “To control viral load”
- “To boost immunity and increase my CD4 count”
- “Medicine is for healing/curing”
- “For healing or treating and this is my hope”
- “Because medication prevents me from falling sick again”
- “They are supposed to work properly to heal or cure me.”
- “So that I can survive because currently I am very sick”
- “To prevent infection as well as to improve immune system”
- “To prevent infection as well as to improve immune system”

- “To prevent infection as well as to improve immune system”
- “They are supposed to heal me, so that my nose will never block again”
- “They are supposed to work properly to heal or cure me, and improve my health status”
- “To suppress”
- “They work on the immune system”
- “They suppress illness”
- “So that one should not be sick, I think they are supposed to cleanse the body”

2.4.5 QUESTION 5: HOW DOES TAKING THE MEDICATION INFLUENCE YOUR LIFE?

The participants were asked to share the influence of the medication in their personal lives. They were asked to share their stories in five spheres of their lives, namely their bodies, school life, life with friends, family and other.

2.4.5.1 Main theme for the influence of the medications on the body: Medication has positive influence and participants are grateful

The participants shared the following in terms of their bodies: They expressed that the medication had good effects or influence on their bodies. Some participants indicated that they experienced discomforts in their bodies which they associated with their medications; one said the medication causes him to have diarrhoea and the other said she sometimes felt like vomiting. One participant said that the influence of the medication on her body is that illnesses are suppressed; she indicated that before taking these medications she used to be sick frequently. The last response given was that the medication is actually what is keeping the participant alive.

In the researcher's view, the bodily influence of these medications on the children is generally positive. This is so in the sense that all, except for two participants with discomforts, indicated that they were experiencing something positive from their medications.

The majority of participants expressed gratitude for the influence that the medication had on their bodies, but it is note worthy to also consider the discomfort that some participants shared. This is specifically important in the sense that such discomforts or side effects could de-motivate adherence to the medication on the part of the children. Van Dyk (2001:71) indicates that; "Current treatments are permanent life-long and it is essential for the patient to adhere strictly to the therapy. Patients often stop treatment because of side effects and this may lead to the development of viral resistance to the drugs".

The main themes from the question were:

- The bodily influence of the medication on the children is generally positive.
- Participants are grateful for the influence of the medication on their bodies.

This confirms the statement made by *Responses to anti HIV treatment* (2008) which says "Thanks to anti HIV treatment many people with HIV are living longer, healthier lives."

2.4.5.2 Sub theme for the influence of the medications on the body: Some bodily discomfort

The medication can cause some bodily discomfort. If it so happens that children on ARVs become de-motivated it would have quite serious implications due to the kind of medication they are on. The implications would not only be personal, as the affected individuals may end up with drug resistant HIV for the drugs they are supposed to be on, but also nationally. Nationally, part of the reason why ARVs are provided is to enable people with HIV to live longer, healthier lives (HIV

& AIDS Botswana, 2009). Therefore these drug resistant issues would defiantly not augur very well for the programme.

For the influence on their bodies, the participants said:

- “Body is okay and immunity boosted”
- “Do not affect”
- “Body is not affected – its okay”
- “I am not well – medication causes diarrhoea”
- “They are making me well”
- “They have good effect- I feel a lot better”
- “Medication treat me well – I used to be unable to play, I was lethargic but now they brought me to a lively status – I no longer feel dizzy I am active and strong, I can run and play football”
- “Sometimes I feel like vomiting”
- “So that I don’t die”
- “I am feeling very well”
- “Body is okay and immunity boosted”
- “It suppresses sickness. Before taking treatment I fell sick often. I could not eat – I had diarrhoea”
- “They make the body to be well /healthy”
- “They help my body because I am not sick any more. I no longer sweat at night and experience fever”
- “They treat me well”

2.4.5.3 Main theme for the influence of the medication on school life: Can continue with school but experience challenging behaviour from other children

The first main theme derived from the responses is that the medication keeps participants well so that they can continue with school. They stated that their medications helped by keeping them well and physically fit to attend school well.

Another main theme is that other children at school posed challenges with regard to them using the specific medication. Some participants said that they were having challenges with classmates. They expressed those challenges as follows:

- “Classmates do not want to play with me, it appears like they know what I am suffering from and this has affected me so much. I have therefore requested to repeat standard 6 in order to join a different class next year”.

The researcher found this quite worrying especially given that this participant is eighteen years of age and still in standard six. The question arises as to at what age he will complete his education and if he ever will, given the Botswana education system which stipulates the age of exit for primary school to be 15 years and for secondary to be at 19 years of age (World Higher Education Database, 2009). The situation of this participant therefore gives the researcher the impression that, given the general age expectations per level of education and the experience that this participant had with his classmates, it may be very difficult for the participant to complete both primary and secondary education. The challenge may come from the system, other children or even from within; he may just feel out of place and decide not to continue.

- “They do not want us to come into contact with their utensils or personal belongings because they think that we will infect them with our illness”.

Further probing with this participant indicated that he personally did experience part of the situation he was describing.

The participants focused on the influence of their medication in their school life and shared the following:

- “Not affected – I get further information on the disease from school”

- “Other students don’t want to use same items with me – they fear that I might infect them”
- “I am able to attend school well because I am better”
- “It is a problem because I can not go to school early – I have to eat first and take medication”
- “They keep me fit and enable me to continue with my studies”
- “Classmates don’t want to play with me. I have asked to repeat to get new classmates who might support me.”
- “They affect my schooling in a positive way. I shall take them even after finishing school”
- “Before I leave for school, I check if I have enough supply, and refill at the clinic if needs be.”
- “They keep me fit and enable me to continue with my studies”
- “They enable me to be fit and go to school”
- “They keep me fit and enable me to continue with my studies “
- “They help me to attend school well because if I were not taking them I would be sick”
- “They help me learn, I am able to be attentive”
- “I attend school well, when its time to come to the clinic we just seek permission from school”
- “They treat me okay”

2.4.5.4 Sub theme for the influence of the medication on school life: Discrimination within the school

There are instances of discrimination within the school setups amongst pupils. This correlates with the study on the *Impact of HIV/AIDS on Primary and Secondary education in Botswana*. According to this study it was revealed that there was little overt discrimination by teachers and pupils. This in the researcher’s view is cause for concern and need to be dealt with. In addition Domek in the *Lancet* (2006:1367-1369) indicates that there is need for increased

attention to education and appropriate disclosure as HIV positive children become healthy enough to attend school. He continues to emphasize that it is important to prepare the teachers and school staff to work with HIV positive students and eliminate stigma in school settings since more and more of them are enabled by ARVs to be in schools.

One participant indicated that she feels that the fact that she has to take her medication at a specific time was a limitation for her. She stated that as a result she cannot go to school early, she has to wait for seven o'clock as she cannot take her medications any time earlier than then.

2.4.5.5 Main theme for the influence of medication on friendships: Receive support but taking the medication causes disturbance during play time

The following themes have been identified:

- Support- Participants generally feel supported by their friends. The researcher perceives this as good thing since friends are usually an important part of one's life. This is particularly important for children due to their desire to want to be part of a group to the point of being easily swayed by peer pressure. (Ministry of Education 2007:20)
- No effect- some participants did not seem to see any relationship or influence of their medication on the friendships they have.
- Disturbance- One participant said that the taking of the medication disturbs her play.
- Disclosure versus secrecy- some participants indicated that their friends are aware that they are on medication and play the role of reminding them to take the medication, advising and accompanying them to go for refills. Other participants however, portray a secrecy stance they only happen to have shared their situation with those who happen to be in the same situation with them. Although this may seem limiting in terms of

mobilizing support towards oneself by these children it is still helpful for them as they give and receive support from others in a similar situation.

Although most participants seem not to have any challenges with their friends in relation to their friendships and play, the participant who feels disturbed needs recognition and appropriate support.

The participants shared the following as for how their medications influenced their lives with friends:

- “You don’t play and forget taking treatment”
- “Friends are supportive – they accompany me to hospital for refills”
- “No problem – I play with friends in a normal way”
- “It disturbs my playing schedule because in between I break to take medication”
- “No problem - most of my friends know I am taking medication/treatment”
- “When medicine time strikes, I leave my friends to go and take medication”
- “No problem”
- “Positively – they accompany me when I go for treatment”
- “They don’t affect my play schedule with friends – in fact friends advise well”
- “When medication time strikes, my friends remind me and I take the medication”
- “Everything is okay with friends”
- “One friend knows and he too is on treatment and we support each other”
- “No problem at all”
- “Just okay”
- “There are no problems; I stop playing at 5pm and go home to do my daily chores and then take my medication at 7pm”

- “Just okay. My mother told me that I should not tell others about my taking of these tablets. However there is another girl who in our neighbourhood who also takes these tablets. We are able to talk about it together.”

2.4.5.6 Main themes for the influence of medication on family: Families provide support

There is a very strong theme of support expressed by the participants. They feel supported and helped by their families. This in the researcher's view is a good thing as it provides the needed environment for people living with HIV as stipulated by Tomeletso (2009:2) who indicates that; “the success of the ARV programme is judged based on adherence created by a supportive environment, quality of care and treatment efficacy.” In addition, Mariba (2009:11) said “....with assistance and love from Debswana, my family and the community I overcome all obstacles and saw light at the end of a dark cold tunnel”.

The issue of the look the participant get from the neighbour, in the researcher's view, can be quite a challenge in relation to the social needs of this child; since while he is keeping in doors for fear of some kind of look he gets from the neighbours, then he misses out on relating with other people as a social being. In addition Van Dyk (2001:272) states that “People infected and affected by HIV need the support of society and not rejection by society.” In this instance therefore it appears that he is not receiving the support he needs, rather he is facing rejection.

One participant said that the family does not want him to visit. He said that they said how could he want to visit when he knows that he is on medication. They seem to believe that it would be unsafe to have him visit since he might end up forgetting to take his medication according to the prescribed schedule. He expressed displeasure over the issue most so that in terms of school trips they allowed him to go. This participant really wished to explore his talent since he

shared that he was very good at traditional dance and wished he could be allowed to join a community group and enjoy himself. This gave the researcher the impression that the family might in good faith be trying to protect the participant, while he does not appreciate it and feels like they are giving double standards; school trips are okay but any other trip is not, while for him all trips are the same.

In relation to the influence of medications with family, the participants indicated that:

- “Not affected at all, since there are other family members suffering from cancer and high blood pressure”
- “My family members don’t want me to visit; they think I might forget to take my treatment. I find it upsetting because if it is a school trip they allow me to participate but for community activities they do not. I am gifted in traditional dance and I am not allowed to enjoy it.”
- “No problem at all”
- “No problem because I have a younger brother who is also on the same treatment, and we share treatment if one runs short of his.”
- “The family is very supportive, especially my grandmother”
- “No problem at all”
- “Family members check if I take medication properly”
- “My family is not affected at all”
- “My life with my family is just okay”
- “The family is just okay, sometimes when my brother and I forget, they discipline with a cane”
- “The family is very supportive, they monitor if I take medication properly”
- “They support me, they come with me to collect my medication from the clinic and they also remind me when it is time for me to take my medication.”
- “In the mornings they check and confirm that I take my medication and they help me”.

- “There are no problems at home, I live with my younger sister and if my medication is finished we share hers and the same is true with hers.”
- “My family knows that I take these medications and they are supportive especially my grand mother.”
- “My family is quite supportive. However, there are some neighbours who appear to be discriminatory towards me. Although they have not said anything to me I see it in the way that they look at me. It is this “look” that makes me so uncomfortable to the point of making me feel like just keeping in doors.”

2.4.5.7 Main themes for any other influence that the medication has on the participants: Medication has no other influence

Most participants gave no comment. The participants who gave no comment tended to feel like they had already shared how the medications influenced their lives and therefore they did not have any other thing to say.

Those who said no problem generally felt that the taking of medication for them did not pose any challenge and if any thing it had benefits. On further probing this is how they expressed themselves:

- “These medications treat me well; I also take care and ensure that I keep them safely.”
- “There is no problem; I am satisfied and pleased with these medications.”

Here the participants were asked to share any other ways that they could see as an influence that their medication has in their lives. This is what they had to say:

- “No comment”
- “The medication is not good for me, I react badly”
- “No problem”
- “Medication is okay”
- “No comment”

- “I am satisfied with the medication”
- “They keep me very healthy, the only problem is that they make me very hungry”
- “I wish to became better”
- “Medication is very good to me”
- “No comment”
- “No comment”
- “No comment”
- “No comment”
- “It is just okay”
- “Its just fine”
- “No comment”

2.4.6 THE MEANING OF TAKING THE MEDICATIONS IN DAILY LIFE

Here the participants were asked to briefly say what they interpret life on ARVs to imply for them on a day to day basis.

2.4.6.1 Main theme for the influence of medication on daily living: They take personal responsibility for their lives by regularly taking the medication

The theme that the researcher identified from these responses is that the influence of the medication on the daily life of the participants is both not a challenge and taking personal responsibility for their lives. This is so in the sense that they said they are used to life on these medications, they have no problems, the medications mean help for them, and they see these medications as contributing to the ability to live and protection from the virus. The researcher sees this as taking responsibility of one's life by the participants. The participants said that being on these medications for them implies taking their medications

daily without failure. For instance one of them said; “When I am at home I always think about taking my medication.”

Taking the medication has become routine or part and parcel of living; the sense gathered by the researcher from these responses is that participants have come to the point of embracing their medication as part of their daily lives.

- “Going for check up is very helpful”
- “It is not a big deal for me”
- “No big deal for me”
- “They did not alter my life drastically – I am okay”
- “I am now used to the routine – it is no big deal”
- “They help to keep me fit”
- “They help protect me from the virus”
- “To prevent spreading the virus further”
- “When I am at home, I always think of taking my medication”
- “It means taking medication every day, and when it gets finished I have to refill”
- “I am able to breath properly and have no blockages”
- “It means I have to take the medication daily, of cause I am used to the routine”
- “I am not affected”
- “It means helping me”
- “It means my fitness and they fight illness and strengthen my immunity”
- “It means my life. So that I can go on living”

2.4.7 ASPECTS THAT THE PEOPLE HELPING WITH MEDICATIONS COULD KNOW OR DO

This was the last area of discussion with the participants, and they were being asked to share with the various service providers their view on the services they

were being provided with. They therefore shared what ever they felt like saying and there were a number of varied responses given. The responses were as follows:

- The only common response given by four participants was “nothing or no comment”. These participants felt that every thing was just going on well and therefore there is no reason to share anything with any body. This is a positive thing in the researcher’s view since it implies that the participants are comfortable with the services they are receiving.
- One participant said taking medication at home is the best arrangement. He further felt that, those taking the medication should take them as instructed in order to get the virus suppressed and when the medication gets finished they should not just stay rather they should go for refilling.
- One participant said “... there should be more communication between us and those who give out the medication. For instance they should tell us about our condition.” He indicated that he only came to know about his condition/status from his aunt and the hospital never told him anything.
- One participant said; those who dispense the medications should make it a point that they give out accurate quantities of the medications, they should not give out more than the required amounts since that can create problems for the patient. She felt that the problem the patient will face is that when he/she turns up with more medication for review it will be interpreted as lack of adherence to the medication on their part. This in the researcher’s interpretation simply implies that dispensing personnel needs to be a bit more cautious, since this participant indicated that it once happened to her and she was quite upset about it. It seemed to her that she felt like she was doing a sincere thing and yet she was not being trusted due to someone else’s mistake. She also said that she thinks friends also need to know that one is taking these medications. How ever she felt that one needs to be cautious about sharing such information about oneself and therefore should just choose one trusted friend to share with.

- One participant felt that the hospital through its hospice service should consider increasing the food rations they are providing. He also wished that the Social and Community Development Office social workers could consider re-instating his mother back as a food basket programme recipient. This in the researchers view had to do with the participant's low socio-economic status since they appeared to be barely able to meet their basic needs on a daily basis at home.
- One participant felt that she wished her elder sister could be helpful in the sense of coming to collect the medication from the hospital on her behalf. She also said that as far as the clinic is concerned there was nothing that she wished they could do.
- One participant said that her comment was to people in general that every body should look after themselves and should desist from touching blood.
- One participant said that she wishes that her family should always remind her to take her medication at the right time.
- One indicated that she is only being assisted and supported by her mother, but otherwise everything else is fine. The researcher here felt that if the participant is only assisted by the mother it could be a limitation since if it so happens for one reason or the other that the mother is unable to, then what will happen to this participant.
- One participant felt that the clinic should make an effort to speed up service delivery. She explained that the queue normally moves at a very slow pace and in the process the younger children would be crying because they want to go back due to hunger. She particularly expressed that she wished that all the pharmacy services points could be functional each day from morning.
- One participant wished that it would be explained thoroughly how the medications are to be taken, otherwise she said that she is happy with the services.
- Another participant said that everything is fine both at the clinic and at home.

- The last participant said that she wants both her family and her friends to remind her to take her medications at the right time. She wished the clinic staff would also keep on educating them on their medications; indicating to them how they ought to take their medication. What the researcher gathered from this participant's messages is that she wishes for on going support from all the service providers and social networks. She did not say that any of her network partners was not supportive but she was just saying that they should continue with the good work they were doing.

2.5 SUMMARY

The above information shared by the participants, shows that children on ARVs have stories to share. The influence was at times quite similar for almost all participants in a specific sphere of their lives and at times quite different. From the questions asked insights from these children's life were gathered, as well as recommendations from them to various groups and individuals involved in their lives.

The main themes formulated from the responses were that the participants were attending the clinic for health reasons; they have no clear idea of the type of medication; some treat their status as a secret; they keep their status a secret for self-protection; they depend on medication for wellness and survival; they have an accurate appreciation that medication cures further illness and helps to cure; the medication has a positive influence and participants are grateful; the medication causes some bodily discomfort; they can continue with school but experience challenging behaviour from other children; some experience discrimination within the school; they receive support from friends but taking the medication causes disturbance during play time; families provide support; and they take personal responsibility for their lives by regularly taking the medication.

The next two chapters of this dissertation will expound more on these stories as they are now related to literature (in chapter 3- literature review) and conclusions and recommendations (in chapter 4) will be passed to the reader.

CHAPTER THREE

CHILDREN AND HIV AND AIDS

3.1 INTRODUCTION

In this chapter, the aim of the literature review is to investigate what other sources of information have to provide in relation to children, HIV and AIDS and how taking ARVs influence their daily lives. The focus of the chapter will be on the child and HIV and AIDS and ARV treatment. The relevance of this study became clear in the search for resources on the topic. Very little information on children on ARV treatment was found. HIV and AIDS orphans, infected adolescents and adults and prevention of infection receive much attention in research.

UNAIDS indicates that every minute of every day, a child under the age of 15 becomes infected with HIV. Ninety percent of the more than 5 million children who have been infected were born in Africa (Uniting the world against AIDS, 2006). Bhana (2008:728) quote Shisana and Simbayi (2002) stating that there is a great deal of evidence that shows children's vulnerability to HIV related risks. A household survey of HIV rates of infection in South Africa found 11.4% prevalence amongst persons aged two years and older.

Children have their own perceptions about their lives on antiretroviral medication (Kgosi, 2008). Some wonder why they need to take those medications; others fail to appreciate the importance of taking their medication; some children are angry at their parents for having them when they knew they were infected with HIV. Their perceptions are not necessarily the same as for adults on ARV treatment. It is thus necessary to explore the lives of children with HIV and AIDS and on ARV treatment.

The discussion on the child and HIV and AIDS seeks to focus the reader's attention on the children as the population of focus in this study, as well as the phenomenon of HIV and AIDS as a global challenge. The heading is therefore further sub divided into the following sub headings; the child, HIV and AIDS as well as HIV and AIDS on the lives of the children. The second heading on antiretroviral treatment (ARV) focuses on what these medications are, how they work and the benefits as well as the possible caution on use of these medications.

3.2 THE CHILD AND HIV AND AIDS

3.2.1 THE CHILD

Sources on the child and child development normally classify persons as children with emphasis on development; whether chronological, mentally or psychologically (Children's Act no. 38 of 2005; Chambers Adult Learners' dictionary, 2005:103; Wikipedia, 2007).

Deacon and Stephney (2007:1) indicate that there is a general consensus that there is an onus on society in general to care for children; and that negative experiences in childhood can have very long-term effects on adults and thus on the future of a society. Children are therefore considered as a special group or sector of any society that they come from. The Ministry of health- *Botswana HIV Discordant Couples Counselling Curriculum* (2009:184) also emphasizes the same principle as it states, "...your child's healthy development depends on your ability to provide a safe, loving, and organized environment." "Children with a secure community and family environment also tend to grow up to create prosperous, sustainable, tolerant, non-violent and democratic communities" (child development, 2008:28). This is also evident in a number of efforts and initiatives both at national and international levels. For instance, at national levels countries have legislature as well as policies that address children's welfare and protection

issues. For example in Botswana, child welfare and protection pieces of legislature include the Children's Act, Short Term Plan of Action on Care of Orphans in Botswana 1999-2001.

Internationally, there are bodies set up specifically to focus and forward child protection issues such as the United Nations Children's Fund (UNICEF). In addition, the Millennium Development Goals (MDG), which represents the targets, set by the international community in the year 2000 for eradicating poverty, reducing child and maternal mortality, combating disease, ensuring environmental sustainability and providing access to affordable medicines in the developing countries does show child issues and welfare as an area of focus. For instance, Goal 4 of the MDG stipulates; "reduce by two thirds, between 1999 and 2015, the under five mortality rate" (UNICEF in the state of Africa's children, 2008:5). In addition, the Human Sciences Research Council (2007:1) quotes the United Nations Convention on the Rights of the Children as quoted by Amon (2002:143) which states that "children are entitled to special care and assistance and that this care and assistance should enable full and harmonious development".

This study therefore, comes as another contribution towards giving children as a special group, and specifically children and HIV and AIDS, some attention. The researcher's interest stems from her personal interest in working with children. This interest was further enriched by eight years of hospital work experience where working with children was part of the workload.

3.2.2 HIV AND AIDS

Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) arrived on the world scene without warning. A mere two decades ago it was unknown. HIV and AIDS is a global development emergency and continue to spread in many parts of the world, sending whole communities

into destitution (Hall, 2007:56). Today HIV and AIDS cover Africa in dark clouds of fear, uncertainty and suffering. The virus has destroyed the innocent hopes, desires and plans of countless numbers of people whose lives have been cut short by an unseen enemy. For those living in Africa, it is a human catastrophe from which no single one in the region will be exempt because HIV and AIDS affect all (Van Dyk, 2001:iii). Hall (2007:57) also emphasises that the epidemic primarily affects the world's poorest communities.

Bariagaber (2001:168) quotes Organization of African Unity (OAU) (1994:2) and United Nations (UN) (1994:10-11) as saying that HIV/AIDS-related mortality has recently become the second important cause of death in sub-Saharan Africa. HIV and AIDS-related mortality surpasses both measles and malaria and in most African states jeopardizes positive gains in health status brought about by primary health care programmes of immunization, child survival strategies, and efforts to reduce adult mortality levels. This is in agreement with HIV & AIDS in Botswana (2009), indicating the impact of the epidemic in Botswana, who states that:

Life expectancy at birth fell from 65 years in 1990 to 1995 to less than 40 years in 2000 to 2005, a figure about 28 years lower than it would have been without AIDS. An estimated 95 000 children have lost at least one parent to the epidemic. It is vital that these children have access to education, but this is problematic in families already weakened by AIDS where children may be providing care for ill relatives or supporting siblings.

In discussing the same issue of challenges brought about by HIV, the *AIDS Map 2009* quotes Black and colleagues in a five-year audit published in the August 2009 issue of *Obstetrics and Gynaecology* (AIDS Map 2009). They state that an audit of maternal deaths for the period 1996-1998 in Durban, South Africa showed facility-based maternal mortality rates for women with HIV to be 323 per 100, 000 compared to 148 per 100, 000 for those not infected. This number is over two times higher.

The above authors emphasize the challenges or burden that HIV and AIDS has in peoples' lives globally, regionally – both African and Sub Saharan, as well as in Botswana. No wonder the former President of the Republic of Botswana made a statement in his speech as quoted by Avert (2009) at the UN assembly in June of 2001, saying, “We are threatened with extinction. People are dying in chillingly high numbers. It is a crisis of the first magnitude.”

3.2.3 HIV AND AIDS IN THE LIVES OF CHILDREN

The above picture of the HIV pandemic does not leave any sector of the population out, for instance, each year as the United Nations' AIDS service organizations (UNAIDS) and World Health Organization (WHO) release the global and regional statistical situation; this phenomenon is quite apparent. The release always provides details of how the adult population as well as children below 15 years of age is affected. For example, according to the 2007 release, globally children accounted for 2 million of the 33 million people living with HIV. The Sub-Saharan Africa region bears the greatest burden of this epidemic since it is home to 1.8 millions of this 2 million (Global report 2009). This represents about 90% of all children living with HIV globally according to UNICEF [sa]. HIV AND AIDS continue to have a heavy toll on children globally, but especially in sub-Saharan Africa. An estimated 2.2 million (88%) of the 2.5 million children younger than 15 years who were living with HIV/AIDS at the end of 2007, was African. Approximately 370 000 African children were newly infected with HIV in 2007, and 290 000 died (Kline, Ferris, Jones, Calles, Mizwa, Schwarzwald, Wanless, Schutze, 2009:134).

A closer look at the HIV situation as it relates to children, further indicates that the bulk of children acquire the infection through the mother-to-child transmission route. Van Dyk (2001:28) states that mother-to-child transmission of HIV is one of the major causes of HIV infection in children. Estimated numbers are that about 600 000 children are infected in this way each year. The figure accounts

for 90% of HIV infection in children. Van Dyk (2001:28) is of the opinion that unless preventative measures are taken, up to 40% of children born to HIV-positive women are infected. AIDS map (2009) further emphasizes this phenomenon in its quote of data provided by UNICEF. The quote indicates as follows:

UNICEF estimates that, in 2003, approximately 700, 000 new HIV infections were among children. Since programmes that offer treatment for the Prevention of Mother to Child Transmission (PMTCT) still only reached about 10% of the pregnant women with HIV, that figure will not drop much until PMTCT implementation improves significantly. If coverage with PMTCT does not increase, there will be an additional 600, 000 children infected with HIV each year. And even with 50% coverage with PMTCT, there will be 300, 000 new paediatric infections per year.

The paediatric HIV situation according to the above information can be changed by the availability of PMTCT service provision. According to Van Dyk (2001:29-31) there are a number of strategies or procedure that can be practiced to reduce the risk of transmission to the baby. These include:

- Use of antiretroviral therapy for mother and baby
- Vaginal cleansing (disinfection of the birth channel with an antiseptic solution such as 0,25% chlorhexidine during vaginal examinations)
- Avoiding unnecessary rupture of membranes
- Avoiding an episiotomy when it is not absolutely necessary
- Minimizing trauma to the foetus (e.g. by avoiding procedures such as foetal scalp monitoring, forceps delivery, vacuum extraction – each of which may cause minor skin lacerations)
- Carrying out a caesarean section if possible
- Safer infant feeding methods

Some countries can currently testify to the rewards of setting the PMTCT programme in place, amongst them Botswana. Botsang (2008:1) indicates that; according to the Botswana Minister of Health, the PMTCT programme since its

introduction in 1999 has yielded 90% up take and reduced mother to child transmission to less than 5% (Botsang, 2008:1).

Efforts to work on the challenges presented by HIV/AIDS in the lives of children at international level include the United Nations Children's Fund (UNICEF) "Call to Action". In 2005 UNICEF addressed a Call to Action to all those working to protect children from the consequences of the epidemic. The call edged the international community to *unite for children unite against AIDS* to ensure that the next generation of children is AIDS free. The initiative was based on the commitment by stakeholders to reaching the Millennium Development Goals and living up to the promises made by world leaders at the United Nation's General Assembly Special Session on HIV/AIDS of 2001.

This Call to Action set four goals for 2010 derived from the child-related articles of the Declaration of Commitment on HIV/AIDS. These goals are as follows:

- Prevent mother-to-child transmission of HIV. By 2010, offer appropriate services to 80% to women in need.
- Provide paediatric treatment. Provide antiretroviral treatment, cotrimoxazole or both to 80% of children in need.
- Prevent infection among adolescents and young people. Reduce the percentage of young people living with HIV by 25% globally
- Protect and support children affected by HIV and AIDS. Provide services that reach 80% of children most in need (Children and AIDS – second stocktaking report [Sa]).

Of all the above goals; this study has focused on the second goal which emphasized the provision of ARVs to children. Boulton, Pepper, Walters, Beck and Miller (1999:5-6) state that the impact of HIV infection with regard to children specifically is to raise the profile of two main concerns. These concerns centre on the children's physical health and on their ability to lead a 'normal life' within their community. Children's physical health and the ability to lead a 'normal life' within

the community are important to all families, but HIV infection transforms them from implicit background concerns to explicit and problematic issues.

3.3 ANTIRETROVIRAL TREATMENT

According to Antiretroviral drugs (2006), antiretroviral drugs are medications for the treatment of infection by retroviruses, primarily HIV. Different classes of antiretroviral drugs act at different stages of the HIV life cycle. A combination of several (typically three or four) antiretroviral drugs is known as Highly Active Antiretroviral Therapy (HAART). These medications are prescribed to control the replication of HIV in the human system, thereby prolonging and enhancing the quality of the infected person's life.

In addition, Response to anti HIV treatment (2008) states that:

Thanks to anti HIV treatment many people with HIV are living longer, healthier lives. In fact many doctors now think that, with the right treatment and good care, a person with HIV will be able to live a more or less normal lifespan.

3.3.1 CHILDREN AND ARV

In terms of children, Van Dyk (2001:68) states that they are treated with the same antiretroviral drugs that are given to adults, but the dosages are adjusted to suit the age or weight of the child. She further expounds that the use of these drugs on children promotes or restores normal growth and development, improves the quality of life, prevents complicating infections and malignancies, and prolongs the child's life. AIDS map (2009) also states that without HIV treatment, approximately 20% of HIV-infected infants born in richer countries like the United Kingdom will develop AIDS or die in the first year of life. This therefore shows the difference that the use of ARVs can make.

Moreover, UNICEF [sa] indicates that the majority of children living with HIV can be saved by timely administration of paediatric antiretroviral treatment. This is emphasized by a study conducted in South Africa, which sought to find out whether it is better to put HIV positive babies under three months old on antiretroviral medications or to wait until their immune systems have declined. This study was conducted at the Chris Hani Baragwaneth Hospital. The research showed that 96% of the babies who got immediate treatment survived, compared to the 84% survival of babies who were given the drug later. This represented a 75% reduction in death rates (Keeton, 2007).

In addition, Clinical Infectious Diseases (2004:725-39), reports a study conducted by Viani, Araneta, Deville and Spector of the University of California, whose aim was to identify the effects of evolving antiretroviral therapy on the immunologic status of and hospitalisation and mortality rates among perinatally infected children, the use of these medication on the children was noticeable. The conclusion of the study was that “HIV-1 associated mortality and hospitalisation rates decreased significantly between 1994 and 2001 in perinatally infected children. This correlated with an increase in CD4 cell percentage and a decrease in HIV-1 RNA load concurrently with the expanded use of HAART.” (Clinical Infectious Diseases 2004:725-39). The impact of highly active antiretroviral therapy (HAART) on clinical outcomes of vertically HIV-1 infected children by the Spanish Group of Paediatricians (Palladio, Bello`, Munoz, Alonso & Munoz-Fernandez) HIV Infection also made a conclusion on how the use of antiretroviral medication benefits children. In their study they intended to update a previous epidemiological survey that demonstrated the benefits of HAART on the clinical outcome of HIV-1 vertically infected children. In their conclusion, they stated that, “We confirm the benefits of HAART in reducing adverse clinical outcomes as AIDS and death in HIV-1 vertically infected children in our cohort of kids living in the Autonomic Community of Madrid” (Palladio, Bello`, Munoz, Alonso & Munoz-Fernandez 2008).

3.3.2 THE INFLUENCE OF ARVs ON THE LIVES OF PEOPLE LIVING WITH HIV

The influence of ARVs on peoples' lives was considered as positive by the outcome of a Ugandan Malaria study. According to this study, antiretroviral treatment was associated with a 75% decline in the incidence of malaria over four years in study participants. This is in view of the fact that individuals with HIV are especially vulnerable to malaria if they have a low CD4 cell count. The researchers found that there was a significant decrease in the incidence of malaria in the first year after starting HIV treatment. This is according to the Ugandan and United Kingdom based researchers at the fifth International AIDS Society Conference in Cape Town (AIDS map, 2009).

Lafraniere (2004:2) also reports the positive influence of ARVs as shared by the Serowe's senior laboratory technician Winnie Muhumuza who stated that, "We used to have many very ill patients. Vomiting, diarrhea, too thin and too weak to draw blood. They had to be lifted from the car to the lab. Now we don't even know who is HIV positive, because they look fine." She continued to indicate that under the Botswana government plan everyone who needs antiretroviral drug treatment will get it, and an infected population will be working instead of bedridden by AIDS-related illnesses (Lafraniere, 2004:2).

In a study conducted to find out the effects of highly active antiretroviral therapy (HAART) on the risk of tuberculosis in South Africa it became apparent that the use of ARVs was beneficial. In view of the relationship between HIV infection and tuberculosis, where tuberculosis as an opportunistic infection occurs regardless of the infected person's CD4 level, preventing active tuberculosis becomes a major public health priority. The finding in this study showed that; "HAART reduced the incidence of HIV-1-associated tuberculosis by more than 80% (95% CI 62-91) in an area endemic with tuberculosis and HIV-1. The protective effect

of HAART was greatest in symptomatic patients and those with advanced immune suppression” (The Lancet, 2002:2059).

The Bio Med Central of July 15, 2009 published a research article on the social-economic impacts of antiretroviral medications on the Kenyan agricultural worker employment outcomes. The concern of the study was in establishing the extent to which improvements in health resulting from use of antiretroviral medication allows individuals to return to work and earn an income. The study also took cognisance of the situation that improvements in health from ARVs may also be associated with reduced impaired presenteeism, which is the loss of productivity when an ill or disabled individual attends work but accomplishes less at his or her usual tasks or shifts to other, possibly less valuable tasks. The findings in this study were that the female index group worked 30% fewer days plucking tea monthly than the matched female comparison group during the final 9 months pre-ART. In addition, they worked 87% more days on non-plucking assignments. While the monthly gap between the two groups narrowed after beginning ART, the female index group worked 30% fewer days plucking tea and about 100% more days on non-plucking tasks than the comparison group after one year on ART. The male index group was able to maintain a similar pattern of work as their comparison group except during the initial five months on therapy.

Although there is a general agreement, as stated above, on the benefits of antiretroviral medications for people living with HIV, there is the usual concern in terms of how these medications are supposed to be used in order for them to yield the expected outcomes. Anderson and Weatherburn (1999:199) indicate that the advent of anti-HIV combination therapy has changed the lives of many people living with HIV and offers hope to many more. An individual's decision to start therapy remains difficult given the complexity of treatment options, the difficulties of managing the therapies and the lack of any data on the long-term consequences of therapy. An understanding of how individuals make such choices remains limited. One of the key concerns for people living with HIV in the

new clinical environment where treatment options are compelling but complex is their own knowledge about HIV treatment and therapy and the information that is available to them.

This lack of knowledge or understanding on ARVs was further proved by a study conducted in Durban South Africa from October 2002 to February 2003. The study was conducted on a collaborator basis by:

- The Centre for AIDS Programme of Research in South Africa (CAPRISA)
- The Miriam Hospital – Providence Rhode Island USA
- Department of Community Health, Brown University Medical School Providence – Rhode Island USA
- HIV AN – Nelson Mandela School of Medicine – Durban, South Africa
- Mailman School of Public Health- Columbia University – New York USA

In this study, semi-structured interviews on knowledge of HIV, antiretroviral treatment, willingness to participate in voluntary counselling and testing and HAART with 54 consenting patients attending a tuberculosis (TB) clinic in Durban South Africa were carried out. The findings in the study were that 74% of patients interviewed reported not knowing anything about antiretroviral treatments (HAART). Knowledge of antiretroviral drugs (ARVs) was restricted to use in preventing mother to child HIV transmission (MTCT). 57.4% of the patients reported having an HIV test in the past, but less than 10% were aware of their current HIV status. Patients who did not know their current HIV status expressed fear and hesitation about testing HIV positive but 91% of the patients expressed willingness to participate in HIV treatment given the opportunity. The findings from this study indicate that knowledge of HIV treatment is limited. As access to HAART expands, information about HIV treatment options should be disseminated. The study indicates that TB centres may present unique opportunities for disseminating HIV prevention, care and treatment options.

On the issue of the complexity of ARV treatment mentioned by Anderson and Weatherburn (1999:199) above, researchers across the world also confirm that decisions related to how ARVs are to be initiated, prescribed and administered are not easy. For instance, the Clinical Infectious Diseases (2006:42- 862) published a study by Resio, S., Resio, R., Micheloud, D., Gutierrez, D.G., Leon, J.A., Ramos, J.T., Ciria, L., de Jose, I., Mellado, J.& Munoz-Fernandez, A. on the *Long-Term Effects of Highly Active Antiretroviral Therapy in Pre-treated, Vertically HIV Type 1 – Infected Children: 6 Years Follow-Up*. In this study, the researchers sought to define the long-term impact of HAART on CD4 cell percentage and viral load according to CD4 cell percentages before HAART was initiated.

The findings of the study were that during the first two years of HAART, HIV-1 – infected children experienced a significant increase in CD4 cell percentage and a decrease in viral load ($p<.05$). During their last four years of receiving HAART, they found a significant decrease in viral load but not an increase in CD4 cell percentage, because the CD4 cell percentage reached a plateau after the second year of HAART. Children with CD4 cell percentage of $<5\%$ at baseline did not achieve CD4 percentage of $>25\%$ after six months of HAART. Children with CD4 cell percentages of 5% to 25% at baseline had a strong negative association with achieving CD4 percentages of $>30\%$ for at least six and twelve months but not with achieving CD4 cell percentages of $>30\%$ for at least 24 months.

Based on the above findings the researchers concluded that the use of long-term HAART allowed for restoration of CD4 cell counts and control of viral loads in HIV-1 – infected children. They also stated that initiating HAART after severe immuno-suppression has occurred is detrimental for restoration of the CD4 cell count.

In addition, the Ugandan researchers at the Conference on Retroviruses and Opportunistic infections of February 2009 shared that treatment switches based on CD4 counts were often unnecessary, because the patients often continued to have undetectable viral load despite a decline in CD4 count. The researchers also suggested that infections such as malaria could be causing temporary dips in CD4 count. They estimated that in a cohort of 125 patients who experience CD4 declines, 107 patients would have been switched to more expensive second-line treatment, \$75, 000 in drug costs to the treatment programme budget (AIDS map, 2009).

This in the researcher's view goes to show how difficult it is to make decisions on how to administer these drugs, in the sense that it shows how a decision to change to the next level of drugs can be unnecessary and costly both at an individual's and national levels. It could be costly at an individual's level in the sense that it would actually reduce the number of treatment options still available for the patient in the future. At the national level, the costs are mainly financial as stated above, and therefore denying other national needs to be met.

Findings from a Western Kenya study confirm the above situation in which 149 patients who were suspected to have treatment failure were investigated (AIDS map, 2009). Of these 149 patients, 58% turned out to still have a viral load below 400 copies, and even among the subset of 42 who experienced a CD4 decline of more than 50% during the previous six months, 43% (18) still had a viral load below 400 copies, indicating that there was no need to switch treatment in those cases. In addition, among those with a CD4 cell count above 200 at the time of suspected treatment failure, two-thirds (66%) had a viral load below 400 copies, compared to 41% of those with a CD4 count below 100 cells/mm³ (AIDS map, 2009).

Tomeletso (2009:1) states, "Whereas the government of Botswana has to be commended for the effort it took to halt the consequences of AIDS by introducing

ARVs, complications abound”. These complications can be witnessed at various levels, for instance Van Dyk (2001:71) mentions them as follows:

Antiretroviral therapy will cause irreversible changes in a patient’s life, and the health care provider should consider every advantage and disadvantage inherent in therapy before recommending or prescribing it to a patient. Each of the following needs careful cognizance:

- A patient who wants to take anti-retroviral therapy should be committed and well informed. The patient should be in a position to adhere to a strict medication regimen. This means that they should be able to take two to three tablets two to three times a day (taking some dosages with food and some on an empty stomach).
- Some patients may experience side effects such as nausea, vomiting, abdominal discomfort, diarrhoea, skin rashes, fatigue, anaemia, liver toxicity, fever, peripheral neuropathy and kidney stones.
- Current treatments are permanent life-long and it is essential for the patient to adhere strictly to the therapy. Patients often stop treatment because of side effects and this may lead to the development of viral resistance to the drugs.
- Drug therapy should be monitored on a regular basis by measuring the viral load. This monitoring enables medical staff to know whether the viruses are successfully suppressed.

Repeatedly, authors and health care providers emphasize the importance of adherence to ARV treatment. For instance, Tomeletso (2009:2) indicates that; “the success of the ARV programme is judged based on adherence created by a supportive environment, quality of care and treatment efficacy.” This indicates that there are certain areas or conditions that have to be in place to facilitate adherence, which will then facilitate benefits from ARV treatment.

The first area is that of a supportive environment; Khumalo, Dlamini, and Shezi, (1998:85) indicate that among youth there is still the misconception that only 'bad' people get AIDS, and that there is a need to involve and work with people living with HIV in order for others to become conscious of the problem. Van Dyk (2001:272) is of the opinion that because HIV and AIDS continue to generate fear, misunderstanding, misinformation and discrimination, it is important that counsellors and other health care professionals do everything in their power to counter negative attitudes. People infected and affected by HIV need the support of society and not rejection by society. Mariba (2009:11) also reiterates the importance of a supportive environment as she states that; "But with assistance and love from Debswana, my family and the community I overcame all obstacles and saw light at the end of a dark cold tunnel".

The second area mentioned above is that of quality of care. Daoust and More (2002) state that with regard to patient counselling for adherence that it is important to have a multi-disciplinary team collaboration to meet the needs of the patient. They further emphasize the value to integrate clinical care and counselling support. This in the researcher's view indicates the importance of joint efforts by various professionals in the care and support of the needs of people on ARV treatment. Daoust and More (2002) continue to indicate that there is also the need to have a two-way collaborative relationship between provider and patient. They state that the provider acts as the guide but both are invested in the outcome. This shows the partnership that the health care provider and the patient need to get into. Anderson and Weatherburn (1999:199) also emphasize the issue of partnership between provider and service recipient by stating that when negotiating their treatment and therapy choices, people with HIV must deal with a variety of social tasks. These tasks include:

- Getting access to appropriate services and assessing the quality of those services
- Building relationships with doctors and other health professionals
- Obtaining and assessing information about available treatments

- Gaining the understanding and confidence to make fully informed decisions
- Managing the impact of treatment regimens on daily life and personal relationships
- Dealing with the long-term influence of treatment on individual identity, life plans and work prospects

The third area mentioned by Tomeletso above is that of treatment efficacy. This implies the capacity of the treatment to produce an effect (Wikipedia, 2009). Van Dyk (2001:70) states that viral load counts should be done at three (3) to four (4) monthly intervals in order to monitor the effectiveness of antiretroviral therapy. If the medication is effective then the viral load should eventually stabilize at acceptable low levels. If the viral load increases, it is an indication that the treatment is not working. The handbook of the Botswana National HIV/AIDS Treatment Guidelines (2008:8) also stipulates that:

Patients who do not suppress viral load to <400 copies/ml at 3 months after HAART initiation may be at increased risk for treatment failure at 6 months, and should undergo intensive adherence intervention and other evaluation for possible causes of treatment failure. All paediatric and adolescent patients who do not suppress viral load to <400/mL by 6 months after HAART initiation must be discussed with a paediatric HIV specialist.

Both the above authors indicate the value of an ongoing monitoring programme or schedule for patients on ARVs as an only surety for the desired effects of these medications.

A further look at the influence of ARV medication on children indicates that there are other challenges that may be of greater concerns for children with HIV than for adults. Kirton, Talotta and Zwolski (2001:397) state that combination antiretroviral drug treatments are the current standard of care. It is possible for clients with HIV infection who are clinically stable to require five different antiretroviral/prophylactic medications with complicated dosing schedules every

day. This often proves difficult for adults, and becomes even more difficult for the HIV infected child required to take antiretroviral medications that may be unavailable in paediatric formulations.

Further more, participants at the joint UNICEF/WHO technical consultative meeting held on 3-4 November 2004 indicated that there were certain limitations in scaling up ARV treatments for children (AIDS map, 2008). They indicated four major areas:

- Diagnosis of infants under 18 months is difficult
- A lack of paediatric expertise and experience
- An incorrect perception that all infected children will die early in childhood. Policy makers, programmers and care providers themselves need to be convinced that ARV treatment is effective and important in the management of HIV in children
- ARV drugs are not easily available (or not available at all) in the appropriate formulations and at affordable prices
- Programmes lack tools to accurately forecast the need for paediatric ARVs and thus generate demand. This makes supply/procurement challenging and manufacturers hesitant to invest in the development of paediatric ARVs.

The influence of ARVs on the lives of children can furthermore be seen in instances of use of ARV drugs to prevent mother-to-child transmission of HIV. More and more babies are likely to become uninfected from their infected mothers, as indicated in the mother-to-child transmission of HIV-1 drug resistance in a French cohort study published in the *Retrovirology* of 9 April 2008. The study states: "The use of antiretroviral drug therapies in HIV-1 infected pregnant women and their infants has resulted in significant reduction in the rates of mother-to-child transmission (MTCT)." Although in instances of mother-to-child transmission reduction the infant only receives ARVs due to exposure by virtue of the mother being infected children do benefit.

However, the use of these drugs in PMTCT settings has a negative influence on the children themselves. First, this negative influence has been identified in the form of drug resistant HIV on those infants who acquired the virus despite attempts to prevent transmission. In a study conducted between January 1997 and May 2006 at Tenon hospital in Paris, France, “18 cases of vertical transmission of HIV-1 were registered in this cohort with an important proportion of infected infants who acquired drug-resistant virus (4/14 – 29%)” (Benizri, Schneider, Kara, Guessant, Marcelin, Tubiana, Tabone, Herve, Vaudre, Dehee, Leverger & Dollfus, 2008:1743) This study therefore in the researcher’s view shows how the use of ARVs in PMTCT can negatively influence a child’s life in the event this child becomes infected. As the researchers in this study put it, it therefore becomes important to carry out viral genotyping to guide prophylaxis regimen and or treatment of infected infants.

At another level, the use of ARVs for PMTCT purposes can also have a negative influence on those children who will not become infected from their infected mothers. This phenomenon became apparent from the study on *Effect of Perinatal Antiretroviral drug Exposure on Hematologic Values in HIV-Uninfected Children: An Analysis of the Women and Infants Transmission* (Pacheco, McIntosh, Lu, Diaz, Foca, Frederic, Handelsman, Hayani & Shearer, 2006:1089-1097). This study was conducted because of the fact that there is an increased use of antiretroviral drugs to prevent mother to child transmission of HIV, resulting in a large number of infants being exposed to ARVs with possible consequent toxicity. In this study, the findings were such that:

Haemoglobin concentrations and neutrophil, lymphocyte, and CD cell counts were significantly lower at 0-2 months in infants exposed to ARV drugs than in those who were not. At 6-24 months, differences in haemoglobin concentrations and neutrophil counts were no longer significant, whereas differences in platelet, lymphocyte, and CD4 cell and persisted CD8 cell count became significantly lower. In comparison with ARV monotherapy, combination therapy was associated with large decrease in

neutrophil, lymphocyte, and CD8 cell counts at age 0-2 months but with only differences in CD8 cell count at 6-24 months.

The findings therefore imply that regardless of whether it was mono-therapy (use of only one ARV drug) or a number of them used together there was change in haematological (blood composition) value for children exposed to ARV drugs used for PMTCT purposes. The conclusion of this study was that infants exposed to ARV drugs have small but significant differences in several haematological parameters for the first 24 months of life. These results indicate the need for long-term follow-up of uninfected infants with ARV exposure (Pacheco *et al.*, 2006:1089-1097).

The influence of ARVs on the lives of the children have also been expounded on by the Lancet (2006:1367-1369) viewpoint article by Domek. In this article Domek discusses “The social consequences of antiretroviral therapy: preparing for the unexpected futures of HIV-positive children” which according to him has given rise to four major areas of concern. The first area is that of disclosing to children that they have HIV. He explains that disclosing to the child that they are infected is important because with ARVs they are no longer expected to die in their first few years, and can now reach puberty. He further indicates that as they grow older they now need to know why they are unwell and understand the virus. In his view young adults have to make decisions about romantic relationships, sexual activity, experimentation with drugs and alcohol, and future planning; and hence the need for them to have an accurate and appropriate understanding of their infection status and the nature of HIV. He therefore recommends social support and open communication in making such an understanding possible. He indicates that clinicians need to work with family members and caregivers to encourage appropriate disclosure practices that take place not as a single revelation but as a gradual and progressive discussion throughout the child’s life. This process also has to be culturally sensitive and tailored to the needs of each individual child in each specific community.

The second area of consideration according to Domek, is that of psychological wellbeing of HIV-positive children as a growing area of concern. He states that these HIV positive children can have clinical anxiety and depression because of “recurrent and cumulative” losses. He indicates that it becomes traumatic for the children to deal with death of family members (from AIDS related illnesses), living in poverty, violence, sexual abuse and comprehending their own mortality. In addition, he states that living with a life threatening and stigmatizing illness is difficult and creates great psychological distress that should be addressed as the HIV positive child grows up.

The third area according to Domek is that of education. He says that because HIV positive children receiving ART are surviving longer, they often go on to attend school, raising new concerns for them (such as absenteeism for doctor appointments, disclosure of infection status to school officials, and stigmatization from classmates and teachers. Domek further indicates that there is need for increased attention to education and appropriate disclosure as HIV positive children become healthy enough to attend school. He continues to emphasize that it is important to prepare the teachers and school staff to work with HIV positive students and eliminate stigma in school settings since more and more of them are enabled by ARVs to be in schools. Domek further recommends that on the basis of the usual association between HIV and poverty, educational support and alleviation of poverty should be seen as “an integral part of the global response to the HIV/AIDS catastrophe in sub-Saharan Africa” in order to succeed in ending the world wide presence of this devastating epidemic.

The fourth and last area of concern according to Domek is that of children growing up in the confined environment of an AIDS hospice or children’s home. He indicates that in countries with high numbers of orphans, institutions such as HIV/AIDS hospice have been erected to take care of these ailing or dying children. The availability of ARVs as well as access to them by these children in those institutions has dictated a review to those set ups, since now children are

healthy and reaching young adulthood. This has therefore lead to a shift from AIDS children's' hospice to children's homes. Domek therefore calls for eventual deinstitutionalization of these children and formulation of community-based programmes to enable extended families and community to care for the children (The Lancet, 2006:1367-1369).

3.4 SUMMARY

In conclusion, the researcher summarises the above subheadings on this review of literature as follows:

- **The Child:** Children are a special sector of the society. They have needs, which are not always necessarily the same as those of other sectors of the society. These needs have to be met in order for them to become valuable members of their societies both in the short and long term.
- **HIV and AIDS:** The presence of HIV in the world has raised a number of challenges for the human race. These challenges can be felt at various levels i.e. globally, regionally, locally or at national level as well as at household and individual level.
- **Antiretroviral medications (ARV):** The availability of antiretroviral medication has brought hope to the world concerning the ability to address the problem of HIV infection. There are many benefits, which have been reported right across the world. These drugs have been used successfully to prevent transmission of HIV (specifically from mother to child), reduced the possibility of a number of opportunistic infection as well as treating HIV infection itself and delaying progression for the disease from HIV to AIDS. There are however challenges concerning the use of the medications as well as conditions to be met to make the use of these drugs more effective and efficient.
- **The influence of ARVs on the lives of children:** The researcher's view on this matter is that care and treatment for children requires sensitivity and understanding of the effect of HIV in their daily lives and the needs and

problems that arise as a result. This in the researcher's view this goes to indicate or summarise how the whole matter of HIV/AIDS and all the other efforts to address it have to be approached in the lives of children.

CHAPTER 4

GENERAL SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

The main aim of this study was to explore the influence of antiretroviral medication on the lives of the children in Botswana. The study focused on children receiving services from the Bamalete Lutheran Hospital in Ramotswa. The project purposed to give children on antiretroviral medication an opportunity to share their perspectives and get their voices heard. The key concepts of the study were child, HIV, AIDS, antiretroviral medication and influence as defined in the first chapter of this report.

Chapter one of the research report, presents the planning of the research process as well as the perspective of the study in the form of the goal and objectives. The research question is formulated. The research approach is that of a qualitative study by virtue of the project's objectives and research question to be addressed. A preliminary literature review was carried out in this chapter to inform the researcher on what is available on literature concerning the subject area. This further facilitated the formulation of the interview schedule for data collection. The data was collected through an unstructured one-to-one interview with the children receiving services from the Bamalete Lutheran Hospital.

The second chapter of this report is devoted to providing the empirical data for the readers of this project. The chapter provides the following information:

- The methodology of the study
- The demographic data of participants
- The research responses
- The themes and sub themes drawn from their responses and the literature reviewed.

Chapter three focused on the in-depth review of literature. The literature was sought and reviewed in connection to the meaning of antiretroviral medications as this was a phenomenological study.

The fourth chapter consists of the overview of all the chapters. The overview is carried out as follows;

- The chapter summary
- Conclusions of the chapter
- Recommendations based on the conclusions drawn

4.2 CHAPTER ONE: GENERAL INTRODUCTION

4.2.1 SUMMARY

In chapter one, the focus of the study was outlined. This indicated the research approach, type of research and preliminary literature review to guide the research process further. A detailed description of the following research aspects was provided:

- **THE GLOBAL PICTURE OF HIV AND AIDS**

Here the HIV and AIDS phenomenon was discussed from the statistical perspective. The information discussed was at the global level, regional level (sub-Saharan Africa) and narrowing down to the Botswana situation. Attention was also paid to the epidemic in the world of children.

- **GOALS AND OBJECTIVES**

The goal for this study was: **To explore the influence of antiretroviral medications on the lives of children in Botswana.**

This goal was achieved in the sense that the children shared how antiretroviral medications influenced their lives from a number of angles, as documented in chapter two of this report.

The objectives of this study were as follows:

i) To do an in-depth exploration into the influence of antiretroviral medication on the lives of children in Botswana

This objective was achieved as participants were requested to share the influence of antiretroviral medication providing insights from their personal perspectives and experiences.

ii) To describe the influence of antiretroviral medications on the lives of children

Here the objective was achieved through the identification of themes and sub themes drawn from the participants' responses as they shared how the medications influenced their lives.

iii) To draw conclusions from the in-depth study and the literature review and make recommendations on the basis of patterns that might present themselves in the stories of the children.

This objective has been achieved as the themes drawn from the children stories were correlated with literature and conclusions documented in this chapter.

• THE RESEARCH PROBLEM

The problem that this study sought to address was the fact that the voice of the children receiving antiretroviral medication is silent and unknown. This situation therefore could create limitations and shortcomings for the service providers working with them. Through this study the voice of the children was expressed including their recommendation to various service providers working with them on issues of taking medication.

- **THE RESEARCH QUESTION**

This research project sought to establish answers to the question: **What is the influence of antiretroviral medication on the lives of children in Botswana?**

This question was answered from the participants' own perceptions through a one-to-one unstructured interview with the researcher. Their responses are documented in chapter 2 of this report.

- **THE RESEARCH APPROACH**

The approach followed in this study is qualitative. The researcher sought to explore from the participants as to how their medications influenced their lives on a daily basis. The information they shared was therefore qualitative as the questions asked were open-ended and flexible in terms of responses expected and focused on their personal experiences.

- **THE TYPE OF RESEARCH**

The type of research in this study was applied. This study adds a dimension towards the care and services provided to children on ARVs which could facilitate improvements in the way that the services are rendered.

- **DESCRIPTION OF RESEARCH POPULATION, SAMPLE AND SAMPLING METHOD**

This study population was children receiving services from the Bamalete Lutheran Hospital Paediatric Clinic in Ramotswa, Botswana. The sample size was sixteen and the purposive sampling technique was used. The participants were aged between nine and eighteen years, having received the services for at least one year.

- **DEFINITION OF KEY CONCEPTS**

This section focused on the key concepts used in the study and the meaning they are supposed to convey. The concepts were; "antiretroviral", "AIDS", "HIV", "child" and "influence".

4.2.2 CONCLUSIONS

The following conclusions were made with regard to chapter 1:

- The preliminary review of literature and the views of the experts on the area of children and antiretroviral medication helped to shape the process of data collection and analysis in this study.
- The qualitative approach used enabled the researcher to get the children's stories straight from them and therefore facilitated their voices to be heard.
- The selection of the study participants was limited by the fact the paediatric ARV clinic focused on children below 12 years while the study sought for children up to 18 years. This therefore led to more days at the facility to ensure that the target age groups were all included and interviewed.

4.2.3 RECOMMENDATIONS

- The researcher recommends that a large scale study be carried out in a different setting(s) in Botswana to get the perspectives of children on the influence of antiretroviral medications on their daily lives. Such a study can provide insight into the children's situation from a broader geographic/cultural setting.

4.3 CHAPTER TWO: THE EMPIRICAL STUDY

4.3.1 SUMMARY

This chapter provided the empirical findings. A qualitative phenomenological approach was utilized. Sixteen (16) participants were interviewed through one-to-one unstructured in-depth interviews. Seven broad areas of discussion were drawn to facilitate the interview process with the participants. The responses

provided by the children in relation to their views of how the use of antiretroviral medication influenced their daily lives were presented. These responses were documented in detail with the themes and sub-themes extracted.

The chapter outline was as follows:

- **The methodology**

This section provides details on the research design followed in this study, providing details of study population, sampling and data collection strategy.

- **The bio demographical data of participants**

Here information on the participants in the study were presented in terms of their sex, age, educational level and length of stay on their medication.

- **Qualitative responses**

In this section the responses from the participants are provided as in their direct words. The themes and sub-themes are also documented.

4.3.2 CONCLUSIONS

The research project led to the following conclusions:

- HIV/AIDS therapy is not inhibitive to schooling because all participants are attending school, and they do not indicate that medication affects their capacity to learn. They are therefore able to carry on with their school life generally with only minor adjustments to make.
- Stigmatization and partial disclosure are still a reality even in the children's realm (mother telling her son not to tell his mates, as well as class mates not wanting to play with their mate who is on therapy).

- In general terms HIV/AIDS and antiretroviral therapy is being understood well even by children, because most of them assert that therapy is not cure, but suppresses ailments as well as boost immune system.
- Medication affects children differently just as it would with adults. Some children indicated that taking these medications gives them some side effects; they experience nausea, diarrhoea; others allege that they get hungry after getting medication.
- Although there are some challenges in families, there is still evidence that the family plays a very supportive role to members in therapy. Some participants submitted that their families provide them with support, and this makes the burden lighter.
- All participants save for two, did not name the medication they were on. Those who got closer were those who gave the description of the tablets they were taking. Whatever reasons they had for being so secretive, the conclusive theme is that participants were not free to openly state their medication since they were very economic in their description.

4.3.3 RECOMMENDATIONS

The following recommendations were made on the basis of the research findings:

- More education on the stigma issue and acceptance is necessary and especially in schools.
- More education is necessary to enable total acceptance by those on medication and those around them such as parents, family members, fellow students and teachers, so that they can take their medication without any fear or pressure. In addition, the health care providers must be flexible and ensure that they tailor-make the schedule to properly accommodate the school going age children, so that they do not feel like having to take medication before going to school makes them arrive late to school.

- There is need for more education to all youth in the school going age so that the very important message of antiretroviral medication not being a cure can be understood by all.
- There is a need to study the extent to which the therapy affects children and the similarities and differences between children and adults.
- More education on the critical role and indispensable support that the family should provide to own members should be given. It is through this type of education that communities will realize that HIV/AIDS is primarily a family affair before it becomes a government issue.
- With more education and ongoing counselling on total acceptance of oneself and the situation one is in, people's confidence can be built to a point that ARVs could be discussed openly like any other treatment without stigma attached.

4.4 CHAPTER THREE: CHILDREN AND HIV AND AIDS

4.4.1 SUMMARY

The researcher in this chapter provided an in-depth review of literature on HIV and AIDS, children and antiretroviral medication and its influence on people's lives. The information was provided under the following outline:

- **HIV and AIDS**

This section looked at HIV and AIDS as a global problem posing a number of challenges for the entire human race.

- **The child**

The section looked at a child as a special sector of the society with needs and vulnerabilities that require societal attention.

- **HIV and AIDS in the lives of the children**

The phenomenon of HIV is further expounded on in relation to children in this section; expounding on how HIV and AIDS are a challenge to them and efforts taken to deal with it.

- **Antiretroviral treatment (ARV)**

This section discusses antiretroviral treatment as a mechanism available to deal with the problem of HIV and AIDS.

- **Children and ARV**

The focus of this section is on how the availability of ARV treatment can make a difference in dealing with the problem of HIV and AIDS in children.

- **The influence of ARVs on the lives of people living with HIV**

This section dealt on how ARVs have impacted on the livelihood of people living with HIV and AIDS. It provides information on the influence both positive and challenges presented by such provision of the medication.

4.4.2 CONCLUSIONS

- HIV and AIDS is a global pandemic which has given rise to numerous other problems.
- Children are a special sector of every society who deserve attention, care and nurturing.
- Children also have been affected by HIV and AIDS in various areas of their lives.
- The arrival of antiretroviral medications has given hope to the world concerning dealing with HIV and AIDS.
- The provision of antiretroviral medications to the children has some challenges and also requires certain considerations.

- Although the influence of antiretroviral medications on the lives of people living with HIV and AIDS has had a lot of positive outcomes, it has also posed some challenges that need to be dealt with in order to maximize on those positive outcomes.

4.4.3 RECOMMENDATIONS

- There is a need for further research in the area of children and HIV and AIDS particularly as it relates to antiretroviral medications. This was evident as the researcher was conducting a literature search; the greatest need is in the social aspects of taking the medication.
- Researchers can consider extending the subjects of their study to include care givers and health care providers and possibly even contrasting their view points to get information from different perspectives.

4.5 TESTING OF THE GOAL AND OBJECTIVES

4.5.1 GOAL OF THE STUDY

The term goal, purpose and aim are often used interchangeably. They convey a broader meaning of what is hoped to be achieved at the end or on a long term basis (Marlow 2001:65). The goal of this study was to explore the influence of antiretroviral medications on the lives of children in Botswana.

4.5.2 OBJECTIVES OF THE STUDY

The objectives of the research refer to the steps undertaken in order to achieve the goal. They are short term, more concrete, measurable and more speedily attainable (Fouché & De Vos, 2005:104-105). The following objectives were formulated in order to address the goal of this study:

4.5.2.1 Objective one

To do an in-depth exploration into the influence of antiretroviral medications on the lives of children in Botswana

The objective was achieved through a one-to-one in depth interview with sixteen (16) children at the Bamalete Lutheran Hospital as well as a literature study on children and HIV and AIDS.

4.5.2.2 Objective two

To describe the influence of antiretroviral medications on the lives of children

The objective was achieved as presented in chapter two of this report. The chapter provides information on the findings as well as the themes and sub-themes presented by the participants.

4.5.2.3 Objective three

To draw conclusions from the in-depth study and the literature review and make recommendations on the basis of patterns that might present themselves in the stories of the children.

Conclusions and recommendations were made after the research process and in depth literature review was conducted as presented in this chapter

4.6 FORMULATION OF THE RESEARCH QUESTION

The research question in this study was: **What is the influence of antiretroviral medication on the lives of children in Botswana?**

The research question was answered. The findings provided clearly how the use of antiretroviral medications influenced the lives of the children from a number of areas. The findings indicated as follows:

- In terms of their bodies or physical influence the participants indicated that the influence was generally positive with only two participants experiencing some discomforts that they associated with the medications. The theme here was that; Medication has positive influence and participants are grateful.
- As far as schooling is concerned these medications helped by keeping participant well and physically fit to attend school well. The main theme here is; can continue with school but experience challenging behaviour from other children
- Concerning friendships the participants felt that there were no problems with friends as in fact friends were supportive. The main theme for friendship is; Receive support but taking the medication causes disturbance during play time
- In terms of the family the influence of the medication was perceived as not problematic, except for one who felt that the family was overly strict on his movements due to the fact that he was on these medications. The main theme was; Families provide support
- Concerning the meaning of taking medication attached to daily life of participants, the answer turned out to be that it meant help for them and a

new lease of life. The main theme here was that; they take personal responsibility for their lives by regularly taking the medication

4.7 CONCLUDING STATEMENTS

The researcher has come to the conclusion that children on ARVs in Botswana have stories to share in terms of the influence of these medications on their lives. Their stories range from how on a daily basis they are grateful to be on these medications to the challenges they find themselves having to contend with due to being on the medications. The children shared on the benefits of being on the medications specifically mentioning their state of health, which enabled them to have much more meaningful life. During the interview with the children it turned out that almost all of them can attest to how sick they used to be before they were on the medication and comparing that to their current situation of good health.

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**APPENDIX 1: LETTER OF
INFORMED CONSENT –
CHILDREN (ENGLISH)**



Faculty of Humanities
Department of Social Work & Criminology

INFORMED CONSENT

(This means that I am freely giving my permission to take part in the research study).

1. NAME OF RESEARCHER

(This is the person who is the leader of the research study and the place where she lives).

Mrs E Mmatli
PO Box 602100
Gaborone
Botswana
Tel: +267 3184511 +267 72543945

2. NAME OF the UNIVERSITY

(This is the name of the university where the researcher is doing her research)

Department of Social Work and Criminology, University of Pretoria, Pretoria, 0002

Contact person:

Dr C.E. Prinsloo, Tel: 012-420-2601

3. RESEARCH TITLE

(This is the name of the research study).

TITLE: The influence of antiretroviral medications on the lives of the children in Botswana. (This means that the researcher will gather information to see in what way the antiretroviral medications affect the children's lives on a day by day basis.)

4. PURPOSE OF THE RESEARCH STUDY

(This explains the reasons for the research study).

The main reason for doing the research is to find out from the children's perspective how being on antiretroviral medications influence their lives.

5. WHAT IS INVOLVED IN THE RESEARCH STUDY

(This explains the way in which I will be involved in the research study).

The research study will gather information by way of carrying out individual interviews with children.

- The children will be asked a few broad questions and they will respond to them according to their will
- The information that the children will share will be documented on paper
- The information that the children share will also be recorded on audio tape.
- This form is for you to sign to give permission for the researcher to obtain this information.

6. RISKS INVOLVED IN THE RESEARCH STUDY

(This indicates whether I will be harmed in any way by taking part in the research study).

I will be participating in the study that seeks to gather information on the influence of antiretroviral medication on the lives of children in Botswana. This study will be conducted in the Bamalete Lutheran Hospital. This is the clinic I visit regularly to receive my services and I feel safe and comfortable when I am there. The information that I will share will be kept in a safe in the Department of Social Work and Criminology, University of Pretoria, for a period of 10 years. I will not be identified through what I share and my name will not be used in the report.

7. BENEFITS OF THE RESEARCH STUDY

(This indicates what the good things are that will come out of this research study).

The Ministry of Health and the Bamalete Lutheran Hospital will receive a copy of the report and see how they may use it to possibly improve on the services they provide on the basis of the suggestions you may have given as service recipients.

8. WHAT ARE MY RIGHTS?

(This means that I am not being forced to give information).

I will take part in the research study freely. This means that I may, if I wish, walk away from the research process at any time. Should I prefer to walk away the information that I may have given will be destroyed and not be used. In this manner, my rights to freely take part in the research study are protected.

9. CONFIDENTIALITY

(This means that my identity and the information that I give will be protected).

The information I give will not be available to any person who is not involved in the research study. The only persons who will look at the information that I give are the researcher and the Bamalete Lutheran Hospital staff. The information that I give cannot be traced to me as my name will not be used. The only time that my name will be used is when I sign this form to indicate that I am willing and not being forced to take part in the research study. The research information may be used again for future research purposes. Here again, the information that I gave as well as my identity will be protected. The research information will be stored in a safe place for a period of 10 years.

10. CONTACT DETAILS REGARDING THE RESEARCH

(This means that I have the researcher's details, should I need to contact her for any reason regarding the research).

Mrs Esther Mmatli

PO Box 602100

Gaborone

Tel: 3184511 or 72543945

11. AGREEMENT TO PARTICIPATE IN THE RESEARCH STUDY

(This means that I freely give my permission to participate in the research study. It also means that I am not being forced to give information against my will).

This document was signed at _____ on the _____ day of _____ 2008.

SIGNATURE OF RESPONDENT:

.....

SIGNATURE OF PARENT/GUARDIAN ON BEHALF OF A MINOR:

.....

SIGNATURE OF RESEARCHER:

.....

MRS E. MMATLI



**APPENDIX 2: LETTER OF
INFORMED CONSENT –
CHILDREN (SETSWANA)**



Faculty of Humanities
Department of Social Work & Criminology

**TUMALANO KA KITSO YA SE O SE DIRANG (O TLHALOGANYA
SE O SE DUMALANANG)**

**(Mo go raya gore ke nna le seabe mo patlisisong ka itlhophelo yame ebile
ke sa patelediwe).**

1. LEINA LA MMATLISISI

(Yono ke ene moeteledipele wa patlisiso le ko a ka bonwang teng).

Mrs E Mmatli

PO Box 602100

Gaborone

Botswana

Tel: +267 3184511 +267 72543945

2. LEINA LA YUNIBESITHI

(Eno ke yunibesithi e mmatlisisi a batlisisang ka fa tlase ga kaelo ya yone)

Department of Social Work and Criminology, University of Pretoria, Pretoria
0002

Yo o ka botswanag mabapi le patlisiso:

Dr C.E. Prinsloo, Tel: 012-420-2601

3. SETLHOGO SA PATLISISO

(Le ke lone leina la patlisiso).

Seabe/phete ya tiriso ya melemo ee ritibatsang bogale jwa mogare mo
matshelong a bana mo Botswana.

(Mo go raya gore mmatlisisi o tla dira potsolotso ka ga go dirisa melemo e e
ritibatsang bogale jwa mogare go amang matshelo a bana a letsatsi le letsatsi ka
teng.)

4. LEBAKA LA GO DIRA PATLISISO

(Se ke tlhaloso ya lebaka la go dira patlisiso e).

Patlisiso e e dirwa ka maikaelelo a go batla go itse go tswa mo baneng gore
tiriso ya melemo ee ritibatsang bogale jwa mogare e ama matshelo a bone ka
ditsela tse di ntseng jang.

5. SE SE DIRAGALANG MO PATLISISONG

(Mo ke tlhaloso ya seabe sa me mo patlisisong).

Patlisiso e tla botsolotsa bana ka bongwe ka bongwe.

- Bana ba tlaa botswa dipotso di se kaenyana mme ba di arabe ka fa ba bonang ka teng.
- Dikarabo tsa bana di tlaa kwalwa mo pampiring.
- Tse bana ba tlaa di bolelelang mmatlisisi di tlaa gatisiwa ka sekapamantswe .
- Pampitshana e e diretswe lona gore lefe tetla ya go botsolotswa mo patlisisong e.

6. BODIPHATSA JO BO KA TLHAGELANG MOTHO YOO NNANG LE SEABE MO PATLISISONG

(Se se tlhalosa gore a ke ka tlhagelwa ke bodiphatsa bongwe ka go nna le seabe mo patlisisong e).

Ke tlaa nna le seabe mo patlisisong ee botsolotsang ka seabe/phete ya tiriso ya melemo ee ritibatsang bogale jwa mogare mo matshelong a bana mo Botswana. Patlisiso etla a bo e direlwa mo kokelong ya Bamalete Lutheran Hospital. Kokelo e, ke kokelo e ke amogelang ditirelo mo go yone ka gale mme ebile, ke ikutlwa ke sosologile fa ke le mo go yone. Se ke tlaa se abelanang le mmatlisisi se tlaa tshwarwa ka tsela ee babalesegileng mo lebakeng la dingwaga tse some. Leina lame le tlaabo le sa dirisewe ka jolo ga gona go nna le kamano epe fa gare game le se ke tlaa se abelanang.

7. BOMOSOLA JWA PATLISISO

(Se se tlhalosa bomosola kana se se ka akolwang ka go dira patlisiso e).

Lephata la Botsogo ga mmogo le kokelo ya Bamalete Lutheran Hospital ba tlaa amogela pego ya patlisiso; mme moo go ba fe sebaka sa go bona gore ba ka e dirisa jang. Go ka nna ga raya gore ba bone kafa ba ka tokafatsang go aba ditirelo/dithuso tsa bone ka teng.

8. DITSHWANELO TSA ME KE ENG?

(Mo go raya gore ga ke patelediwe go tsena mo potsolotsong)

Ke tla a tsenelela potsolotso ka tshosologo. Mo go raya gore ke ka tswa kana ka tlogela patlisiso ka nako nngwe le nngwe e ke e batlang. Fa go ka diragala gore ke tswe mo patlisisong e, dikgang tse ke setseng ke di buile ga dina go dirisiwa e le bontlha bongwe jwa maduo a patlisiso, mme di tlaa senngwa. Ka tsela ee ntseng jalo ditshwanelo tsame tsa go tsenelela patlisiso di sireletsegile.

9. BOSEPHIRI

(Mo go raya gore leina lame le dikgang tse ke tlaa di buang le mmatlisisi di tlaa tshegediwa e le sephiri).

Dikgang tse ke tla a di ntshang mo patlisisong e ga dina go bonwa ke ope yo o seng bontlha bongwe jwa patlisiso e. dikgang tse di ka bonwa fela ke mmatlisisi le badiri ba Bamalete Lutheran Hospital. Mme ebile tsone dikgang tseo ga gona ka fa go ka itseweng ka teng gore di ne di tswa mo go nna ka jaana ga gona go dirisiwa leina lame. Leina lame le a go dirisiwa mo pampering e fela, jaaka ke tla a bo ke tlhalosa gore ga kea patelediwa go tsenelela patlisiso. Dikgang tse ke tla a bong ke di ntshitse di ka dirisiwa go dira patlisiso e nngwe, mme fa go ka diragala jalo e tla a bo e tse e le mo tsamaisong ee tshwanang ya go sireletsa bosephiri. Dikgang tsa patlisiso e di tlaa bewa ka tsireletsego lebaka la ngwaga tse some.

10. TSELA YA GO BONA MMATLISISI

(Mo go raya gore ke itse gore ke ka bona mmatlisisi jang fa ke mo tlhoka).

Mrs Esther Mmatli

PO Box 602100

Gaborone

Tel: 3184511 kana 72543945

11. TUMALANO YA GO NNA LE SEABE MO PATLISISONG

(Mo go raya gore ke tsenelela patlisiso e ke gololesegile ebile ke sa patelediwa).

Mokwalo o o saenetswe kana o beilwe monwana kwa
_____ ka di _____kgwedi ya
_____ 2008.

MONWANA WA NGWANA:

.....

MONWANA WA MOTSADI/MOTLHOKOMEDI MO BOEMONG JWA NGWANA:

.....

MONWANA WA MMATLISISI:

.....

MRS E. MMATLI



APPENDIX 4: INTERVIEW SCHEDULE (ENGLISH)



Interview schedule

1. Why do you think you are attending this clinic (Bamalete Lutheran Hospital)?
2. What medications do you get here at the clinic?
3. Why do you think you need these medications?
4. What do you think these medications are supposed to do?
5. How does taking these medications affect your life?
 - a. Your body?
 - b. Your school life?
 - c. Your life with your friends?
 - d. Your life with your family?
 - e. Other?
6. Or what does taking these medications mean in your daily life?
7. Is there anything that anybody who helps you with these medications could know or do?



APPENDIX 4: INTERVIEW SCHEDULE (SETSWANA)



Interview schedule

1. Ka fa o tlhologanyang ka teng ke eng o tla kokelwaneng e (Bamalete Lutheran Hospital)?
2. Melemo ee fiwang fano ke e fe?
3. Ke eng fa o tlhoka melemo e?
4. Melemo e tshwanetse go dira eng/bereka eng?
5. Go dirisa melemo e go ama Botshelo jwa gago jang?
 - a. Mo mmeleng wag ago?
 - b. Mo go tseneng sekole ga gago?
 - c. Botshelo jwa gago le ditsala tsa gago?
 - d. Botshelo jwa gago le balelwapa la gago?
 - e. Ditsela tse dingwe tse wena o di bonang?
6. Kgotsa go tsaya melemo e go raya eng mo botshelong jwa gago jwa letsatsi le letsatsi?
7. A go nale sengwe se ope yo o go thusang ka tsela epe mabopi le go tsaya melemo ya gago o ka se itseng kana a se dira?