THE ACCESSIBILITY OF HIV/AIDS RELATED HEALTH INFORMATION TO PEOPLE LIVING WITH HIV/AIDS IN KHOMAS REGION (WINDHOEK).

A THESIS SUBMITTED IN FULFILMENT OF THE REQUIREMENTS FOR

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MASTER OF ARTS IN NURSING SCIENCE

AT THE

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STUDY SUPERVISORS: PROF. A. VAN DYK
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DECLARATION

I, Penehafo Angula hereby declare that this thesis is a true reflection of my original research, and has not been submitted for a degree in any other institution of higher learning.

PENEHAFO ANGULA

………………………..

Signature **Date:**

COPY RIGHT

DEDICATION

This study is dedicated to all the people who are living with HIV/AIDS in Namibia, their families, relatives, friends and caregivers.

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First of all I thank the Almighty God for giving me strength and wisdom to be able to complete this study.

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ABSTRACT OF THE STUDY

HIV/AIDS is a worldwide problem generally and a particular one in Namibia. Acquired Immune Deficiency Syndrome (AIDS) is a fatal disease caused by the Human Immune Virus (HIV). This disease has become an epidemic, infecting tens of millions of people worldwide. The virus, which is transmitted from one individual to another through the exchange of body fluids (such as blood or semen, and breast milk) attacks white blood cells, thereby causing the body to lose its capacity to ward off infection. As a result many AIDS patients die of opportunistic infections that strike their debilitated bodies. Living with HIV/AIDS is a challenge. (Hirsch, Kett & Trefil, 2002, p. 1).

The purpose of this study is to explore and describe the accessibility of HIV/AIDS related health information to people living with HIV/AIDS (PLWHA) in the Khomas region in Namibia.

The objectives of the study are to:

- Explain the experiences of those diagnosed with HIV/AIDS.
- Determine the accessibility of HIV/AIDS related health information for People Living with HIV/AIDS (PLWHA)
- Determine the knowledge of PLWHA on support systems

A qualitative approach formed the basis of this research design. Qualitative research is a means

of exploring the depth, richness and complexity inherent in a phenomenon. Qualitative methods are particularly useful when describing a phenomenon from the “emic” perspective, which is the perspective of the informants’ point of view (De Vos et al., 2002, p. 357). This specific approach was selected because the researcher intended to explore and describe how people living with HIV/AIDS access information to live positively with the disease. The in-depth interviews were conducted where the participants gave their experiences on living with HIV/AIDS.

On the accessibility of health information in general, this study found that only some people have access to HIV/AIDS information. But access to HIV/AIDS related information is limited for some participants who identified language, lack of interest, alcohol abuse, time allocation as some of the barriers. Most reading materials are either written in English or Afrikaans which made it impossible for most of PLWHA to understand it. Those who understand those languages do not share it with others because of stigma.

Participants also indicated that alcohol abuse does contribute to inaccessibility to such information. Participants stated that some PLWHA are abusing alcohol and do not listen when information is presented whether through the radio or at community meetings. Some participants also claimed that the time allocated to HIV/AIDS programme on National television (NBC) and radio stations is not enough. All these factors made it impossible for PLWHA to have access to relevant information.

Recommendations were formulated. Problems such as the language issue need to be looked at by all stakeholders who are responsible for preparing information materials. More programmes on

HIV/AIDS are needed on radios and NBC television in local languages. Stigma and discrimination need to be addressed seriously from all levels of society. This will enable PLWHA to live positively. Poverty was also identified as a barrier to living positively with HIV/AIDS. It is, therefore, recommended that specific programmes/projects need to be developed to reduce poverty among PLWHA. Approaches to enable men to participate in HIV/AIDS issues should be developed and strengthened. Further research related to this study is recommended.

ABBREVIATIONS AND ACRONYMS IN MY THESIS

A, B, C,	Abstinence, Be faithful, Correct and Consistent Condom use.
ACT	AIDS Care Trust
AIDS	Acquired Immune Deficiency Syndrome
ANC	Ante-Natal Clinic
ART	Antiretroviral therapy
ARV	Antiretroviral drugs
CAA	Catholic AIDS Action
CBO	Community Based Organization
CCN	Council of Churches in Namibia
CD4	Cell surface receptor molecules expressed on some T-Lymphocytes and Other Immune System Cells
ELISA	Enzyme-Linked Immunosorbent Assay
ELCINAA	Evangelical Lutheran Church in Namibia AIDS Action
FHI	Family Health International
HBC	Home Based Care
HIV	Human Immune Deficiency Virus
IEC	Information, Education and Communication
I-TECH	International Training and Education Center on HIV
LE	Lironga-Eparu
MOHSS	Ministry of Health and Social Services

MTCT	Mother to Child Transmission
MTP II	Second Medium Term Plan
MTP III	Third Medium Term Plan
NACP	National AIDS Control Programme
NACOP	National AIDS Coordination Programme
NANASO	Namibian Networks of AIDS Service Organizations
NASOMA	Namibia’s Social Marketing Campaign of Condoms
NBC	Namibian Broadcasting Corporation
NBC TV	Namibian Broadcasting Corporation Television
NGO	Non Governmental Organization
NVP	Nevirapine
OI	Opportunistic Infections
PCP	Pneumocystis Carnii Pneumonia
PCR	Polymerase Chain Reaction
PGL	Progressive Generalized Lymphodenopathy
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
STIs	Sexual Transmitted Infections
TAKMOS	Tate Kalunga Tukwathela Momukithi GwoAIDS
TB	Tuberculosis
TV	Television
UNAIDS	United Nations Programme on HIV/AIDS
VCT	Voluntary Counseling and Testing

VZV	Varicella-Zoster Virus
WHO	World Health Organization

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CHAPTER 1

1.1 INTRODUCTION AND BACKGROUND TO THE PROBLEM

This chapter gives an overview of the background to the problem of HIV/AIDS in general and for Namibia in particular. The research has been focused on those people who are infected with HIV/AIDS and their accessibility to health related information. This chapter also gives an overview of the problem statement, the purpose of the study as well as the specific objectives. In addition the operational concepts are defined according to this study.

Acquired Immune Deficiency Syndrome (AIDS) is a fatal disease caused by the Human Immune virus (HIV). In recent years this disease has become an epidemic, infecting tens of millions of people worldwide. The virus, which is transmitted from one individual to another through the exchange of body fluids (such as blood or semen, and breast milk), attacks white blood cells, thereby causing the body to lose its capacity to ward off infection. As a result many AIDS patients die of opportunistic infections that strike their debilitated bodies. Living with HIV/AIDS is a challenge (Hirsch, Kett & Trefil, 2002, p. 1).

According to Meiring (2003, p. 36) people living with HIV/AIDS go through stages and degrees of health and illness. Some days they feel fine and healthy, while others they feel ill, anxious or depressed. The people who are living with the virus have fears. They fear death and dying. They have fear of what will happen to their children once they are gone. Some are worried about what will happen to their infected children if they become ill. Some are worried about their possessions, and others are afraid of becoming sick and unable to care for themselves. They are concerned about what their friends will say once they realise that they are HIV positive. Therefore, almost every individual reacts differently when they learn about their HIV status, and by implication it means that they will deal differently with their lives afterwards. In some cases people living with HIV/AIDS may become depressed, angry, bargaining and later on acceptance may follow (Health Systems Development Unit, 2001, p. 13).

This is evident from the study of Meiring (2003, p. 119) where she found that one of her participants wanted to commit suicide after receiving his HIV positive results. Some people avoid their family once they have tested positive and keep their HIV status a secret. The same participant in Meiring's study (2003, p. 119) also indicated that it was difficult for him to disclose his HIV status to his family. He felt like keeping the results to himself. This is where the problem of dealing with the disease of HIV/AIDS becomes problematic.

Infected people face different opportunistic infections that need proper treatment. They also face conditions like anxiety, fear, physical and emotional pain. When they are not supported on how to deal with the infections and conditions, their lives can become very stressful.

There are many programmes available where the HIV/AIDS infected persons and their relatives can learn about the disease and how to live a meaningful life with it. However, it is not always possible for persons living in rural areas particularly to have access to these programmes and thus the needed information, since they don’t have media like televisions, radios and newspapers to access information (Lush, Samaria, Petrus & Elago, 2003, p. 17).

On the other hand, review reports on HIV/AIDS in Namibia state that there is a high level of awareness among the general population (89%) on many aspects of HIV/AIDS, but generally this awareness is inadequately translates into action as cited in Third Medium Term Plan (MTP III) (2004-2009) (MOHSS, 2004, p. 7). The consequence is that although people have access to all this information (spread, prevention, abstinence, use of condoms) people are still infected every day. This is evident from the following statistics; by the end of 2003, there were 37,8 million people infected with HIV/AIDS in the world; 17 million of them were women, while 2,1 million were children under the age of 15. In the same year, 4,8 million people were newly infected with HIV and 630,000 were children; while 2,9 million people died from HIV/AIDS related causes. UNAIDS as cited in Global Health Council report (2005, p. 2) predicts that by the year 2010, an additional 45 million people will be infected with HIV in 126 low-income and middle-income countries, unless the world succeeds in mounting drastically expanded global prevention efforts (Global Health Council report, Nov. 2005, p. 2).

According to the epidemiological report HIV infected people in Namibia were 99,532 by the end of 2001. By 2003; people who were infected with HIV were 136,000

(Government of Namibia, MOHSS, 2002, p. 1). The total number of 6,881 persons were hospitalised due to HIV/AIDS related diseases and infections. The total number of deaths from AIDS has increased to 15,080 since the beginning of the epidemic (MOHSS, 2002, p. 1). It is evident from the statistics that millions of people are living with HIV/AIDS in the world. The question to be asked is how accessible is all the HIV/AIDS related information to PLWHA in Namibia. It might be that people have access to the necessary information. On the other hand, it could also be assumed that many don’t have that access. This usually leads to ineffective coping mechanisms, which cause ineffective responses, disrupting the integrity of the person and suggesting that this notion could easily be broadened to the family unit where ineffective family coping patterns lead to family functioning problems. People living with HIV/AIDS can live healthy and productive lives when they have access to HIV/AIDS information, treatment, care and support.

1.2 PROBLEM STATEMENT

Although the Ministry of Health and Social Services had already launched a National AIDS Control Programme (NACP) in 1990 with the aim to educate people about HIV/AIDS and to give them information on many aspects of HIV/AIDS, Namibia still faces a problem concerning the increase of the disease statistics. Furthermore, there are counsellors who give health information on how to live positively with HIV/AIDS, but they are far too few. This results in a statement made by Lush, Samaria, Petrus & Elago (2003, p. 48) that in many instances people are just given their results without being counselled, or they are just quickly counselled with not much attention, and not much information.

Over and above all these constraints most reading materials that are available are either written in English or Afrikaans, making it difficult for people who do not understand these languages to get the information they so desperately need. Thus, people who are living with HIV/AIDS are frequently left to cope without information.

The problem is that it is not clear how people from different environments have access to information concerning HIV/AIDS to enable them to live a positive life. It is not clear what support in the form of acceptance, affection, respect, love, moral support, access to necessary medical treatment, healthy diet, clean water and accommodation, they receive from the community, friends and families. It is also not clear what information concerning sexual behaviour, transmission from mother to child and anti retroviral treatment such people receive. Therefore, this study seeks answers to the following study questions:

1. Is information concerning living positively with HIV/AIDS accessible to all people?
2. If not, what should be done to make it more accessible to all people?
3. If it is accessible, do people apply it correctly?

1.3 PURPOSE OF THE STUDY

The purpose of this study is to explore and describe the accessibility of HIV/AIDS related health information to People Living with HIV/AIDS (PLWHA) in the Khomas region (Windhoek) in Namibia.

1.4 RESEARCH OBJECTIVES

The objectives of the study are to:

- Describe the experiences of PLWHA when diagnosed with HIV/AIDS.
- Determine the accessibility of HIV/AIDS related health information for PLWHA.
- Determine the knowledge of PLWHA on support systems.

1.5 PARADIGMATIC PERSPECTIVE

1.5.1 Ontological assumptions

The assumption is that there is a reality out there that can be studied namely people diagnosed with HIV/AIDS and their access to information about it. The related assumption of determination refers to the belief that phenomena are not haphazard events, but rather have antecedent causes. If a person is diagnosed with HIV/AIDS it is assumed that there must be reasons why such persons do or do not live a "healthy life". Furthermore these reasons can be identified and understood. Therefore, the investigation will be directed to try to understand the underlying reasons of the phenomena (Blackie, Appleby & Orr, 1998, p. 182).

It can be argued that the concept of a "healthy life "is to do with human behaviour, and human behaviour is complex. However, humans have the ability to shape and create own experiences (Clark, 1998, p. 102).

According to Tomey & Alligood (1998, p. 531), Pender's health promotion model identified cognitive perceptual factors in individuals that are modified by situational, personal and interpersonal characteristics which result in the participation in health-promoting behaviours in the presence of a cue to actions.

The individual's perceptions of his/her own ability to change his/her health can motivate his/her desire for health. Once a person realises that s/he is able to do something for his/her health, then s/he will feel motivated. If a person who is HIV positive learnt that there are drugs (ARV) which are available to prolong lives for People Living with HIV/AIDS (PLWHA), that person would be motivated to look for treatment. S/he will even be motivated to apply other actions that help to prolong her/his life.

Furthermore the individual's strong belief that new behaviour is possible can influence the occurrence of that behaviour. When PLWHA are taught/informed to practise safe sex to prevent re-infections, they can develop that perception that safe sex is possible. Once they believe that, then they would put it into practice, thereby promoting their health and prolonging their lives. It is, therefore, concluded that perceived efficacy is associated with change in behaviour.

Also, individuals may be more inclined to begin or continue health-promoting behaviour if the benefits of such behaviour are considered high. Living positively includes many changes in lifestyle behaviour. They need to stop using alcohol and smoking. They need to eat nutritious food. They need to practise safe sex or even abstain, if possible. They need to look after their own health well by preventing occurrence of opportunistic infections. They are expected to adapt to new changes in order to keep their immune systems as normal as possible. These are challenges for them. However, looking at the benefits which they could gain if they change their behaviour could motivate them to change. This would only be possible if health information is made accessible to such people.

1.5.2 Epistemological assumptions

The researcher is a lecturer in community health nursing science, and has observed numerous problems in the community with persons diagnosed with HIV/AIDS who do not have information on how to live a healthy lifestyle. These phenomena motivated the researcher to become involved.

The researcher attempted to hold her personal beliefs and biases in check so far as possible during the study, to avoid influencing the phenomena under investigation. Furthermore she sought to be objective as far as possible in her pursuit of knowledge (Polit & Hungler, 1999, p. 11).

1.5.3 Methodology

The method that was used was the qualitative approach, because the researcher wanted to describe the dimensions, variations and importance of the phenomena. The method and design will be described in chapter 2.

1.6 OPERATIONAL DEFINITIONS

1.6.1 Accessibility: According to Allen (1991, p. 7) in the Concise Oxford Dictionary of the Current English, accessibility means something within the reach of people. In this study accessibility means that health information should be within the reach of all those who are HIV positive throughout the country. It should be written/given in the languages that the people can read and understand. It could also be given through radio and television.

1.6.2 Health information: Generally speaking, health information can be seen as the information concerning health problems, health needs, the methods of preventing and controlling health related conditions (Dennill, King & Swanepoel, 2001, p. 36). This includes information on how to promote health. In this study health information refers to the information on how to live positively for HIV positive people. Such information is concerned with balanced diet, exercise, healthy lifestyles, prevention of re-infection and protecting others; health information related to opportunistic infections and their treatment; health information related to seeking medical care, when the need arises; health information related to supplements, vitamins and minerals to boost the immune system; information about support groups where to find them and how. And finally information related to antiretroviral treatments and the criteria of receiving it (MOHSS, 2001, p. 25).

1.6.3 People Living With HIV/AIDS (PLWHA): These are people who tested HIV positive as well as those who have developed AIDS (MOHSS, 2001, p. II). HIV and AIDS are two different terms. Being HIV positive does not mean that a person has AIDS. There is a difference between being HIV positive and having AIDS. In this study PLWHA are those who tested HIV positive and those who have HIV and AIDS related diseases/ conditions.

Human Immune Virus (HIV): This is a virus that causes AIDS. HIV positive means having antibodies to HIV in the blood (Health Systems Development Unit, 2001, p. 12).

Acquired Immunodeficiency Syndrome (AIDS): This is the advanced stage of HIV. When a person develops opportunistic infections, the immune system is depressed and the CD4 count could not be replaced any more. This is the end stage of HIV infection (Schoub, 1999, p. 35).

1.6.4 Living positively: In this study living positively means having a positive attitude to living with HIV/AIDS, to help a person to live as long as possible by doing the following: -eating a balanced diet whenever possible, staying as active as possible, resting when tired and getting enough sleep. In addition to such a person should continue to work for as long as possible, keep him/herself busy and earn money, get both physical and emotional affection, meet with friends, family and with other PLWHA, and talk to someone about one's illness, joining support groups if possible, seek medical attention when needed, maintain personal hygiene, avoid smoking and alcohol, and avoid getting STDs, re-infection and spreading the infection to other people (MOHSS, 2001, p. 25).

1.7 SUMMARY

This chapter covered the background of the problem. It looked at the overview of

HIV/AIDS globally as well as in the Namibia context. The problem statement, on which the study is based, was described. The purpose of the study, which has focused on the people who are infected with HIV, and their accessibility to health information, is discussed. The study objectives are explained. The paradigmatic perspective for the study is described. The operational definitions to clarify the meaning of different concepts according to this study are also explained. The next chapter will be on the methodology and design that is used in this study.

CHAPTER 2

RESEARCH DESIGN AND METHOD

2.1 INTRODUCTION

The purpose of this chapter is to describe and justify the research design and method of this study. The study is conducted to determine how people who are living with HIV/AIDS access health information to enable them to live positively with the virus/ disease.

2.2 RESEARCH DESIGN AND METHOD

A research design is defined as a set of guidelines and instructions used by the researcher to make appropriate decisions to address the research problem (Polit & Hungler, 1999, p. 12). A qualitative, explorative, descriptive and contextual design is used to gain insight into the meaning of accessibility of HIV/AIDS related information to people living with HIV/AIDS (PLWHA).

- **Qualitative**

A qualitative approach forms the basis of this research design. Qualitative research is a means of exploring the depth, richness and complexity inherent in a phenomenon. Qualitative methods are particularly useful when describing a phenomenon from the "emic" perspective, which is the perspective of the informants' point of view (De Vos, Strydom, Fouche & Delport, 2002, p. 357). This specific approach was selected because the researcher intended to explore and describe how people living with HIV/AIDS access information to live positively with the disease.

Furthermore, this design is based on the notion that it involves human beings and their environment (Morse & Field, 1998, p. 8).

❖ Exploratory

The concept “explore” implies scrutinising unknown regions for the purpose of discovery. Such research strives to explore the dimension of a phenomenon so that it provides more insight (Babbie & Mouton, 2001, p. 272). This study was exploratory in nature because the literature was explored and interviews were conducted in order to gain more insight into and understanding on how people diagnosed with HIV/AIDS access health information to live positively with the disease.

❖ Descriptive

A descriptive study attempts to provide a truthful account of a phenomenon and experiences in the world around us. It describes how things actually are (De Vos et al., 2002, p. 109). It is the researcher’s intention and main goal to describe how people living with HIV/AIDS access health information to live a positive life with the disease.

❖ Contextual

When using a contextual research design, the immediate and intrinsic nature and significance of a phenomenon of interest is studied in terms of its immediate context (Schneider, Eliot, LoBiondo-Wood & Haber, 2003, p. 141). This study is contextual because it focuses only on people living with HIV/AIDS and their access to information about the disease.

2.3 TARGET POPULATION

The target population refers to the population that the researcher wished to study. The population in this study consists of people who are living with HIV/AIDS, and those who have opportunistic infections in Khomas region, Windhoek.

2.3.1 SAMPLE AND SAMPLING METHOD

Purposive sampling method is used. Purposive sampling is a method of sampling in which the sampling units are deliberately selected according to certain criteria that are known to be important and are considered to be representative of the target population (Burns & Grove, 2005, p. 352). Purposive sampling is a conscious selection by the researcher of certain subjects to be included in a study. Participants must have similar characteristics in order to increase the theoretical understanding of the phenomenon being studied. Purposive sampling was used because the logic of power behind purposeful selection is richness of information. It was difficult to get participants for the study because of factors such as stigma and fear, to name a few. Fourteen (14) participants were willing to participate in the study. They are between 22-40 years old. Only two of them are males.

Due to the sensitivity of the topic it was not easy to get participants. After many attempts the researcher cooperated with an organisation called Lironga Eparu (LE). It means “learning to survive”. This is an organisation of the people who are living with HIV/AIDS. Their head office is based in Windhoek. These are the people who disclosed their HIV positive status publicly. This organisation assisted the researcher to meet the participants in Khomas region, Windhoek. Eventually fourteen (14) participants agreed to be interviewed.

2.3.2 DATA COLLECTION.

Data collection instrument

Data collection refers to a series of interrelated activities aimed at gathering rich information to answer emerging research questions. In this study data were collected using a semi-structured interview guide with participants. In depth interviewing was selected because it is a type of interview, which researchers use to elicit information in order to achieve a holistic understanding of the interviewee’s point of view or situation. It can also be used to explore interesting areas for further investigations. Open–ended questions can be used in this type of interview and probing for more information when necessary.

According to Berry (1999) (http; // www.leeds.ac.uk/educol/documents/000001172.htm.) the interview guide allows for in-depth probing, and it also permits the interviewer to keep the interview within the parameters traced out by the aim of the study. The purpose of probing is to deepen the response of a question and to get as much information as possible.

Before the interviews were conducted a pre-testing of the interview guide was conducted.

Pre-testing

One interview was done with a person with HIV/AIDS, who was willing to participate, to test the interview guide that was used. Some questions were then rephrased. After that the researcher also visited a HIV/AIDS counsellor to determine what information he usually covers during post-test counselling sessions.

Both the interview and the visit to the counsellor helped the researcher to prepare better for the interviews with the participants. Following this, the researcher made the necessary adjustments to the interview guide.

Interview guide

Interview guide refers to guidelines that are set up prior to the interviews to guide the researcher. It is a data collection tool (DeMacro, 2005, p. 52). Although the researcher has used an interview guide, the participants were free to talk as much as they wished.

The following aspects were developed in the interview guide and were used during the interviews:

- Experiences of living with HIV/AIDS: when tested, what information given regarding the meaning of HIV positive results.
- Information on behaviour change: sexual activity (safe sex, pregnancy), life style (alcohol, smoking, stress) and nutrition.
- Information received on health care and treatment of HIV/AIDS: opportunistic

infections (what, when and where), anti retro viral therapy (aims, when, CD4-testing, adherence, and side-effects, other drugs interference), PMTCT-programme, sources of information (Counsellors, health professionals, media, CBOs).

- Information received on support system: groups (social, spiritual, financial, HBC-givers and family).

The interview guide was prepared in English, but most of the interviews were conducted in Afrikaans and in Oshiwambo. The reason for that was that the majority of the participants could not understand or speak English. Only two interviews were conducted in English. Another two were conducted in Afrikaans. The balance (ten) was done in Oshiwambo. Among these fourteen interviewees only two were males. Questions were not in a fixed order and their wording was not necessarily the same. For the interviews that were done in languages other than English, the researcher translated data into English without changing their meaning. After the interviews some participants asked her questions. She gave them answers and appropriate advice. After each interview the researcher prepared a complete record of the interview.

❖ Preparation for the field visits

An employee at the Lironga Eparu centre assisted the researcher to meet the participants and build a trust relationship with them. The contact person (employee at Lironga Eparu) was briefed and presented with research proposal. The participants were briefed by Lironga Eparu employee before the researcher arrived. The day of the interviews the researcher briefed and informed the participants about the purpose of the interviews and what is expected from them. She also introduced herself to the participants before the interviews. As some did not have money for transport to come to the centre money was provided to them as well as refreshments. When rapport was established the researcher started to conduct the interviews that same day.

- **Conducting the in-depth interviews by the researcher**

The interviews were conducted at the LE centre in Windhoek in a private room, which was a quiet location that was free from distractions and in a comfortable atmosphere. The duration of each interview ranged between 45-50 minutes. The researcher created an atmosphere of trust, friendliness and openness from the moment the participants arrived. The researcher conducted the interviews alone.

The following introduction was used by the researcher to obtain information on how the participants access information regarding HIV/AIDS. "*First of all I would like to thank you for coming to the interview. You were specifically selected since you are able to provide valuable information regarding access to health information on living positively with HIV/AIDS. I would also like to tell you that the aim of the interview is to collect information concerning access to health information about HIV/AIDS to be able to address problems in this regard. No report will be prepared which identifies the views of any participant. All information will be kept confidential.*"

After the introduction participants were assured that no tape recorder would be used and the researcher explained that she would take notes during the interview.

The interview then started by the researcher posing the following question: *"Tell me* *what information did you get about HIV/AIDS when you were tested for HIV?*

❖ Role of the researcher

The researcher was a primary data collector. According to Morse and Field (1998, p. 76) data collection in qualitative research requires minimum researcher-imposed structure and maximum participant-free involvement. This principle was maintained throughout the interviews. Furthermore, the researcher maintained a close social interaction in order to enhance access to the information.

❖ Communication Techniques

In this study the following communication techniques were utilized in face to face interviews to obtain information.

Probing: This is the technique employed in interviewing to obtain a more complete answer to a question. It is a non-directive phrase or question used to encourage the respondent to elaborate on an answer (Burns & Grove, 2005, p. 397). In this study the questions were skilfully asked to encourage the participants to explain their experiences in depth, without affecting the nature of the subsequent responses.

Paraphrasing: According to Concise Oxford Dictionary of Current English (Allen, 1991, p. 863) paraphrasing is the expression of what someone else has said or written using different words, especially in order to make it shorter or clearer. It is done to confirm the understanding of the interviewees in regard to what they have said. Whenever necessary, the researcher in this study restated what the participants said during the interview in order to confirm the information provided.

Clarifying: This involves questioning statements that are not understood by the interviewer or a participant with the purpose of gaining an exact understanding (Shifiona, 1998, p. 20). In this study such questions were asked to clarify unclear statements. The participants were also informed of their right to ask for clarification in case the questions were not clear to them.

Minimum Response: This is the ability of the interviewer to do more listening than responding to avoid biasing the participants. After the interview begins the interviewer encourages the participants to continue talking by nodding her/his head (Burns & Grove, 2005, p. 397). In this study the participants' perspective was obtained through attentive listening.

❖ Field notes

Field notes refer to a written account of things that the researcher heard, saw, experienced and thought in the course of collecting the data through an interview (Polit & Hungler, 1999, p. 368). Field notes were taken during the interviews and utilised later, during data analysis.

❖ Language

The interviews were conducted in English, Afrikaans and Oshiwambo. The reason for that was that some participants could not understand or speak English. Those that were conducted in Afrikaans and Oshiwambo were translated into English.

2.3.3 DATA ANALYSIS

Qualitative data analysis occurred concurrently with data collection. Qualitative analysis techniques make use of words rather than numbers as a basis of analysis. Analytical reasoning skills are required when conducting content analysis (Burns & Grove, 2005, p. 548).

The primary purpose of qualitative data analysis is to discover and reveal how accessible health information is to people living with HIV/AIDS. The researcher needed to be familiar with the data that were gathered. This involved reading notes and transcripts and recalling observations and experiences until the researcher became immersed in the data. The steps that were followed to analyse the data were as follows;

Data management and reduction

Because of the volume of the data acquired in a qualitative study the initial effort at analysis was focused on immersion with the data and data reduction to facilitate examination (Burns & Grove, 2005, p. 548).

Immersion in the data

This process involves reading and rereading the script and notes, recalling observations and experiences until the researcher becomes immersed in the data (Burns & Grove, 2005, p. 549). The researcher spent a lot of time reading the notes and field notes and trying to learn about the experiences of people living with HIV/AIDS and how they access information regarding living positively with HIV/AIDS.

Data reduction

This refers to a technique for analysing qualitative data that focuses on decreasing the volume of data to facilitate examination (Burns & Grove, 2005, p. 548). During this phase the researcher started attaching meaning to elements in the data in order to discover common ground regarding access to information on HIV/AIDS.

Developing of themes and categories

A good starting point in analysing qualitative data is to look for themes and sub-themes that have emerged and to use these to structure the results section of the research report (Hancock, 2002, p. 34). A theme is an abstract entity that brings meaning and identity to a current experience and its variant manifestations. In this study three themes and their sub-themes were developed.

2.3.4 TRUSTWORTHINESS

Measures to ensure trustworthiness of the data are described according to Lincoln and Guba's model (1985, pp. 290-291). Trustworthiness is a method of establishing rigour in a qualitative research without sacrificing relevance. Lincoln and Guba's model of trustworthiness involves four criteria namely credibility, transferability, dependability and confirmability.

Strategies to ensure trustworthiness of the data

❖ Credibility

Credibility is the truth-value obtained from the discovery of human experiences as they are lived and perceived by the participants. The activities that increase the probability of credible findings are: prolonged engagement, persistent observation, peer debriefing, member checking, and establishing the authority of the researcher (Lincoln & Guba, 1985, p. 300). In this study credibility was demonstrated through data source triangulation, where by people living with HIV/AIDS were participants.

Prolonged engagement

In this study this was achieved because the researcher spent a reasonable time in establishing rapport and trust with the participants and assured them that their anonymity would be maintained.

Persistent observation

According to Lincoln and Guba (1985, p. 304) persistent observation provides depth to an inquiry. It involves identifying those characteristics and elements in the situation that is most relevant to the problem being pursued and focusing on them in detail. In this study the researcher took notes of the typical events and explored them further as the interviews progressed.

Member checking

Member checking entails that information, interpretation and conclusions are checked with the participants from whom data were originally collected. This was done by follow up questions to verify the experiences of the participants.

Peer review

Peer review provided the researcher with an opportunity to eliminate bias that might have clouded good judgement. For this study, research proposal was scrutinised and approved by the relevant research committees.

❖ Transferability

Transferability is the strategy used to ensure applicability. It refers to the extent to which the findings can be applied in another context. The study provided the background information about the participants and the context and setting to allow others to assess how transferable the findings could be. If the same study were repeated especially with people who tested HIV positive before the introduction of ART, the findings would be the same. However, this might differ from region to region (Polit & Hungler, 1999, p. 699).

❖ Confirmability

Confirmability means obtaining direct and often repeated affirmations of what the researcher has heard, seen or experienced with respect to the phenomenon under study. Confirmability includes the researcher obtaining evidence from participants about findings and interpretations (Morse & Field, 1998, p. 105). In this study the following were done:

- Raw data were recorded and field notes were made during the interviews
- Coding reduced data and the products were analysed

- Data were categorised in themes, sub-themes and conclusions
- Independent co-coder was used to verify the accuracy of the data analysis.

2.4 ETHICAL ISSUES

Since the research was on a very sensitive topic, briefing about the need for the study was done in cooperation with Lironga Eparu centre. The participants were asked to give consent voluntarily. Anonymity was ensured, therefore no names of participants have been written, and a coding system was used instead. Confidentiality was also assured. Participants were given freedom to withdraw from participating in this study without any pressure (none withdrew; all participated till the end). Their privacy was respected; therefore participants were interviewed individually (alone). One participant was interviewed at a time and was alone with the researcher.

2.5 SUMMARY

This chapter has covered the research design, sampling and sample selection. The reasons for choosing that specific sample were explained. Data collection method was explained and motivated. The themes and sub-themes, which were formulated during data collection, were described. Data analysis, trustworthiness and ethical issues in this study were described.

CHAPTER 3

ANALYSING OF THE DATA AND LITERATURE REVIEW

3.1 INTRODUCTION

The findings of this study have been presented using the coding system and themes. Three main themes and their sub-themes were identified. These themes are derived from the interview guide that was used during the interviews. The interview scripts and field notes were used to analyse the data. Before analysing the data, a summary of all the interviews was compiled. That made it easier for researcher to make references to the interpretation of her findings.

The following themes and sub-themes were arrived at. Analysis of the data was done together with literature review.

3.2 THEMES AND SUB-THEMES

THEMES	**SUB THEMES:**
3.2.1 THEME 1: Positive and negative aspects experienced when diagnosed with HIV/AIDS	❖ Counselling and testing ❖ Sharing health information

3.2.2 THEME 2: A need to access basic and specific information when diagnosed with HIV/AIDS	❖ Basic information ▪ Sexual activity ▪ Lifestyle ▪ Nutrition ❖ Specific information ▪ Opportunistic infections ▪ Antiretroviral therapy (ART) ▪ Prevention of Mother to Child transmission (PMTCT)
3.2.3 THEME 3: Participants' knowledge on support systems	❖ Groups ❖ Families

3.2.1 THEME 1: POSITIVE AND NEGATIVE ASPECTS EXPERIENCED WHEN DIAGNOSED WITH HIV/AIDS.

3.2.1.1 Introduction

HIV/AIDS is diagnosed by means of a blood test. “HIV antibody testing has benefits, risks and responsibilities that should be weighed before an individual decides on whether to be tested or not” (Ungvarski & Flaskerud, 1999, p. 42). It is against this background that a person needs to be counselled properly (given proper and accurate information) before testing as well as after testing. Furthermore, people should be counselled by well-trained counsellors.

3.2.1.2 Counselling and HIV testing

Counselling refers to the help trained counsellors give to a person to make an informed decision and to prepare the person to receive the results. There are two types of counselling. The **pre-**test counselling, which refers to the counselling that is done before the HIV test. Pre-test counselling helps a person to decide whether s/he wants to be tested or not. **Post**-test counselling is the counselling that is done when the person who was tested is given her/his HIV test results. It helps the person to make future life choices and decisions based on those results (Catholic AIDS Action, 2004, p. 2).

HIV Tests

These refer to tests when a blood is taken from a person to determine that person's HIV status. Generally health care workers may look at patients and try to guess if they have HIV infection. This is actually wrong. The only way one can be sure is through Voluntary, Counselling and Testing (VCT). The blood tests that detect HIV antibodies are the most commonly used HIV test. The antibody tests include **Rapid tests** that are being used at VCT Centres and enzyme-linked immunosorbent assay (**ELISA)** that is being done in laboratories. The virus can also be detected directly by using **Polymerase chain reaction** (**PCR**) technology. The PCR is more expensive and is not widely available. In Namibia it is mostly used to test HIV in infants, and is only available in

Windhoek currently (October, 2007). When HIV antibody test results are positive they indicate that the person has been exposed to HIV infection and has developed antibodies to the virus after the window period of up to 12 weeks. Western Immunoblot test is used as confirmatory test (I-TECH participant handbook, Jan-Feb., 2007).

Although it is indicated in the literature how important it is to know one’s HIV status, not everybody is willing to be tested voluntarily. However, the advantages of knowing one’s HIV status versus the disadvantages of not knowing are well documented. In spite of this people sometimes fear to be tested and know their HIV status. They are afraid of all the problems of living with HIV/AIDS. This statement is also supported by the study done by Nashandi (2002, p. 18) that people infected with HIV fear the discovery of their HIV status. They fear stigmatisation and rejections by partners, friends and families as well as by their colleagues. This is also evident from the study of Meiring (2003, p. 110) which indicated that some people distance themselves from others, once they learnt that they are HIV positive.

However when tested for HIV, preparation, explanation and counselling before and after being tested are needed. It is a basic right and a need of people to be informed about the diagnostic tests to be conducted, as well as the diagnosis, treatment and their health status in general.

In this study it was found that some people who tested HIV positive were given their results without being given proper information on how to live with the disease positively (post-test counselling). No difference was made between being HIV positive and having

AIDS. This is evident from the following statements:

“When I was given my HIV positive results in 1995, I was told that I have AIDS”

“I was given my HIV positive results without counselling. I went home to wait for death”

“In 2001 I was sick and tested HIV positive. No proper counselling was done. I was only encouraged to tell my parents about my HIV status”

“I was given my HIV positive results at Walvis Bay in 1996 without any counselling. In 2004 I was re-tested in Windhoek. It was at that time I got information.”

“I was a blood donor and tested HIV positive in 1997 (Windhoek). I was not counselled properly. I was also too young to understand HIV/AIDS issues” a statement from a 29-year old participant.

“I was pregnant and sick in the nineties. (She did not remember the exact year). I tested HIV positive. (Pre counselling was not done properly to prepare her.) I started crying before I received my results. I had problems with accepting them that was why I tore up my hospital card (health passport). I did not go for follow-up as I was told.”

These statements are supported by findings in other studies. According to Jackson (2002, p. 185) discussions with some doctors in Zimbabwe revealed that they do not have enough time to counsel patients effectively. This experience is also echoed in many countries. For instance hospitals in Ghana, some patients who are suspected to have HIV-related diseases are tested without their consent. Some are referred for counselling only after their test. They do not receive pre-test counselling. This places a heavy burden on the counsellors who will conduct the post-test counselling on those patients who have been tested without pre-counselling and without giving informed consent (Jackson, 2002, p. 185). In Namibia the same situation is experienced as cited by Nashandi (2002, p. 18).

Post-test counselling varies from client to client. It is being done according to the needs, stage of illness, the context of the test and the personal coping style and life situation of the client. Some studies indicated that in many cases people will be too shocked to respond to post-test counselling. A further appointment is needed where a partner or other relative can be included. The other alternative is to refer them to support groups (Jackson, 2002, p. 200).

One participant said *"I was told about support groups by a counsellor at Grootfontein. When I came to Windhoek I went to AIDS Care Trust (ACT), Catholic AIDS Action (CAA) and to Red-Cross to get HIV/AIDS related information."*

Some positive remarks were also made. There were some participants who said that they were given information (counselled) properly when they received their HIV positive results. This is evident from the following statements.

One participant said: *"I was tested HIV positive in 2001 in Windhoek. I was counselled at the hospital"*

Another one states*: "I was tested in 1999 in Windhoek and was properly counselled at* *hospital"*

"I was tested HIV positive in 2000 (WHK). I was counselled at hospital as well as at Lironga Eparu centre."

"I went for a visit to Botswana in June 2004. I became sick and was tested HIV positive. Pre-test counselling was done before testing. After my results I was post-test counselled."

"When I got my HIV positive results, only doctor counselled me psychologically. It was in 2001. Only when I came to Windhoek in 2005, then fell pregnant that I was counselled by a counsellor from Lironga Eparu."

These positive experiences were also found in other studies. For example Jackson (2002, p. 188) indicated that many studies have found that access to information on one's HIV status is a human right. People have the right to know their HIV status so that they can protect themselves and others from infections and re-infections. It also helps to improve their health care and plan for the future.

Early knowledge of HIV infection can help people seek appropriate medical care on time. People can also look for other support that helps them to cope better psychologically and medically with the infection. Many studies (Jackson, 2002, p. 188; Health Systems Development Unit, 2001, p. 13) reveal that voluntary counselling and testing (VCT) has benefits. There are clear preliminary indicators that VCT is important in helping people to reduce risky behaviours, although societal and cultural pressures may sometimes override these. VCT also enable people living with HIV/AIDS to access appropriate services, make decisions about the future and family planning. It also enables them to benefit from intervention to prevent HIV infections and mother to child transmission (MTCT) (Jackson, 2002, p. 188).

3.2.1.3 Sharing of health information between health workers, HIV positive patients and family.

The results revealed that there were also positive and negative aspects concerning sharing of health information with a person who is diagnosed with HIV/AIDS. Health information refers to any information concerning health problems, health needs and methods of diseases prevention and how to control and treat them. It also includes information on health promotion (Dennill et al. 2001, p. 36). By implication it also means that knowledge should be shared. People diagnosed with HIV/AIDS should get all the information they need to live positively with the disease, but they should also get a chance to raise their concerns on how to live positively.

As one participant said: *" I was only told to abstain from sex. No other options such as condom use were discussed."*

Some participants in this study indicated how difficult it is to live positively even if they have HIV/AIDS related information. This is evident from the following statement.

"Circumstances force people not to live positive. For example some of us practised unsafe sex in exchange for money and food."

Health workers inform people on health issues by using health education as a strategy. Education is the strongest weapon in combating the fear and stigma associated with HIV/AIDS care in rural communities (Ruxin, Binagwaho & Wilson, 2005, p. 31). Therefore, giving people living with HIV/AIDS (PLWHA) health information on how to live positively, is giving them the strongest weapon to combat the fears they have. Education could help these people to change their unhealthy life styles to positive living life styles.

Health education can be done verbally or non-verbally. In most cases it is done verbally and this can cause constraints. One of the constraints is the language issue. The following concerns regarding the language issue were raised by the participants.

"Media has information, but language is the problem. Many people who are HIV positive, including me do not understand English well."

"Information is enough. The problem is the language. Most people do not understand English and Afrikaans."

"Language is the problem in access to information"

"I can read English, but I do not understand it well. This makes it difficult to follow information that is written/given in English."

"Language is the problem in access to information. Most people who are HIV positive do not know English."

Important of understanding the message

For the message to be understood, the means of communication should be effective. Any communication must attract attention so that people will make the effort to listen or read it. Once a person pays attention to a message s/he then tries to understand it, depending on the perception of the person, the message could be misunderstood. Misunderstandings can easily take place when complex language and unfamiliar technical words, or pictures containing complicated diagrams and distracting details are used. Another reason for misunderstanding is when too much information is presented and people cannot absorb it all (Hubley, 1993, p. 48).

A message will be understood if the information presented is relevant, appropriate, acceptable and put across in an understandable way. The message will also be understood if it is given or written in a familiar language. However, there can be problems, even when people speak the same language, if unfamiliar or technical words (i.e. medical terms) are used.

According to Lush et al. (2003, p. 67) there are many obstacles that make it difficult for PLWHA to access health information. Some of the obstacles identified are illiteracy and lack of human resources to give information.

It is a known fact that illiteracy is a problem in Namibian communities, especially those from the previously disadvantaged groups, but illiterate people can be accommodated by using non-verbal communication. Because of this need to communicate with illiterate people, health educators often put emphasis on pictures rather than words in posters and leaflets. Pictures are regarded as a universal language (Hubley, 1993, p. 57). To access health information regarding HIV/AIDS this strategy can also be applied.

People living with HIV/AIDS are frequently dependent on personnel at health care facilities (clinics or hospitals) to share information with them. However, the remarks were not always positive about this. One participant said:

"*I don't get information at hospitals due to nurses' attitudes. Their attitudes make me uncomfortable. I feel I can't ask them anything."*

Health workers' attitudes can be an obstacle in sharing information as indicated in the above statement. For a message to be understood, the sender/source needs to have certain qualities. The source/sender of information should be trusted by the receiver. The receiver also looks at the credibility of the source. For example, a person from the same background, who shares the same language, ideas and motivation can be a good source of information. This person is likely to be a good communicator or message sender. In some cases health workers are not the most credible source of information. Hence the need to find the most credible sources from the intended audience (Hubley, 1993, p. 49).

Most of the participants indicated that they get information from the media such as newspapers, radio and television. Some get information from friends and families while others indicated that they receive information from churches and organizations such as

LE, Catholic AIDS Action (CAA), AIDS Care Trust (ACT) and Red-Cross. Some participants received information from counselors and from health workers at health facilities.

One male participant said: "*I get information from the media such as radio, television and newspapers. People make dramas and role plays in radio and television. The problem is those who do not want to apply what they are told*."

Another one said: *"at church people are given information, especially on sexual activities. They are encouraged to be faithful to their partners*."

On the other hand, some participants indicated that they do have other problems regarding accessing information through the media. This is evident from these statements.

"*We don't have television. We only listen to the radio when it has batteries."*

"People at our house prefer to listen to Omulunga radio, for music. I do not get the chance to listen to educational programmes on HIV/AIDS issues in NBC."

Some participants said that one problem that makes people not receive information is alcohol abuse. This is evident from these statements:

"Some people do abuse alcohol. That leads them not to get information when it is presented. This contributes to the practice of unsafe sex."

"Information is enough. The problem is the people who do not want to listen. Some only drink alcohol and do not pay attention to what is being said."

It can be assumed that information is enough but if people do not have the means to get it or the attitude to receive it, then they do not have access to the needed information.

3.2.2 THEME 2: A NEED TO ACCESS BASIC AND SPECIFIC INFORMATION WHEN DIAGNOSED WITH HIV/AIDS.

3.2.2.1 Introduction

Access to information on one's HIV status is a human right. People have the right to know their HIV status so that they can protect themselves and others from infection, to improve the health care and plan their future (Jackson, 2002, p. 188).

3.2.2.2 Basic information

The basic information to be given to a person with HIV positive results includes many aspects. Firstly, information on behaviour change regarding harmful behaviours and unhealthy life styles. Harmful behaviour may help to suppress the immune system and activate the disease. Secondly, a person needs to be informed thoroughly about the transmission of the virus, safer sex and re-infections. Thirdly, information on pregnancy and prenatal transmission should be given, especially for female clients. Fourthly, information on opportunistic infections and on symptoms associated with the spectrum of HIV disease. Fifthly, the person should be well informed on where to get help, when the need arises. Sixthly, the person should be given information on antiretroviral drugs (ARV), assessment of CD4 counts and the importance of regular check-ups. Lastly a person should be given information on support systems and psychological services. Ongoing counselling should also be explained and encouraged (Unguvarski & Flakskerud, 1999, p. 44). (See also report of visit at New Start Centre, Appendix 2).

One participant said: "*I was told to change my behaviour because it plays a role in my life. I was told that behaviour influences my immune system. I could die or live longer depending on my behaviour.*"

Another one said:"*I was informed about the consequences of practising unsafe sex such as re-infections. I was also told about the influence of alcohol to the immune system of a person who is HIV positive.*"

Sexual activity

Sexual activity accounts for the majority of HIV/AIDS cases around the world. It is regarded as the principal mode of transmission (Unguvarski & Flakskerud, 1999, p. 131). It is, therefore, very important to give relevant information about it. Unguvarski and Flakskerud (1999, p. 134) further argued that: "human sexuality is inextricably woven into the fabric of all human beings, and the promotion of sexual health is a legitimate and essential function of both physicians and nurses."

It has been documented that there is a relationship between specific life events, sexual and lifestyle practices and exposure to HIV infection. Having multiple partners, having sexual intercourse during menstruation and pregnancy, the presence of genital ulcers and not being circumcised are some of the factors which are associated with HIV infection (Unguvarski & Flakskerud, 1999, p. 29).

Being HIV positive does not make a person less human. Even after the person has tested HIV positive s/he can still have sexual feelings, therefore it is very important to receive proper information regarding sexual activity. Such information will prevent re-infection and pregnancy. If a person who tested HIV positive is not given proper information about sexual activity, s/he might spread the virus to others. S/he can also get re–infections and sexual transmitted infections, which will suppress the immune system. In case of a woman, she might become pregnant and transmit the virus to her baby, during pregnancy, during labour or through breastfeeding.

Data gathered from the participants indicated that they did not know much about the transmission of the virus from mother to baby, or through breastfeeding. This is evident in the following statements.

As one participant said:*"In 2005 I was pregnant and went to clinic for the check*-*up. I was told about the prevention of mother- to- child transmission programme. We were informed as a group. I opted for testing. I was found to be HIV positive. I was counselled,* *but attention was more given to breastfeeding, safer sex and diet."*

Another one said: "*I was pregnant in 2004. I heard about the programme of prevention of HIV infection in babies at the clinic. I decided to be tested. When my results came positive I was counselled."*

Another participant said: *"I became pregnant while I was on ARVs, because I was not given information. (She started ARVs at Oshakati in 2005). I wanted to commit suicide, because that was my sixth pregnancy. I was afraid of the reaction of my relatives. I gave birth in 2006. (Baby was only a month old during the interview, and he looked sick. His results were not out yet.) I was taken to hospital. A counsellor from Lironga Eparu counselled me then."*

Some participants were told neither about the risk of re-infection, nor about the risk of pregnancy and transmission of the virus to the baby. Some of the participants were only told about condom use. No other information related to sexual activities was discussed. This is evident from the following statement:

"When I was tested in 1995 nobody told me about re-infection. I was not even told about mother-to-child transmission. As I was married and had no child I became pregnant in 2000. I gave birth and I breastfed my baby. As a result I infected my child. He is five years old now and is also HIV positive."

In this study some of the participants also indicated that they were given information on the risk of re-infection. They were also told about the influence of pregnancy on their immune system and the chance of transmitting the virus to the baby. Some were informed, but did not apply what they were told. This is evident from the following statement:

"When I was tested in 2000 for the second time, I was counselled. I was told about the risk of re-infection. I was also told about pregnancy and the chance of infecting my baby if become pregnant. I moved to Grootfontein and fell pregnant in 2001, but when I gave birth I refused to breastfeed my baby, because I was afraid to infect her. (Staff at Grootfontein hospital did not know her status at that time)."

Voluntary counseling and testing (VCT) can play a major role in preventing HIV infection to babies among HIV positive mothers and in motivating couples when the mother is HIV negative to ensure that she stays negative. The knowledge that the baby can be infected during pregnancy or through breastfeeding can be a strong motivator for couples to practise safe sex. According to Chtsike (2001) as cited in Jackson (2002, p. 148) a pilot project in Harare, which provided VCT and short-course antiretroviral therapy (ART) to pregnant mothers and their partners has motivated some men to use condoms (Jackson, 2002, p. 148).

Lifestyles

The next sub-theme derived from behaviour change is lifestyle. Lifestyle refers to the way in which someone lives. There are healthy lifestyles and unhealthy ones, which help to suppress the immune system. Unguvarski and Flakskerud (1999, p. 46) showed that through changing lifestyles, people living with HIV infection and even those with HIV-related diseases could minimise or eliminate immunosuppressive factors. Promoting healthy lifestyles and avoiding harmful behaviour can boost the immune system (Unguvarski & Flakskerud, 1999, p. 46). Lifestyle behaviour such as alcohol consumption and smoking are unhealthy, even for those who are not HIV positive. However, for the HIV positive people too much alcohol and smoking are more dangerous.

There are different findings from several studies regarding alcohol consumption and its effect on the progression of HIV disease. Kaslow and colleagues (1989) in their study (as cited in Unguvarski & Flakskerud, 1999, p. 47) claimed that they did not find any evidence of effect of alcohol on the progression of HIV disease. However, Bagastra and associates' study in 1993 (as cited in Unguvarski & Flakskerud, 1999, p. 47) found that alcohol intake did increase HIV replication, while Pol and associates found an improvement in CD4 counts after alcohol withdrawal in HIV positive alcoholic patients (Unguvarski & Flakskerud, 1999, p. 47). These are valuable findings which could convince a person that alcohol can indeed suppress the immune system in an HIV positive person, hence the importance of informing PLWHA accordingly.

Alcohol can also make a person forget to practise safe sex. This in turn might lead to re-infection as well as to pregnancy. A person may also forget to take his/her treatment if s/he is drunk or has a hangover. Alcohol might also interact negatively with some ARV drugs.

Smoking is also one of the unhealthy lifestyle activities that was looked at under the behaviour change theme. Generally smoking may cause diseases in any person regardless of his/her HIV status. But in HIV positive people smoking may influence the course of HIV disease as well as the development of pulmonary opportunistic infections (e.g. TB and pneumonia), oral mucosal lesions and periodical disease (Unguvarski & Flakskerud, 1999, p. 47).

In this study it was found that those who were counselled properly were informed about the influence of alcohol and smoking on their immune system. This is evident from the following statement:

"I stopped drinking alcohol after I was told its influence on my body."

Some participants have indicated that they were told about the importance of rest and sleep, but nothing was mentioned about alcohol consumption. Smoking was also not talked about in many cases; maybe it was not regarded as important for the non-smokers. (Participants of this study are all non-smokers) Some participants were informed on how to manage their stress, because it can also influence their immune system. One participant said:

"I was advised to prevent too much stress as it can affect my health."

Nutrition

Nutrition is another sub-theme which refers to the processes involved in taking in, assimilating and utilizing nutrients. The following nutritional processes are needed to enable the body to utilize the nutrients: ingestion, digestion, absorption, and metabolism. Nutrients are needed for tissue growth and repair as well as for body maintenance. In HIV disease any of these processes can be impaired. If one of the above-mentioned processes is impaired, malnutrition can occur. Different types of malnutrition in chronic diseases are characterised in terms of metabolic and nutritional changes. All these types can also be seen in HIV disease. There are those which are related to lack of protein-energy so that the body's needs cannot be met by diet. This results in weight loss. This type of malnutrition is called protein-energy malnutrition. It can be seen in all stages of HIV disease. The other type is acute phase response malnutrition. This is caused by metabolic changes such as infection, stress or inflammation. This type occurs during acute episodes of infections or when a person has stress. The other type of malnutrition is cachexia that occurs at the end stage of HIV disease (Pratt, 2003, p. 321).

Problems such as pain and dysphasia are secondary to a number of opportunistic infections. A person can also develop problems of nausea and vomiting due to infections. These might cause reduction of food intake and results in protein- energy malnutrition (Pratt, 2003, p. 322).

Malnutrition is the major cause of immune suppression worldwide. For an HIV positive person whose immune system is already suppressed by the virus, it is crucial to understand the importance of nutritious food in his/her daily meals. Nutritional counselling and support can improve the nutritional status of people. A high nutrient intake improves the CD4 count and it reduces the development of AIDS (Unguvarski & Flakskerud, 1999, p. 467). Hence the need to give PLWHA correct and adequate information on nutrition, which will help prolong their lives. Although food cannot cure HIV/AIDS nutrition plays a very important role in the continuum care of PLWHA (MOHSS, 2006, p. ii).

Supplementing diet with micronutrients is also helpful. Studies have shown that starting micronutrients in the first two years of HIV infections slows down the onset of AIDS. However, it is also important to know that overusing micronutrients can be dangerous. It is, therefore, necessary to explain all this information to people living with HIV/AIDS (Unguvarski & Flakskerud, 1999, p. 34). In this study there are some participants who were diagnosed with HIV in 1999 and in 2000 respectively. These participants were given information (counselled) properly. They received adequate information regarding diet. At the time of the interview they looked healthy and they said that they had not started with ARV drugs yet. In the continuum of care of HIV/AIDS nutrition is a basic requirement, therefore it is very crucial for the people living with HIV/AIDS to understand it. It is the responsibility of the health care providers and HIV/AIDS counsellors to give this information to PLWHA (Johns Hopkins University, 2005, facilitator's manual). According to the Ministry of Health and Social Services (2006, p. 6) "the more PLWHA and their caregivers know about nutrition management of HIV/AIDS and practise healthy eating, the more they can do to maintain good health and live longer."

In this study it was found that most of the participants have information on diet. They are aware of balanced diet and understand it. They know that they need to eat fruits and vegetables to keep their immune system strong. But it is not always possible to have a balanced diet. They said that owing to poverty they could not buy vegetables and fruits. This is evident from the following statements:

"I *was given information on food. I was told to eat fruits and vegetables that are available in the shops such as apples, oranges, cabbage, and carrots, but I cannot buy them. I do not work and I do not have money*."

" I want to eat a balanced diet but cannot afford it."

Some participants indicated that they were given information on diet as well as on local fruits and vegetables (nuts, beans, spinach, and some local fruits available at the north). Some participants were provided with pamphlets to go and read for themselves.

Those who received information on supplements said that they were informed not to use any supplements without consulting a doctor. The reason is to prevent drugs interference, especially for those on ARV treatment. This study has found that information on nutrition is adequate. The problem is lack of financial resources to enable people living with HIV/AIDS to have enough nutrients. It is good to encourage people to eat local food which can be obtained without paying for it.

3.2.2.3 Specific information

This study has also identified that PLWHA need information on specific aspects such as opportunistic infections, antiretroviral therapy and prevention of mother to child transmission of HIV.

Opportunistic infections (OIs).

Opportunistic infection is an illness that is caused by a germ that might not cause illness in a healthy person, but will cause illness in a person who has a weakened immune system (MOHSS, PMTCT Facilitator’s guide, 2005, Annex 6). The opportunistic infections associated with AIDS are rarely curable. They can be controlled during an acute episode. Some needs long-term therapy to prevent recurrence. It is very crucial for the health care workers or who ever are responsible in information dissemination, to understand the epidemiological characteristics of certain pathogens to provide accurate information to clients (PLWHA). This will help to prevent these opportunistic infections (Unguvarski & Flakskerud, 1999, p. 195).

As the years have passed, the incidence of AIDS-related opportunistic infections has stabilised, delaying the development of AIDS. Owing to the use of antiretroviral therapy and prophylactic drugs to prevent opportunistic infections, the lives of the people living with HIV/AIDS can be prolonged. Therefore they need information on where to get treatment when the need arises (Unguvarski & Flakskerud, 1999, p. 194).

Some of the common opportunistic infections are Tuberculosis (TB), Candidiasis, persistent diarrhoea, oral manifestations (i.e. oral thrush), respiratory conditions (such as pneumocystis carinii pneumonia (PCP)), skin infections (dermatitis) such as herpes zoster, Kaposi sarcoma and scabies (MOHSS, Guidelines for the clinical management of HIV and AIDS, 2004, p. 10).

One participant said: *"I am trained as a home based care giver by ACT. I visit other PLWHA, render first aid and refer them to hospital when necessary*.

Tuberculosis (TB)

Tuberculosis is one of the most common opportunistic infections, which threatens the health and the lives of millions of people. According to Pratt (2003, p. 125) at least one-third of the 36,1 million people living with HIV/AIDS at the beginning of 2001, were also infected with *Mycobacterium* Tuberculosis. Patient living with HIV/AIDS are more susceptible to developing TB. It is important to inform HIV/AIDS patients on different aspects of TB such as how to recognize the signs and symptoms of TB, such as coughing for more than a week, fever, lymph node swelling and so on. This will enable them to seek treatment on time. To give them hope, it is important to inform them that TB is curable even in HIV positive patients. People with HIV-related TB are four times more likely to die than those with TB who are HIV negative (Pratt, 2003, p. 134). The early diagnosis of TB is essential in reducing the risk of infecting others. It is also important so that the infected people can benefit from specific treatment such as antiretroviral therapy (ART).

One participant said: *"I was diagnosed with TB in 2004, I completed my TB treatment and now I am cured from TB."*

Skin infections

Examples of skin infections that are common in HIV infected people are herpes zoster (shingles). Herpes zoster is a skin condition caused by human herpes virus known as *varicella-zoster* virus (VZV). Shingles often occurs in HIV-infected people and is more severe because of their weakened immune system (Pratt, 2003, p. 88). Some people, especially Oshiwambo-speaking ones, do believe that herpes zoster come as a result of witchcraft. That is why if they develop it, they seek help from traditional healers rather than medical treatment. It is evident from this statement.

"*I developed some sores (like burn wounds) and went to a traditional healer. She gave me some herbs to smear on the sores and she also told me to go to the clinic*."

Diarrhoea

Diarrhoea is seen in most patients with symptomatic diseases either early or at the late stage of HIV disease. It can be caused by bacterial, protozoal, fungal or viral infections of the gut. There are also other opportunistic micro-organisms which are associated with diarrhoea in patients with early and late symptomatic HIV disease such as *Shigella, Isospora belli, Salmonella, Strongyloides stercoralis* etc. (Pratt, 2003, p. 2). In treating diarrhoea it is necessary to identify the causative agent, otherwise it will be difficult to treat. It is also important to inform people living with HIV/AIDS about food hygiene and food storage. This will help to prevent food contamination and infections of the gut. It is also necessary to give them proper information on how to treat diarrhoea at home when is not complicated and on when and where to seek medical treatment. Certain conduct could be applied to reduce the episodes of diarrhoea. It can be reduced by drinking clean water and by eating clean safe food. The PLWHA should avoid fatty foods as well as cold foods. They have to avoid high fibre foods and milk products. The PLWHA also need to be informed on what to do at home when they have diarrhoea. Personal hygiene should be emphasised such as hand washing after using a toilet and taking extra liquid to maintain their body fluids. However, they also need to be informed on when they have to seek medical help. For example, they have to seek medical help when diarrhoea is severe and when it is accompanied by vomiting (MOHSS, 2001, p. 13). In about 50% of patients with persistent diarrhoea and HIV/AIDS, no treatable infections agents can be identified. The only important form of management is maintenance of hydration and adequate nutrition (MOHSS: Guidelines for the clinical management of HIV and AIDS, undated, p. 17).

In this study two participants indicated that they were given information on how to treat diarrhoea at home. This is evident from the following statement.

"I attended a course for home based care at AIDS Care Trust. Therefore I know about treating opportunistic infections, including diarrhoea."

However, the remainder of the participants indicated that they were not given specific information on how to treat diarrhoea. One participant said:

"They *did not give me any information on how to treat diarrhoea. They told me to go to any health facility for help if I become sick."*

Candidiasis (thrush*)*

This is usually an infection of the os-pharynx, oesophagus, trachea, bronchi, lungs or vagina with yeast-like fungi of the *Candida* family, usually *Candida albicans* (Pratt, 2003, p. 432). The os-pharyngeal candidiasis is more common in early symptomatic disease as a result of advancing HIV disease and declined CD4 T cells. A patient might complain of pain in the mouth and difficulty in swallowing. The other type of candidiasis is the vulvovaginal. This is found in women. They experience abnormal creamy white vaginal discharge, vaginal or vulva itching, or dysuria and/or pain during sexual intercourse (dyspareunia). Both these forms of candidiasis respond well to treatment, although recurrence is common (Pratt, 2003, p. 86).

The findings revealed that participants were not informed regarding this opportunistic infection as is evident from the following statements of participants.

"I was only told about TB and diarrhoea. I was never told about the problem of vaginal fungus."

"I was only told to look out for any sexual transmitted infection, but not specific ones."

Pneumocystis Carinii pneumonia (PCP)

According to Pratt (2003, p. 445) *Pneumocystis carinii* is originally thought to be a protozoon, now known as a fungus belonging to *Ascomycetes* yeast. It causes pneumonia, which is called pneumocystosis, pneumocystis pneumonia or PCP in immunocompromised people. PCP is the most common cause of death in people with AIDS. However, with the effective chemo-prophylaxis for PCP and the availability of ART in most developed and some developing countries, the incidence of PCP has decreased (Pratt, 2003, p. 94).

According to the guidelines for the clinical management of HIV and AIDS (MOHSS, 2003, p. 70), cotrimoxazole is being given to prevent pneumonia caused by PCP. In this study it was found that some participants were not informed about pneumocystis carnii pneumonia (PCP).

"I was only told about diarrhoea, no other infections."

Antiretroviral therapy (ART)

ART is a treatment regimen that incorporates a combination of different antiretroviral drugs (ARVs) (Pratt, 2003, p. 437). In simple words antiretroviral drugs (ARV) can be seen as the weapons that are used to attack the HIV in the body.

After several studies, medical personnel started to understand the viral replication. They devised a technique to monitor the virus (HIV). This made it possible for them to plot the predictable stages and events associated with a changing inverse relationship between a rising viral load and falling CD4-cell counts. When the viral load is higher, the CD4 falls down and there is higher chance for opportunistic infections to occur. This will lead to the worsening of a patient’s health. Antiretroviral drugs were then developed to slow down the destructive viral replication (Pratt, 2003, p. 363). According to Jackson (2002, p. 70) antiretroviral drugs reduced AIDS and AIDS-related deaths in developed countries.

ARVs slow down HIV replication, making the viral load very low or even undetectable in the blood. This helps CD4 counts to recover. As a result a person’s immune system will be normal again. A person will not develop opportunistic infections any more, and will not need prophylaxis as long as the ARVs remain fully effective (Jackson, 2002, p. 70).

These ARVs were first only available in developed countries. In Namibia, antiretroviral therapy (ART) was introduced in 2003. It became accessible in some state health facilities. Before that only few people who had medical aid schemes or money were able to afford antiretroviral drugs. However, with the help of Global Fund to fight AIDS, TB and Malaria, and or the Namibian government in general and of the Ministry of Health in particular, accessibility of ARVs to people becomes a reality. Guidelines to constitute the basis for ART in Namibia were developed (MOHSS, 2003, p. ii).

According to ART guidelines there are only two ARV regimens that are followed in the Namibian context. Therefore, it is very important for the client (PLWHA) to understand ART adherence to prevent therapy failure or toxicity. Once a person develops treatment failure with the first line ARV regimen, s/he will go for second line therapy option.

However, the number of second line therapy options is limited. It is less effective than the first line therapy. There also may be cost implications. For many patients on ART, the second line regimen is their last option for durable suppression (MOHSS, 2003, p. 14).

For the people who are not on ART yet, it is necessary to inform them about the availability of ARVs. They need to know where they can get them and when. Yet, it is also very important to make them understand that ART is not an emergency. It is the last option of HIV/AIDS care continuum. They also need to know that there is a criterion that is looked at before the commencement of therapy. For example, the CD4 counts, drugs adherence and lifelong commitment are some of the things that are looked at before ART (MOHSS, 2003, p. 6).

According to the Ministry of Health and Social Services ART guidelines (2003, p. 2), adults can start ART when they have clinical AIDS (WHO-stage IV HIV disease), irrespective of CD4 counts. They can also start with ART when their CD4 counts are below 200/mm3. It is very important to inform PLWHA who are not on ARV yet to keep their CD4 counts in the normal range. This will help to delay the start of ART.

Antiretroviral drugs are toxic drugs. They can build up poisons in the body. These poisons can cause side-effects, such as liver diseases, nausea and vomiting (Jackson, 2002, p. 72). ART is a life long treatment. It needs personal commitment. Therefore, it is better to delay it whenever it is possible. Once the PLWHA are properly informed and have support, they will be able to delay ART. Those on ART need to be empowered to adhere to treatment. They also need support. This will help them to live positively and adhere to treatment.

In this study some participants have received sufficient information about ART. Nine (9) of the participants who are on ART, indicated that they are well informed about ART. They know the importance of treatment adherence. They are aware of possible side-effects. They are also well informed about the drugs interaction which is why they do not take other medications without their doctors' prescriptions. These nine participants started with ART in Khomas region. This is evident from these statements:

"I was told not to take any drugs without consulting the ARV clinic staff."

"I was told about the importance of treatment."

One participant had started her ART at Oshana region (Oshakati Hospital) in 2005. She came to learn more about ARVs at Lironga Eparu in Windhoek. She indicated that she had a problem finding a treatment supporter, because she did not disclose her HIV status at that time.

However, there is one participant who is also on ARV, but is not well informed about

ART. She receives her ARVs at Katutura medical centre. This is evident from her statement that follows:

"My child is also HIV positive. The doctor said she should start with treatment (ART) but the hospital staff do not want to give her. They said they do not trust me, because I do not bring her for her TB follow up. I am worried."

This is an indication that this participant was not given proper information about ART criteria.

The other participants who are not on ARV yet have also indicated that they are aware of ARVs. They know where to get them. Their CD4 counts are being checked regularly. This will help to detect when CD4 counts are decreasing, so that they can start with ARVs.

With the availability of ARVs, HIV/AIDS may become a manageable chronic illness. This might result in restoration of economic productivity and social functioning. However, the success of the implementation of ART depends on the commitment of both the client (PLWHA) and the health care system (health care providers) and all stakeholders in HIV/AIDS matters (including society at large).

Prevention of Mother-To-Child Transmission of HIV (PMTCT)

Mother-to-child transmission (MTCT) is known as vertical or perinatal transmission.

This transmission can occur during pregnancy (**in utero**), during birth (**intrapartum**) when the newborn comes into contact with maternal fluids, shortly after birth (**post partum**) or during the early months of life through breastfeeding (Pratt, 2003, p. 212). According to Jackson (2002, p. 143) HIV transmission to babies is the second most common mode of transmission in Sub-Sahara Africa. Without PMTCT interventions, 30% or a higher percentage of HIV positive pregnant women will pass HIV to their babies. About 3,600 of the estimated 12,185 positive pregnant women in Namibia will pass the virus to their babies (I-TECH, PMTCT notes, January-February, 2007).

The PMTCT programme was launched by the Ministry of Health and Social Services in March 2002, in Namibia. The aim of the programme is to prevent mother to child HIV transmission. It has been established that using ARV reduces the chances of children being infected by their mothers during pregnancy and during labour and delivery (MOHSS, 2004, p. 1). The drug that is being used for this programme (PMTCT) in Namibia is Nevirapine (NVP). It is used as a single dose to the mother and exposed newborn. It is simple to administer, making it a more feasible option in a resource limited setting. There are no side-effects from a single dose which is also one of its advantages. Nevirapine has been chosen because of its simplicity, low cost and potential for widespread use (MOHSS, 2004, p. 7).

This programme applies four strategies to prevent mother to child HIV transmission or rather parent to child transmission:

1. To prevent HIV infection in women of reproductive age.
2. To prevent unintended pregnancy in HIV infected women.
3. To prevent of mother to child transmission through the use of ARV

and other practices.

4. To provide comprehensive care to HIV infected women, partners

and children (MOHSS, 2004, p. 1).

However, all these four strategies will only be effective if the people have access to health information.

This study has looked at the women who are already infected and their access to information regarding PMTCT. Prevention of pregnancy in HIV positive women is one of the positive living behaviours. Those who came to know their status while pregnant need to be informed about the programme. One participant said*:" I was pregnant when I found out that I am HIV positive. I was informed about the risk of transmitting the HIV to my baby. That is how I became a member of the orange baby programme at LE."*

This will help reduce mother to child transmission. Although the emphasis of this programme is on mothers, there is also a need to look at the partners/fathers. Once male partners are aware of the risk of transmitting the virus to their babies, they might act responsibly. They will understand the importance of practising safe sex to reduce the chance of transmission.

In her study, Nashandi (2005, p. 25) points out that encouragement of pregnant women to come with their husbands/partners for pre-counselling is being emphasised during health education sessions at antenatal clinics. This is an indication that it is necessary to include men in this programme of prevention transmission in children. Nashandi also indicated that according to World Health Organization (WHO, 1999, p. 21) one strategy that can be used to make PMTCT a success is mother–to-mother-to-be (m2m2b). This is a mentorship programme for HIV infected pregnant women. The mothers who have recently delivered return to antenatal clinic (ANC) as mentors. The aim is to educate, counsel and support HIV infected pregnant women. At the clinic, mentor mothers share personal experiences. They encourage adherence to treatment plans for the pregnant women. However, Nashandi did not indicate whether this programme is also available in Namibia or not (Nashandi, 2005, p. 26). But some participants in this study have pointed out there is a similar programme in Namibia at LE that is called orange babies programme. Group counselling is given to the pregnant women at ANC. They are being informed about the programme and its benefits. Those who opted for HIV testing would then receive comprehensive counselling. On follow up visits, mothers are given continuous counselling on different aspects. They are informed about psychological support, infant feeding, nutritional counselling, family planning and opportunistic infections treatment (Nashandi, 2005, p. 5).

In this study the people who tested HIV positive while pregnant, before the introduction of PMTCT, were not informed of mother to child transmission. This is evident from the following statements.

"I was tested in 1995 for the first time. I was HIV positive. In 2000 I became pregnant with my first child. I was tested again. I was not informed about the chance of transmitting the virus to my baby. I breastfed him for 3 months, then I was advised to stop. He was already infected. He is 5 years old and he is also HIV positive."

"I became pregnant in 2005, while on treatment. I was not informed about the risk of giving the virus to my baby. I was never counselled properly, until I became pregnant. After that I was referred to Lironga Eparu. That is where I got information about PMTCT. Now I am a member of 'orange babies'. I am even sterilised not to become pregnant any more."

"I was pregnant in 2000 and tested HIV positive for the second time. I was not informed about the chance of transmitting the virus to my baby. I breastfed her, then I was asked by a doctor why I breastfeed while I am HIV positive. No further explanation was given."

Those who were tested HIV positive after the introduction of PMTCT (in Windhoek) indicated that they were well informed. They are aware of the risk of transmitting the virus to their babies. This can be done either during pregnancy, during labour and delivery, or through breastfeeding. One participant suggested that condom use should be encouraged as family planning method for HIV positive, rather than other methods.

Once PLWHA understood the risks of transmitting the virus to their children, there is hope that mother to child transmission will be reduced. This will only be possible, if they are well informed about those risks.

3.2.3 THEME 3: PARTICIPANTS' KNOWLEDGE OF SUPPORT SYSTEMS

3.2.3.1 Introduction

"Support and self-help groups have been proposed as the key interventions for people living with illness" (Uys & Cameron, 2004, p. 81). According to Uys & Cameron (2004,

p. 81) support groups can be family members, friends and neighbours who care for the sick people they know out of sense of love or duty. In the case of PLWHA, support groups can be people who are also infected or affected by HIV/AIDS. Sometimes there are people who volunteer to care or to support for others but they also need support from outside.

3.2.3.2 Support groups

In Namibia there are several support groups. These groups support PLWHA in different ways. Some support groups give moral support, some render physical care to the sick ones, some do continuous counselling, whist others even provide materials such as food and clothes to the needy people. This study looked at the awareness of PLWHA regarding these groups. The findings are that most participants are aware of these support groups. Friends or relatives informed PLWHA about support groups. Most participants were referred to Lironga Eparu for support, whilst others participants are members of support groups elsewhere.

All participants in this study are aware of support groups in their communities. They know where to go when they need them. They used to go to support groups for psychological and emotional support. They do share information. Some do receive spiritual support from their respective churches. This is evident from the following statements.

"I was told by fellow patients about Lironga Eparu. That is how I joined it."

"When I was pregnant I was referred to Lironga Eparu by the nurses from ante-natal clinic."

"I do receive spiritual support from our church. I am a member of women's group in our congregation and we talk about HIV/AIDS related issues."

3.2.3.3 Family support

Many people who are HIV positive rely on their families for support. But in some cases family members and relatives reject them. They do this because of fear or stigma as is evident from these statements:

"My brother-in-law has thrown me out of his house, once he learnt that I am HIV positive."

"My relatives do not support me. They discriminate against me. I think that they lack information about HIV/AIDS."

"My boyfriend abandoned me after he learnt that I am HIV positive."

This is an indication of lack of information and misconception regarding HIV/AIDS. There is a need to educate families and relatives of PLWHA about the fundamentals of HIV/AIDS. With correct information they will be able to support their infected family members. According to Jackson (2002, p. 212) the quality of care given by family and community members is likely to improve greatly, if they are offered some basic training in counselling and nursing. The carers also need support to know that they are doing the right thing. Meeting the needs of the carers and families is also important just like meeting the needs of PLWHA (Jackson, 2002, p. 212).

The rest of the participants indicated that they receive support from their family members and relatives.

3.3 SUMMARY

This study has found that some people have received information that helps them to live positively. However, there are some who did not receive proper information. This was supported by quotes of the participants. Some have indicated language, alcohol abuse, and lack of interest as the barriers in making health information more accessible to PLWHA. It was also indicated that even if information is adequate, the problem is how to apply it. Some participants try to live positively. Yet some pointed out that it is not always easy since there are some circumstances that force them not to live positively. Accessibility to information alone is not enough to make people live positively. Multi-faceted approach is needed.

CHAPTER 4

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

4.1 INTRODUCTION

This study aimed to explore and describe the accessibility of health information related to HIV/AIDS that helps PLWHA to live positively with the disease. The study focused on the people who are living with the disease. Obviously they were the most suitable people to answer these study questions:

1. Is the information concerning living positively with HIV/AIDS accessible to all?
2. If it is not, what should be done to make it so?
3. If it is accessible, do people apply it?

4.2 CONCLUSIONS

Conclusions are made according to the objectives that were set for the study.

4.2. 1 OBJECTIVE 1

Describe the experiences of the participants when diagnosed with HIV/AIDS

It was concluded that participants made both negative and positive remarks concerning their experiences when they were diagnosed with HIV/AIDS. Some were not prepared properly or counselled concerning the testing and diagnosis, while others were counselled.

Some participants were given their HIV positive results without being counselled, whilst others were even told that they have AIDS instead of being told that they are HIV positive. Most of the participants who were not well informed are those tested in the nineties, as well as those tested in regions other than Khomas region. This could be caused by lack of updated information and shortage of human resources.

According to Jackson (2002, p. 199) for many people it is very difficult when they hear that they are HIV positive for the first time. Some people might be shocked and this makes it difficult for them to pay attention to what is said during post-counselling sessions. Acceptance helped people to cope, whilst those who did not accept their HIV positive status when they were told for the first time, had problems in coping. However, after accepting their status they started to cope. Acceptance plays an important role in changing behaviour, so if someone does not accept his/her HIV positive status, change behaviour would not be possible.

Furthermore, according to the guidelines for the clinical management of HIV and AIDS (MOHSS, undated, p. 11) receiving an HIV positive diagnosis has a profound impact on any person’s life. It is even more profound for a healthy person and adequate preparation of the person for the diagnosis is important to facilitate acceptance and positive living. Appropriate counselling, ensuring informed consent, confidentiality and non-discrimination are essential components of this process.

4.2.2 OBJECTIVE 2

Access to basic and specific information concerning living positively with HIV/AIDS

It was concluded that some PLWHA had access to health information that helps them to live positively with the disease. They were well informed when they were tested and knew the difference between HIV and AIDS, while other participants indicated that they did not know the difference between HIV-positive and AIDS. Some do not have access to basic and specific information on how to live positively with the disease. Those who do not have access to information concerning all aspects of HIV/AIDS do not have the advantage of trying to live a healthy and positive life.

On the other hand, some participants indicated that although they knew about the importance of living positively, for example, through protected/safe sex, they still had unprotected sex though they knew their HIV status.

Unguvarski and Flakskerud (1999, p. 131) pointed out that unsafe sexual activities are the most common mode of HIV transmission. Some PLWHA in this study indicated that they were aware of the risks of re-infections and they were also aware of the risk of pregnancy and transmission of the virus from mother to child. However, they did not always practise safe sex. The problem remains of how people can be convinced to change their sexual behaviour to minimise risks. Nobody can play policeman/policewoman in other people’s bedrooms. However, something needs to be done to change people’s behaviour and perception about practising unsafe sex. Thus, although information is available, putting it into practice is another story.

This study found that most PLWHA who are on ART did understand the purpose of treatment. They are aware of possible side-effects and they knew the importance of treatment adherence. Those who are not on ART are being followed up. Their CD4 counts are being monitored regularly. This enables them to start with ART when their CD4 counts falls. This study concluded that information regarding ART is adequate for those who are already on treatment (ART). However, these findings cannot be generalised to all PLWHA.

Generally this study found that only some people have access to information whilst others do not have access and some participants indicated that access to information is limited. They identified language, lack of interest, alcohol abuse, time allocation as some of the barriers in accessibility to information. Most reading materials are written in either English or Afrikaans. This made it impossible for most of PLWHA to understand it. Those who understand those languages do not share information with the others because of stigma. Some have identified lack of interest from PLWHA. They said that some people do not pay attention to what is being said about HIV/AIDS matters and do not know about it. Participants also indicated that alcohol abuse does contribute to inaccessibility to information. They said that some people abuse alcohol and do not listen when information is presented, whether through the radio or at community meetings. Some also claimed that the time allocated to HIV/AIDS programmes on National television (NBC) and radio stations is insufficient. All these factors made it difficult for PLWHA to have an access to information.

4.2.3 OBJECTIVE 3

Determine knowledge of PLWHA on support systems

It was concluded that some participants know about support groups and benefited from them, while others did not. Some did not even have support from their families and were discriminated against. Some participants in this study also indicated that they were discriminated against by their relatives, families and neighbours because of their HIV status. Some were thrown out of the house when they revealed their HIV status. Thus stigmatization and discrimination are still very rampant.

Stigma is a label that society imposes on people, which undermines the way people are viewed and/or the way people view themselves. Discrimination is regarded as the unfair treatment of a person based on things like race, gender, religion and sexual orientation. (I-TECH training notes, 2007). “HIV infected individuals are vulnerable because of the connotations linked to the most widespread transmission modes i.e. homosexuality, drug addiction, multiple sexual affairs.” This leads to stigmatisation, violation of their privacy, breach of confidentiality and social exclusion (Bernett & Erin, 2003, p. 62).

This study found that stigmatisation contributed to unsafe sexual practices. Some participants pointed out that they had unprotected sex while they knew their status. They did it because they were afraid to tell their partners, being afraid of rejection and isolation. This study had also concluded that stigma can prevent people living positively.

This study also concluded that poor male participation/involvement in HIV/AIDS issues contributes to stigmatisation and discrimination. This leads to unsafe sexual activities. The two male participants in this study indicated that there is a concern for poor male involvement in HIV/AIDS matters. They pointed out that men generally do not want to go for HIV testing. Those who tested positive do not want to disclose their status, unlike most women. This study suggests that stigmatisation and discrimination need to be addressed seriously from all the angles to enable PLWHA to live positively.

Furthermore, this study also concluded that some participants could not live healthy lives because of poverty. According to Pratt (2003, p. 419 in the WHO report of December 2001) it was indicated that “poverty causes diseases and that disease causes poverty, a cycle that cripples economic growth in developing countries.”

This study had found that poverty made it impossible for some PLWHA to live positively. Some women (HIV positive) did indulge in unprotected sexual activities in exchange for money/food. Although they were aware of the risks of re-infection and pregnancy, they were forced by circumstances beyond their control. These are the real problems on the ground.

This study concluded that although PLWHA have adequate information regarding nutrition, their main problem is poverty. Some of them indicated that even if they knew that they should eat fruits and vegetables, they were unable to buy them. Most PLWHA were unemployed and had no financial support. During counseling sessions people are told to eat fruits and vegetables as well as to have a balanced diet. The reality is that they cannot afford to do so. It is, therefore, concluded that poverty prevents PLWHA from living positive, even if they have access to information.

Furthermore, even if PLWHA have knowledge on support systems, they do not receive enough support to enable them to live positively. It is, therefore, necessary to strengthen the support systems in the communities.

4.3 RECOMMENDATIONS

This study identified some barriers, concerns and shortcomings to access health information that help PLWHA to live positively with the disease. The following recommendations are made:

4.3.1 Experience on living with HIV/AIDS

It was found that stigmatisation and partner involvement are some obstacles in living positively with HIV/AIDS. Therefore, this study suggests that stigmatisation and discrimination need to be addressed seriously from all the angles of society to enable PLWHA to live positively. It can be done through the following strategies.

- **Prevention**

Re-education should be conducted regarding HIV/AIDS. Society at large should be educated not to discriminate against others. It needs to understand ways of HIV transmission. Society should be informed about how a person can prevent HIV. “HIV/AIDS should become a disease ‘spoken about’ and ‘not whispered about’“(Nashandi, 2002, p. 96). The NDF programme “**REMEMBER ELIFAS**” should be used to sensitise men about HIV/AIDS issues. This programme is aiming at educating people (especially soldiers) on sexual change behaviour regarding HIV transmission and prevention measures. Men should also be encouraged to accompany their wives/partners to ante-natal clinics. They will get a chance to understand prevention from mother to child transmission. Hopefully it will also help them to practise safe sex to reduce mother-to- child infection.

- **Training and health education**

Health care workers should be well trained in HIV/AIDS issues. They would then act as role models to the society. Once the health care workers understand HIV/AIDS issues well, they would transfer the information to others. Organisations such as CAA, ELCINAA, and TAKMOS should teach people not to discriminate against others. The church should play a role in fighting stigma and discrimination. Male politicians, especially those in parliament, should act as role models. They should educate other men through their contributions during parliament discussions.

- **Approaches**

A new approach is needed to reach out to men since poor partner involvement was indicated as an obstacle in practising safe sex. Men who have knowledge in HIV/AIDS should help other men. This can be done either through meetings for men only, visiting them at their workplaces, using radio programmes and so forth. The Ministries such as those of Gender Equality and Child Welfare, Safety and Security and the Defence should be responsible to reach out to men. Ministers can use preaching approaches during church services to put the message across.

4.3.2 Accessibility to information

Language was identified as one of the barriers in access to health information. Therefore, the following suggestions are made:

- **Language**

The language issue needs to be looked at by all the stakeholders who are responsible for preparing information materials. More reading materials should be written in local languages. Pamphlets and leaflets that are written in local languages should be available to all. Pictures with clear messages should also be used as ways of communication. This will help to reach illiterate people. The Information, Education and Communication (IEC) unit from MOHSS should be responsible for compiling such leaflets and pamphlets.

- **Approaches**

More programmes on HIV/AIDS are needed on radios and NBC television in local languages. The Ministry of Information and Broadcasting should work hand in hand with NBC to enable it to change some existing programmes or add new programmes that cover HIV/AIDS aspects. The government in general and the MOHSS in particular and the organisations for PLWHA should be at the forefront for these developments. The following health education methods are suggested to make information more accessible.

- Community meetings can be held through community leaders/regional councillors where people can be educated on HIV/AIDS.
- Church leaders can play a role in giving health education and information on HIV/AIDS aspects to their church members.

It is, therefore, recommended that these methods be strengthened.

4.3.3 Support systems

The results of this study revealed that support is lacking specifically on the question of poverty. Although poverty is a complicated aspect to deal with, more could be done to assist in this regard. Poverty was identified as a major obstacle to living positively with HIV/AIDS, because of the lack of financial means, for example to afford proper nutrition to help live positively with the disease. The following suggestions are made.

- **Projects/income generating activities**

It is recommended that projects for PLWHA need to be developed throughout the country. The PLWHA should be asked to identify possible projects that can be developed for them in their respective areas. For example, they can start with gardening projects which would help them with income and food provision. The coordinators for these projects should be PLWHA themselves to ensure transparency. LE, CAA and Red-Cross should be assigned the role of monitoring the projects to ensure that the beneficiaries are real those who are in need.

- **Financial support**

The donor agencies such as UNAIDS, the Global Fund, and local entrepreneurs should be approached for financial assistance. The MOHSS should re-consider the re-introduction of the social grant for poor, unemployed people who are HIV positive. Needy people (PLWHA) should at least be provided with N$150.00 per month or provided with food. This would help them to have nutritious food and boost their immune system.

It is against the background of these findings that this study suggests the need to research the following aspects further:

- Stigmatisation and discrimination against those living with HIV/AIDS.
- Poverty as a barrier to living positively with HIV/AIDS.
- Approaches to enable men to participate fully in combating HIV/AIDS.

4.4 LIMITATIONS

Limitations applicable to this study are the sample size and the setting. The sample size of this study was limited because of the sensitivity of the topic. It was not easy to get hold of PLWHA to participate in this study. The participants were only those belong to support groups. Most of them are members of LE.

Furthermore, the participants were only urban based, namely from the Khomas region. It is, therefore, not possible to generalise these study findings to other PLWHA, who live in rural areas or who are not members of LE. This study could not find more male participants. That limited the findings as regards gender balance.

4.5 SUMMARY

This chapter looked at the study conclusions, recommendations and limitations. The conclusions are made according to the study objectives and are explained in this chapter. Recommendations are discussed and further possible studies are suggested. Study limitations are also described.

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APPENDICES

APPENDIX ONE

SUMMARY OF THE MAIN STUDY PARTICIPANT

PARTICIPANT 09

Background information of participant 09.

She is a young woman, 23 years old and a single mother of six. Her biological mother is mentally sick and divorced by her father. Therefore, she was not brought up by her biological parents. She used to stay with relatives who did not give her much attention. She has completed Grade 10 and is then struggling to complete her Grade 12 through correspondence. She is unemployed and depends on relatives for financial support. She belongs to the Lutheran church. She used to stay with her older sister (married), but at the time of the interview she had accommodation problems. Her brother-in-law threw her out of the house because of her HIV status. She wants to go back to the village in the Omusati region, but she does not have money for transport.

She gave birth for the first time at the age of 13. Her lastborn was only one month old at the time of the interview. The other five children are with relatives in the village.

Observational notes

Participant 09 looks healthy and clean. Her baby does not look well. He was coughing and looks underweight. His HIV results were not out at the time of the interview. She was due for follow up that day. She looked comfortable during the interview. She wanted to share a lot of information with the researcher, although some information was not relevant to the study. She needed someone to whom to open up her heart.

Key

R: Researcher **P 09:** Participant 09

Setting

She was interviewed at LE centre in Khomasdal, Windhoek when she came there for orange babies programme. The interview took place in a private room, free from noise and disturbances. She was offered refreshments. She was also offered N$ 20.00 for taxi fare.

Actual interview (done in Oshiwambo) – English translation

R: First of all, I would like to thank you for coming to the interview. You were specifically selected because you can provide valuable information regarding access to health information on living positively with HIV/AIDS. I would also like to inform you that the aim of the interview is to collect information concerning access to health information on HIV/AIDS to be able to address problems on this. No report will be prepared which identifies the views of any participant. All information will be kept confidential. My first question to you will be: “What experiences do you have regarding HIV/AIDS?”

P09: I had a boyfriend who committed suicide in 2001. He is the father of my second last child. He left a note for me. In that note he informed me that he would kill himself because he had tested HIV positive. He asked me to go for testing for myself as well as our baby. I then decided to go for testing in 2002. I got my HIV positive results at Outapi hospital (Omusati region). But I did not take my baby for an HIV test.

R: Were you prepared for the HIV testing?

P09: No, I was not prepared at all. I was only supported psychologically by a doctor at the hospital after receiving my results. I kept my results a secret. I did not disclose them to anybody.

R: You said that only the doctor supports you psychologically, can you explain to me what did s/he tell you?

P09: He just tried to calm me down, because I was crying.

R: Was that all he did?

P09: Yes, but he also told me to come back to hospital when I was not feeling well.

R: After that, did you get any information regarding HIV/AIDS?

P09: Well, I heard some information here and there but I did not give much attention to it. I was well until in 2004 when I developed skin problems. I did not go to hospital. Later on I developed abscesses and decided to go to Oshakati to see a doctor there. I took my old HIV positive results with and showed them to the doctor. Then the doctor took my blood and tested my CD4 count. My CD4 count was low so I was then put on HIV drugs (ARV) in 2005.

R: Before the doctor put you on treatment, did he or any counsellor explain to you about the treatment?

P09: Not really. I even had a problem in finding a treatment supporter because I did not want to disclose my HIV status.

R: How did you manage to get a treatment supporter?

P09: I had a friend at Oshakati. I told her about my problem. I then disclosed my HIV status to her and she agreed to be my treatment supporter. She was the only person I disclosed my HIV status at that time. I started with treatment on 16th September 2005 and on the 27th December 2005 I moved to Windhoek.

R: Why did you decide to move to Windhoek when you had just started with your treatment?

P09: I came to look for job, but I could not find any. I just got a new boyfriend who supported me with money. I did not tell him about my HIV status. I was afraid of rejection and to be alone. He did not ask me or insist on using a condom when we had sex. As a result I became pregnant. I was very upset and was afraid of my relatives' reaction because that was my sixth pregnancy. I decided to kill myself by taking pills. I had no hope of living anymore. With these problems of attempted suicide, I was admitted to Katutura State hospital. A supporter from Lironga Eparu (LE) was called to come and talk to me. A supporter took me with her to LE centre. I was counselled and encouraged to disclose my HIV status to my older sister. I agreed and disclosed my status to my sister. My sister was very supportive. After that I joined the orange babies programme at LE.

R: What is this orange-babies-programme?

P09: That is the programme for HIV positive mothers at Lironga Eparu. The mothers are informed about the prevention of HIV transmission from mothers to babies. We also receive some formula feed for our babies for those who choose not to breastfeed their babies. This programme supports HIV positive mothers and their babies.

R: What else did the supporter at LE tell you regarding HIV/AIDS?

P09: At LE centre I was informed about the Prevention of Mother-to-Child Transmission programme. I was told about the risk of transmitting HIV through breastfeeding. I gave birth in September 2006 and I do not breastfeed my baby.

R: It means that your baby is one month old?

P09: Yes, he is one month old.

R: How is he doing? I hear that he is coughing.

P09: Well he is fine, but he has this coughing problem and his nose is a bit blocked.

R: Did you take him to the clinic for check up?

P09: No, I didn’t but I will take him after the interview. I am going to get his HIV results today. If they do not admit him I plan to go to the north (to the village), but I do not have transport money. I have accommodation problems. I was staying with my sister and her husband but he threw me out of their house after he learnt that I am HIV positive.

R: Can the father of your child (your boy friend) not give you money for the transport?

P09: When he heard that I am HIV positive he does not want me anymore. I will talk to our supporters here (at LE), maybe they will help me.

R: OK, let us go to our next question. What information did you receive on how to live positively with HIV/AIDS?

P09: When I was tested in 2002, I did not understand the meaning of the term ‘HIV positive’. Even in 2005 when I started with treatment I was not given proper information. When I joined LE I got more information. Now I know the difference between HIV and AIDS. I know what to do to live positively with the virus, but it is not easy.

R: Why are you saying that?

P09: Because sometimes you are told to do things which you cannot do. For example to eat balanced food but you cannot afford it. Or even to abstain from sex, but you can’t.

R: What specific information did you get regarding living positively with HIV/AIDS?

P09: When I was tested at Outapi hospital I was not counselled properly. I was not told about the risk of re-infection when having unprotected sex. I was also not informed about the influence of pregnancy on my immune system. I was not told about the chance of transmitting the virus to my unborn baby if I become pregnant. Because of lack of information I became pregnant while on treatment. When I joined Lironga Eparu I got enough information. I was also informed about family planning. I decided to undergo sterilisation after the birth of this baby. At the hospital I was informed about abstinence and condom use. I was also advised to change my lifestyle.

R: What information did you get regarding changing your lifestyle?

P09: I was informed about the influence of alcohol and smoking on my immune system. I was also informed to minimise stress. I was told that stress can affect my immune system negatively. I got all this information from LE.

R: Were you also informed about diet?

P09: Yes I was.

R: Can you please explain to me the information you got about diet?

P09: At both ANC clinic and LE I was informed about diet. I was told to eat fruits and vegetables. I want to follow what I was told but it is not always easy. You know, I am not working. I do not have money to buy fruits and vegetables. If the government can give us money then I will be able to buy those things. I have applied many times to get a job, but I never succeed. I even wanted to join the army but they will test me for HIV. So life is difficult.

R: I see. Let us go to our next question. Do you have any information regarding health care and treatments for HIV/AIDS?

P09: Yes, I got this information from Lironga Eparu. I got information about some infections. I know about sicknesses such as TB. We were even taught how to prepare oral rehydration solution (ORS) for diarrhoea. At least I will be able to do something for myself before I go to hospital.

R: What do you know about antiretroviral therapy (ART) treatment of HIV/AIDS?

P09: I started ART in the north in 2005. At that time I was not given proper information. I was not even told about any side-effects. I only came to get enough information about ART when I joined LE. At hospital there is not enough information. But here at Lironga Eparu we get enough information. I also feel free to ask questions and supporters will give me answers without discriminating against me. I also attended training on ARV.

R: Are you being discriminated against?

P09: Yes, some people do discriminate people who are HIV-positive. Even my own family are not always supportive. That is why my brother-in-law threw me out of his house. My sister could do nothing, because it is not her house. Even the army (Namibian Defence Force) does discriminate because they do not want to recruit people who are HIV positive. I think this is unfair.

R: At the ARV training what did you learn?

P09: I was told about the side effects of medication. I was also told not to take any medication without consulting with the staff at ARV clinic. I was also told about the importance of adherence to treatment.

R: How did you come to know about Prevention of Mother to Child Transmission programme (PMTCT)?

P09: I was informed about this programme through counselling at LE. I was informed about the risk of transmitting the virus through breastfeeding. I was informed about family planning as well. That is why I decided to have sterilization. I opted not to breastfeed my baby. I give formula/ replacement feed. I receive milk formula from the orange baby programme here at LE.

R: Except from getting information from LE, where else do you get information?

P09: I got information from LE and from hospital. I do not get much information from radio (NBC), because people at our house only listen to Omulunga radio. They only like to listen to music. I do not get chance to listen to HIV/AIDS programmes from NBC. I know that one can also get information from TV and newspapers. At church there are different programmes for PLWHA. Information is given in different ways. I try to apply that information in my daily life. Now I have hope.

R: Our next question is about support systems. How did you learn about them?

P09: I learnt about support groups when I was admitted to Katutura State hospital. A supporter from LE came to see me, when she was called to come and talk to me. Since then I joined support groups at LE. I did not get much support from my family, except from my sister.

R: Do you have any comments you want to make regarding HIV/AIDS in general?

P09: Yes. There is a problem of misconception about HIV/AIDS. There is also a problem of stigma. That is why most people are afraid to disclose their status. They are afraid to be discriminated against, as in my case.

R: Thank you very much for your time. This is the end of our interview.

APPENDIX TWO

Report of the visit to New Start Centre at CCN (Katutura-Windhoek)

Introduction

The visit took place on 8th of August 2006. The purpose of the visit was to familiarise the researcher with the post-counselling content that is being covered during post-counselling for persons who tested HIV positive. One counsellor was interviewed. He told that generally they do not advise their clients but rather give them options. They then make their own decisions according to their situations and circumstances. They give basic information as well as specific information.

Basic information

Basic information given to persons who tested HIV positive includes the meaning of HIV positive results and CD4 counts. CD4 counts are explained to clients. They are referred to health facilities for relevant tests/investigations and treatment. They talk about acceptance of being HIV positive as the starting point to living positively.

He also pointed out that giving post-counselling for the first time when a person has only just received his/her results is not very effective, because the client might be in a state of shock. A lot of information is covered in counselling, hence the need for follow–up or continuous counselling. This also helps to establish a good relationship with their clients. The counsellor also told the researcher that they encourage clients to involve their partners in testing and counselling. This helps to reduce the risk of re-infections. At the start centre they also do offer couple counselling. This is more complicated than the individual counselling, especially when one partner is HIV negative while the other is HIV positive. Such results are called discordant HIV results.

Specific information

There are specific topics that are covered during post-counselling for a client with HIV positive results. He explained that the following topics are discussed:

- The meaning of HIV positive results
- Change behaviours
- Sexual activity
- Balanced diet
- Supplements and other treatments rather than ARVs.
- Opportunistic infections such as TB, STIs and others like diarrhoea.
- Vulnerability through a low immune system
- Medical care
- ARVs (not in detail, just as an introduction with referring clients to health facilities.)
- Support system, namely family, friends, support persons, NGOs e.g. Life-Line and Lironga Eparu.

Additional information

The counsellor also talked about misconceptions and myths about HIV/AIDS in the community. These prevent people from living positively. Stigma is also a problem that needs to be addressed seriously if we want people to disclose their status.

On the question of accessibility of information he said that there are specific programmes on NBC TV and radio in all languages. He also indicated that information is simplified to make it understandable by everybody. At the start centre clients are provided with pamphlets, to go and read for themselves for those who are literate. He also said that they provide *E-pap* to clients who cannot afford to buy immune boosters.

Conclusion

This visit to the New Start Centre helped the researcher to have a clearer picture of what to ask her study participants, regarding information. According to what the counsellor said it seems that the information given during post-counselling is adequate. However the question remains that what do PLWHA do with the received information? The other question is whether this information is really accessible to all PLWHA or only to those in urban areas. Are the clients really being followed up to support them? Some of these questions are answered by this study, but some would need further investigation.