FACTORS CONTRIBUTING TO PATIENTS ON ANTI-RETROVIRAL THERAPY DEFAULTING ON TREATMENT IN OSHAKATI HOSPITAL IN NAMIBIA

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ABSTRACT

Defaulting from treatment remains a challenge for most HIV/AIDS control programmes. It may increase the risk of drug resistance, prolonged infection or death. The aim of this study was to explore and describe factors that contributed to patients defaulting in taking Highly Active Anti-Retroviral Therapy (HAART) in Oshakati and to propose appropriate interventions. The method used in the study was a combined quantitative and qualitative approach (mixed method). A cohort of patients who defaulted in their HAART treatment in Oshakati as at the end of July 2007 was identified using the pharmacy ART dispensing tool that could generate a list of defaulters for that month. In the quantitative phase a structured questionnaire with potential predictor factors drawn from literature review was administered to 76 (95.0 %) of 80 defaulters who were successfully traced. In the qualitative phase, a focus group discussion comprising of 12 defaulters was conducted.

The reasons for defaulting were unclear in the quantitative phase of the study. During the focus group discussion of the qualitative study, reasons given by informants were complex and included the treatment process, poor patient-provider relationships ultimately leading to dissatisfaction with services provided, financial constraints to pay for food and transport, the long distance between the facility and place of residence, lack of accurate information about the treatment and its outcome, illiteracy, lack of psychosocial support, lack of immediate beneficial effects and/or harmful effects after initiating on treatment. The default rate in this study was relatively low compared to other studies. ART facilities should ensure that patients' addresses are complete and correct.

It was recommended that efforts aimed at increasing literacy and reduction in stigma and discrimination should be targeted towards both the patients and the community, ART services should be decentralised and, where possible, home based treatment care, instituted where adherence levels can be ascertained.

DECLARATION

I, Greatjoy Njabulo Mazibuko, hereby declare that this study is a true reflection of my own research, and that this work, or part thereof has not been submitted for a degree in any other institution of higher education.

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CHAPTER ONE

INTRODUCTION AND BACKGROUND TO THE PROBLEM

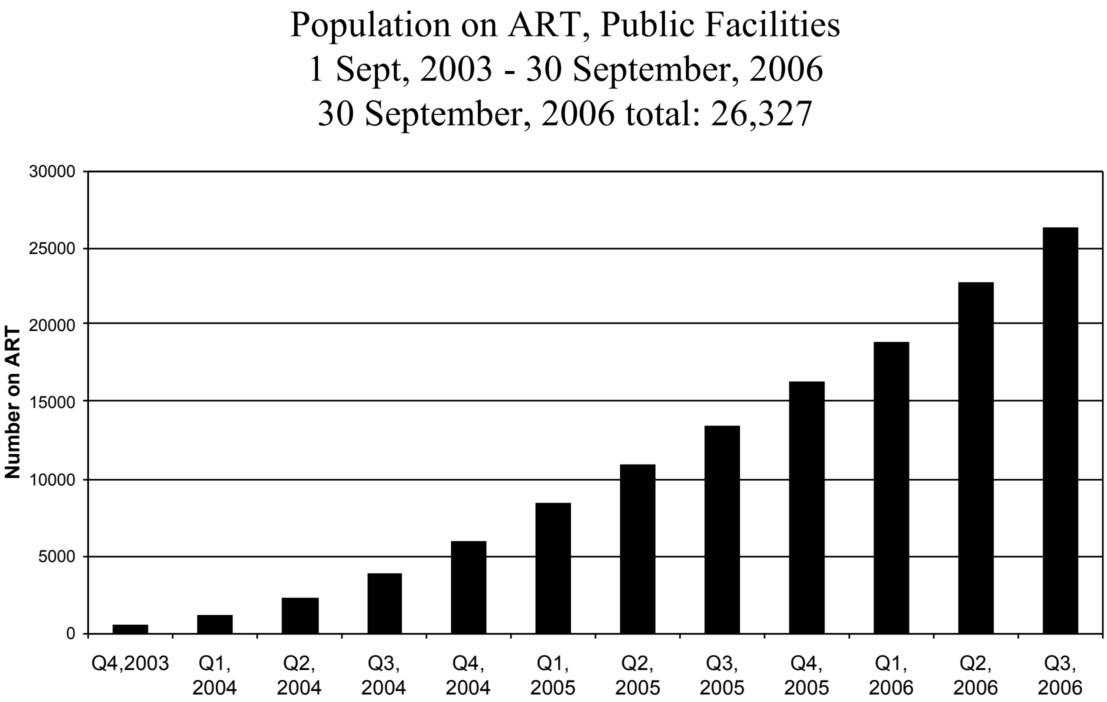
1.1 Introduction

An estimated 38.6 million people worldwide were living with HIV at the end of 2005, while about 4.1 million people became newly infected with HIV and an estimated 2.8 million lost their lives to AIDS (UNAIDS, 2006a, p. 4). With Africa remaining the global epicentre of the AIDS epidemic, the epidemic in Sub-Saharan Africa, one of the worst affected areas in the world, shows no evidence of decline. At the end of 2005, about 25 million people were living with HIV and the HIV prevalence rate was about 6 %. This number was more than half the global number of those living with HIV. In the SADC region alone, Swaziland had a national HIV prevalence rate estimated at 33.4 %, Botswana 24.1 %, and Namibia 19.7 % (UNAIDS, 2006a, p. 6).

According to the 2001 population and housing census, “Namibia has a total population of 1,830,330 people with an annual growth rate of 2.6 %,” (Central Bureau of Statistics, 2003, p.1). The population distribution in the country is 33 % urban and 67 % rural. As at the end of 2001 it was estimated that 230,000 Namibians were living with HIV/AIDS. During the last 10 years, the disease has become a serious public health problem and remains one of the major obstacles to socio-economic development because it deprives the country of scarce human and financial resources. In Namibia's 13 regions, HIV prevalence rates range from 9 % in the Kunene region to 42.4 % in the Caprivi region. The Oshana region had the sixth highest prevalence ratio of 25.2 %, (Ministry of Health and Social Services (MoHSS), 2005, p.7). Oshakati state hospital where the study will be carried out is the only referral Hospital in the Oshana region.

As part of the commitment by the Government of the Republic of Namibia to the global targets set by UNAIDS and the World Health Organization (WHO) ("3 by 5" initiative), to provide 3 million people living with HIV/AIDS in low and middle income countries with life-prolonging Anti Retroviral Treatment (ART) by the end of 2005, Namibia launched the Prevention of Mother to Child Transmission (PMTCT) programme in 2002 and the ART programme in 2003. Two referral hospitals, namely Oshakati and Katutura Intermediate hospitals, were pilot sites for the programme, which has subsequently been rolled out to many other hospitals and clinics countrywide. By the end of September 2006, the number of patients receiving ART countrywide in public facilities stood at 26 327 (MoHSS, 2006, p.1) as outlined in fig 1.1 below.

Fig 1.1 ART Statistical progress (MoHSS, 2006, p.1)



Khomas, Omusati, Oshana and Oshikoto regions account for the largest number of patients with each region reporting about 4000 individuals on treatment. At the end of September 2006, the total number of patients registered as active in Oshakati State Hospital stood at 4170, with 4385 in Khomas region and 4858 in Omusati region (MoHSS, 2006, p.2)

The services provided at the Oshakati hospital CDC include:

- Counselling offered to patients who qualify for HAART as stated in the guidelines and who are enrolled for prophylactic treatment for a period that satisfies the health care provider that the patient will adhere to the treatment

(PRE-HAART Counselling). It also includes counselling offered to patients who have gone through the prophylactic phase and have to start the ART (ADHERENCE Counselling).

- Clinical services offered include doctors' consultations, assessment of all patients who have tested HIV positive, laboratory assessments, nursing care, and counselling services for new and follow-up patients.
- Pharmacy services include dispensing of medicines to new and follow-up patients, counselling services mainly ADHERENCE counselling. Regular follow-up patients receive their medication monthly.

(HAART) is a 'standard care' for HIV positive patients. It consists of a regimen that includes three antiretroviral agents," (The Foundation for Professional Development, 2001, p.6), namely a combination of two nucleoside reverse transcriptase inhibitors (NRTI) and a non-nucleoside reverse transcriptase inhibitor (NNRTI), or a protease inhibitor or the NRTI abacavir (MoHSS, 2003, p.3). In Namibia, the first line regimen consists of the dual backbone of the NRTIs, zidovudine, lamivudine, stavudine, didanosine, tenofovir and one NNRTI of either efavirens or nevirapine. For second line therapy, protease inhibitors that include Indinavir/ritonavir or Lopinavir/ritonavir are adjuncts to the dual backbone of the above-mentioned NRTIs. However, zidovudine cannot be used with stavudine for the dual backbone as they antagonize each other in vivo and in vitro (Pham & Flexner, 2005, p.54).

Anti-retroviral therapy has five goals:

- Clinical goal: Prolongation of life and improvement in the quality of life of patients.
- Virologic goal: Greatest possible reduction in viral load (preferably < 20-50c/mL) for as long as possible to prevent or delay progression of the disease or to halt it entirely.
- Immunologic goal: Immune reconstitution that is both quantitative (CD4 cell count in normal range) and qualitative (pathogen-specific immune response).
- Therapeutic goal: Rational sequencing of medicine in a fashion that achieves the above-mentioned goals while maintaining treatment options and limiting drug toxicity and facilitating adherence to medicines.
- Epidemiologic goal: Reduce HIV transmission.

The main factors determining the effectiveness of HAART in repressing viral replication are selection of the appropriate regimen, regimen potency, adherence to prescribed therapy, the absence of severe immune suppression at the start of therapy, and prior exposure to antiretroviral agents. Treatment with single drug regimens should not be used. A drug-resistant virus might emerge and cross-resistance to antiretroviral agents is inevitable. The synergistic use of three agents produces a potent and sustained reduction of viral load because of action by the medicine on the virus at multiple anatomical sites that reaches various cellular compartments. There is increasing evidence that defaulting on HAART is associated with virologic failure, as most patients who default HAART do not introduce any drugs into their bodies for viruses to mutate. However, good adherence in the absence of complete viral suppression is associated with increased rates of drug resistance (Bangsberg, 2003, p.1925). Because the effects of either defaulting or non-adherence are immunologic and clinical failure, which accelerate disease progression, careful monitoring of patients is essential to avoid patients progressing to AIDS with resistant HIV strains and spreading it into the community, which would defeat public health efforts to curb increasing mortality and morbidity rates associated with HIV/AIDS.

The various methods of monitoring disease progression require baseline assessments of different patient characteristics and subsequently regular (1-3 months) follow-up (MoHSS, 2003, p.11).

1.2 Problem statement

National Guidelines on the management of HIV/AIDS are non-specific as to the identification, tracing and monitoring of defaulters and non-adherent patients despite stating clearly the importance of 100 % adherence to antiretroviral therapy. Furthermore, most researchers focus more attention on adherence assessment of regular follow up patients and overlook or give minimal attention to defaulters to treatment and follow up. The researcher therefore felt that the reasons for patients defaulting on follow up and consequently treatment have to be investigated as these were not known and this led to the generation of the following purpose and objectives for the study.

1.3 Purpose and objectives

The purpose is to explore and describe contributing factors to patients' defaulting on HAART in Oshakati and to propose appropriate interventions.

Specific objectives are:

- To identify and trace defaulters of highly active anti-retroviral therapy in Oshakati.
- To describe the profile of defaulters to highly active anti-retroviral therapy.
- To determine what factors cause patients on highly active anti-retroviral therapy to default.
- To propose interventions to ensure improved return rates of anti-retroviral therapy patients.

1.4 Significance of the study

Through the course of the study, methods to trace defaulters will be introduced and also the barriers predisposing patients to default will be investigated and appropriate interventions proposed to improve the return rates and monitoring of the patients. Secondly, the study could inform, and link with, similar and future studies on related topics such as adherence assessment of patients on HAART programmes, which also poses a challenge to effective management of these programmes.

1.5 Operational definitions

Active patient

This refers to a patient who has been registered and receives regular ART treatment at the Oshakati ART Clinic. The patient may travel to other facilities but eventually always comes back to Oshakati for treatment.

Adherence

Rabkin, El-Sadr and Abrams, (2005, p.11), define adherence as "the engaged and accurate participation of an informed patient in a plan of care. It is broader than "compliance"- the extent to which patients follow the instructions of their health care providers – and it implies understanding, consent, and partnership." In HIV management it includes continuing in a programme, attending to scheduled visits, taking medicines as prescribed, lifestyle and behaviour modifications.

Appointment

Refers to the date a patient is booked for a scheduled service at the Oshakati Communicable Diseases Clinic.

Defaulter

A patient who misses two consecutive visits for pharmacy / medical appointment at Oshakati Communicable Diseases Clinic and has not obtained any service from any other facility that offers HAART assuming that the patient does not take any ART medication during that period or later.

HAART

Refers to highly active anti-retroviral therapy, which is 'standard care' for HIV positive patients. It consists of a regimen that includes three antiretroviral agents (The Foundation for Professional Development, 2001, p.6).

In -transit patient

A patient registered as active at another facility and has not been formally transferred from that facility but receives services from Oshakati Communicable Diseases Clinic for any reason that makes it impossible for the patient to obtain services at the facility where he/she is registered.

Missed visit

Failure of a patient to turn up for a scheduled appointment at the Oshakati Communicable Diseases Clinic is regarded as a missed visit.

Transferred out patients

These are patients registered at Oshakati Communicable Diseases Clinic who are formally sent to another facility accompanied by a transfer letter signed by a medical officer/nurse in charge of Oshakati clinic.

Regimen

Implies a combination of medicines meant to treat a particular condition. For HAART it refers to a combination of at least three antiretroviral drugs.

1.6 Presentation of the study report

Title of the report

The report is presented under the title,
Factors contributing to patients on anti-retroviral therapy defaulting on treatment in Oshakati Hospital in Namibia.

Organization of the report

The report is presented in five chapters:

Chapter 1: Introduction and background of the problem
Chapter 2: Literature review
Chapter 3: Methodology
Chapter 4: Data analysis and discussion
Chapter 5: Summary of findings, conclusion, recommendations and limitations

1.7 Summary

Defaulting on follow up ultimately leads to treatment interruption. There is a strong link between non-adherence to treatment and defaulting on follow up. The consequences of either are disease progression and emergence of resistant viral strains. This is a major problem for Namibia and the world as it may defeat public health efforts to halt the spread of HIV/AIDS and resistant viral strains. Little attention is given to those who default on treatment and most researchers focus on patients who routinely report to the clinic for follow-up to assess their adherence to treatment. This leaves a gap in the holistic approach to ensure patients' adherence to treatment. Moreover guidelines on the management of HIV/AIDS are non specific and shallow when it comes to the identification, tracing and monitoring protocols of defaulters and non-adherent patients. This deficiency creates non-standardized and often inefficient strategies as to the management of this group. In this study, the main purpose is to explore and describe the factors that cause patients to default on follow-up and treatment and to propose interventions to improve the return rates of patients.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

A literature search is necessary for topic selection, integrating existing knowledge on a particular topic to what is being studied, to ensure that a proposed topic has not been tackled before and lastly to define an area of study as being original (Sharp & Howard, 1996, p.74). Most research generally builds on existing knowledge which guides present research within an appropriate framework. This serves as a springboard for the generation of research hypotheses and for making a less formal attempt at organizing a phenomenon under study.

This chapter reviews literature on defaulters to HIV treatment as well as other chronic treatments. The objectives of this literature review are to:

- describe the conceptual framework for the study;
- describe the pathogenesis of HIV and the pathophysiological basis of HIV treatment;
- explore the consequences of defaulting on treatment;
- obtain a background knowledge on reasons people default on chronic treatment protocols;
- explore the meaning of the term “defaulters”; and

- identify those strategies employed to improve return rates of patients in other studies or other countries.

Defaulting on treatment is a complex biosocial phenomenon that cannot be explained by considering a human being as merely a biological and physical being. Polit & Hungler (1995, p.13) clearly attribute the obstacle to research concerning human behaviour or attitudes to be the complexity of the central topic of discussion - people. Each human being is unique in a number of ways with respect to personality, learning capabilities, values, perceptions, adaptations to environmental influences and lifestyle. Several models have been successfully used in behavioural research to deal with concepts relevant to the construction of more formal theories on human behaviour. These include the health belief model, transtheoretical model, social cognitive theory to mention a few. Naidoo & Willis (2000, p.92) explain that models of health promotion are not guides to action but attempts to delineate a contested field of activity and to show how different priorities and strategies reflect different underlying values. In this study, Pender's health promotion model (HPM) was used as a conceptual framework. A conceptual framework is the abstract, logical structure of meaning that guides the development of the study and enables the researcher to link the findings to a body of knowledge (Naidoo & Willis, 2000).

2.2 Conceptual framework (Health Promotion Model)

The health promotion model is a framework that explores the complex biophysical processes that motivate individuals to engage in behaviours directed towards health enhancement (Gorin & Arnold, 1998, p.26). In this study health enhancement is described as compliance to HIV treatment protocols and schedules for clinic visits and a zero defaulter rate. The model links individual characteristics and experiences and behaviour-specific cognitions and affects - including benefits of and barriers to action, interpersonal and situational influences - to a commitment to a health promoting behaviour. The final behavioural outcome is concomitantly influenced by immediate competing demands and preferences which can derail or enhance a health promoting action (Gorin & Arnold, 1998, p.27). An understanding of each variable and their relationship in influencing a person's behaviour from being a defaulter to seeking health promoting behaviour is essential in applying health promoting strategies to improve patient return rates. The analysis of each variable and definition of concepts in the context of this study is given below.

2.2.1 Individual characteristics and experiences

Prior Related Behaviour

Empirical studies indicate that often the best predictor of behaviour is the frequency of the same or similar behaviour in the past. Prior behaviour is proposed as having both direct and indirect effects on the likelihood of engaging in health promoting behaviour (Pender, Murdaugh & Parsons, 2002, p.68). Outcome expectations are anticipated or experienced benefits from engaging in behaviour and if desired short term benefits are experienced early then the behaviour is likely to be repeated. Thus focusing on benefits of complying with treatment schedules and follow-up in the treatment of HIV/AIDS can help to shape a positive behavioural history for the patient. The behaviour of seeking treatment and adhering to it may be repeated. This may involve identifying barriers to attending all scheduled appointments.

Personal Factors

These are categorized as but not limited to demographic, socio-cultural, socio-economic, medical related and service related characteristics in this study. Despite having numerous personal factors, Pender et al (2002, p.69), suggest limiting the scope to the few theoretically relevant factors to explain a given target behaviour.

2.2.2 Behaviour specific cognitions and affects

Perceived Benefits of Action

These are defined as one's opinion of the efficacy of the advised action to reduce risk or seriousness of impact (Glanz, Lewis & Rimer, 2000, p.45). An individual exhibiting an optimal level of beliefs in positive or re-enforcing consequences of a particular behaviour would be expected to engage in health promoting behaviour. This according to Pender et al (2002, p.69) is based on personal outcomes from direct experience. Examples of benefits of complying with ART treatment may include prolongation and improvement of the quality of life of the patient (intrinsic benefits) and the ability to be economically active and earn monetary rewards (extrinsic benefits). These benefits may influence a patient to be consistent in the schedule set out for his/her treatment. Evaluation of the benefits is part of the cost-benefit analysis that an individual undertakes.

Perceived Barriers to Action

Barriers affect intentions to engage in a particular behaviour and the actual execution of that behaviour. These barriers may be imagined or real and are hurdles, blocks and personal costs of undertaking a health promoting behaviour (Pender et al, 2002, p.70). A patient may view as expensive, time-consuming and inconveniencing to be always attending the ARV health centre for services to be provided to him/her. If these barriers outweigh the perceived benefits then it is highly likely that the patient will default on treatment.

Interpersonal Influences

According to the HPM, interpersonal influences are cognitions concerning the behaviours, beliefs, or attitudes of others (Pender et al, 2002, p.72). Cognition is defined as the process by which knowledge and understanding is developed in the mind (Oxford, 2006, p.213). Family, friends, peers and healthcare providers are a primary source of interpersonal influences. They play a significant role in affecting an individual's predisposition to engage in particular health behaviour. The patient gains power through the transfer of knowledge and skills from these groups of people (Gorin & Arnold, 1998, p.95), particularly through the establishments of social norms, social support systems and modelling. If it is culturally acceptable and the norm to seek alternative medicine in the treatment of HIV/AIDS to that being offered at health centres, this may influence the individual's decision to be compliant with treatment at a particular centre.

Situational Influences

"These are perceptions of options available, demand characteristics and aesthetic features of the environment in which a given behaviour is proposed to take place," (Pender et al, 2002, p.72). An environment filled with cues to action that trigger action may directly affect behaviours, for example posters explaining the consequences of treatment interruption/defaulting may serve as a demand characteristic for not defaulting to treatment from the community.

2.2.3 Behavioural outcome

Ultimately, the choice not to default on treatment is influenced not only by the factors described above according to Pender et al, (2002, p.72), but also by immediate competing demands and preferences. Competing demands are viewed as behaviours over which the patient has a relatively low level of control such as migration forces, level of family dependency and work- related commitments. Competing preferences, on the other hand, are behaviours with powerful reinforcing properties over which the patient exerts a relatively high level of control. These may sway a patient from a course of action. A good example is attending to social events if they fall on the same date as scheduled follow-up visits to the ARV health facility.

A closer look at the pathogenesis of HIV infection will give us a clear understanding of the consequences of non-adherence and non-compliance to HIV treatment. This aspect will be discussed next.

2.3 Pathogenesis of HIV infection

2.3.1 Molecular biology of the virus

Anatomy

HIV is a member of the lentivirus sub family of the retroviridae family. It is a retrovirus, and in a retrovirus genetic information must change from RNA into DNA for human cells to be infected. There are two types of HIV: Type 1- responsible for global epidemic whilst HIV Type 2 is less pathogenic (Damond, Worobey & Campa,

2004) and largely restricted to West Africa and countries with limited spread to other countries (African Network for the Care of Children Affected by AIDS, 2005, p22). According to Wilson, Naidoo, Bekker, Cotton & Maartens (2002, p.15), HIV1 strains are further classified into groups, M (Major) and group O (Outlier). Another strain (non M and non O) has been described in Cameroon. There is a further subdivision of the HIV strains into subtypes (Clades) which bear the letters of the alphabet A to J.

2.3.2 HIV Genes, proteins and their functions

Table 2.1 HIV-1 proteins and their functions. Source Wilson et al (2002, p.17)

Name	Size	Gene	Function
Structural proteins			
GagM	p17	gag	Matrix protein
CA	p24	gag	Core capsid protein, protects genome
NC	p7	gag	Nucleocapsid protein
NC	P6	gag	binds RNA
Env SU	gp120	env	Surface glycoprotein, binds CD4 and co-receptors.
TM	gp41	env	transmembrane protein, anchors the SU
Viral enzymes			
Protease	p15	pol	Cleavage of gag and gag-pol precursors, Virus maturation
Reverse Transcriptase	p66	pol	reverse transcribes the viral RNA, also has RNA-ase H nuclease activity
Integrase	p31	pol	Integrates proviral DNA into cell genom

Fig 2.1 The HIV cell: Source Roshanpakistan, (2008, p.3).

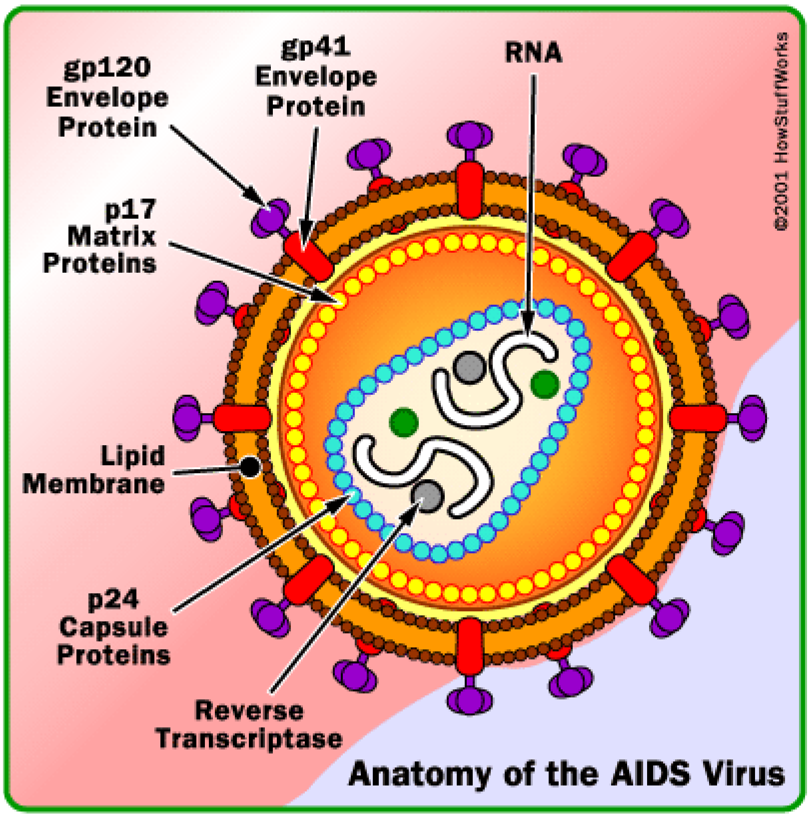


Fig 2.1 is a pictorial example that shows the HIV cell with its different proteins and table 2.1 above clearly outlines the different functions of each of these proteins and a summary is given below.

The viral envelope is the outer coat of the virus. It is composed of two layers of fatty molecules, called lipids. Embedded in the viral envelope are proteins from the host cell. There are also about 72 copies of Env proteins that protrude from the envelope surface. The Env consist of a cap made of three or four molecules called glycoprotein (gp) 120, and a stem consisting of three to four gp41 molecules (Gladysz & Smolinski, 2003, p.697).

There is an HIV matrix protein p17 that lies between the envelope and the core. The viral core contains 2,000 copies of the viral protein p24, and this protein surrounds two single strands of HIV Ribonucleic acid (RNA). Each strand contains a copy of the nine viral genes. Three of these genes, gag, env and pol contain information needed to make structural proteins.

The surface proteins discussed above play a major role in the attachment and interaction between the viral cell and CD4 cells. The cellular receptors for HIV and the reproduction of the HIV virus are discussed next.

2.3.3 Cellular receptors for HIV

HIV only infects certain type of cells. Usually these are cells expressing the CD4$^+$ cells or T4 cells, other types of white blood cell, including monocytes and macrophages. Other types of cells that express the CD4$^+$ receptor that can therefore become infected include glial cells in the central nervous system and chromafin cells in the skin. However, it should be noted that some cells (e.g. neurons) that do not manifestly express the receptors may become infected with HIV, raising the possibility that other cellular targets for the virus may exist (The Foundation for Professional Development, 2001, p.14) . The stages of reproduction inside these cells serve as a basis for HIV treatment and they will be discussed in depth.

2.4 Physiological and Pharmacological basis of HIV treatment

2.4.1 Stages of HIV reproduction and antiretroviral agents for HIV

Binding, fusion, and virus entry

HIV binds to cells via interaction between viral glycoprotein (gp120) and the CD4$^+$ molecule (Tang & Chan, 2007). The glycoprotein, which resides on the surface of the virus, undergoes conformational changes enabling interaction between itself and the co-receptor on the CD4$^+$ molecule. This interaction triggers the insertion of the transmembrane protein (gp41) into the cell membrane and fusion of the virus with the cell. The core is released into the cytoplasm, and the viral RNA released (Wilson et al, 2002, p.19). Entry inhibitors work by preventing HIV from entering healthy CD4 cells by blocking specific proteins on the surface of either HIV or CD4 molecule required for virus to gain entry. The first agent belonging to this class was Enfuvirtide also known as T-20 (Bartlet, 2005, p.141). After the viral material has entered the host cell, viral RNA must then be transcribed into DNA and the process is called reverse transcription.

Reverse Transcription

“The viral RNA is reverse transcribed into double-stranded DNA; all these functions are fulfilled by the reverse transcriptase which occurs as a dimmer with both reverse transcriptase and RNA-ase H nuclease activity. Reverse transcriptase enzyme has no proof-reading function and, on average one error is introduced per genome per replication cycle. Non-nucleoside reverse transcriptase inhibitors stop HIV production by binding directly onto the reverse transcriptase enzyme and preventing the conversion of RNA into DNA" (Harvey & Champe, 2000, p.461). Drug agents known include Nevirapine, Efavirens and Delavirdine mesylate (Bartlet, 2005, p.137).

Nucleoside/nucleotide analogues also known as "nukes" or nucleoside reverse transcriptase inhibitors, act by incorporating themselves into the DNA of the virus, thereby stopping the building process. The resulting DNA is incomplete and cannot create a new virus (Harvey & Champ, 2000, p.462). Many antiretroviral agents fall in this class and include Stavudine, Zidovudine, Lamivudine, Abacavir, Emtiricitabine, Didanosine and Tenofovir (Bartlet, 2005, p.86).

As clearly shown above there are two classes of medicines that have been developed to act at this stage, the nucleoside reverse transcriptase and the non-nucleoside reverse transcriptase inhibitors. The next stage in the viral reproduction is integration.

Integration

The pre-integration complex is transported to the nucleus, the enzyme integrase, catalyses the process of integration in the chromosomal DNA. The integrated virus at this stage is referred to as the pro-virus. It serves as a template for the transcription of viral genes (Nisole & Saib, 2004). The transcription and translation process will be discussed next.

Transcription and translation

The host enzymes transcribe the pro-viral DNA using the host cellular machinery. In this process the viral RNA is either singly spliced or not spliced to make the structural proteins, or they are multiple spliced to generate RNAs to make the regulatory and accessory proteins. The full length unspliced RNA is shifted to the membrane surface for inclusion into new virus particles (Yuntao, 2004). The structural proteins generated must be assembled and included to form new virions.

Assembly, budding, and maturation

Structural proteins, including the gag-pol precursor protein, aggregate at the cell surface for inclusion into new virions. The virus particles eventually mature to form infectious viruses by cleavage of precursor gag-pol polyprotein by the viral protease enzyme (African Network for the Care of Children affected by AIDS, 2004, p.27; Cleghorn, Reitz, Popovic & Gallo, 2005). Protease inhibitors work at this stage of the viral reproduction cycle. They prevent HIV from being successfully assembled and released from the infected cells (Ministry of Health and Social Services, 2007, p.5). The virus buds through the membrane, taking the cellular lipid bilayer with it, to form mature virus particles. The gp160, embedded in the membrane of an infected cell, is cleared by cellular enzymes to generate functional gp 41 and gp120 to form a mature virus. The mature virus is now ready for transmission and further infection of uninfected CD4 cells.

2.4.2 HIV transmission

Epidemiological studies have demonstrated that HIV is transmitted by sexual, parenteral (blood-borne), and perinatal means (Anderson, 2000, p.17). Transmission rates from the infected host to the uninfected recipient may vary by both mode of transmission and specific circumstances.

Initial infection at the mucosal surface

When HIV enters the body at mucosal surfaces (e.g. oropharynx, genitalia) it encounters Langerham cells. These are a type of follicular dendritic cells (FDC) that is abundant at mucosal surfaces and which traps virus particles and antigens. The virus then reaches aggregates of FDC containing lymphoid tissue that lie immediately below the mucosal surface. A few days after infection, the virus can be detected in neighbouring lymphocytes and monocytes, and thereafter in regional lymphoid tissue, which also contain FDC's. The virus becomes increasingly disseminated leading to primary viraemia.

Primary viraemia

Primary HIV infection (PHI) is also called the seroconversion illness or acute HIV infection. It represents the stage of infection after the acquisition of the virus when antibodies are developing. "Between 25 % and 65 % of people have been found to present with symptoms at the time of seroconversion," (Weiss, Dalgleish, Loveday & Pillay, 2004, p.726). These can range from a mild, glandular fever-like illness to an encephalopathy. The severe symptoms are rare.

At the time of PHI there is sometimes a high rate of viral replication, leading to a transient rise in HIV viral load and concomitant immune-suppression due to a short lived fall in the CD4 count (Mindel & Tenant-Flowers, 2001). This may result in manifestations of HIV disease which are normally seen later in the infection, for example, oral candida. Diagnostic confusion as to the stage of HIV infection may arise, which can only be resolved by following up the patient for long enough to see the symptoms and signs resolve, HIV antibodies appear, the viral load fall and the CD4 count rise.

The course of infection thereafter depends on a number of factors that include but are not limited to availability and administration of HAART. The course of infection differs greatly between treated and untreated HIV.

2.4.3 Untreated HIV infection

CD4 cell and other anti HIV cells such as CD8 cells are created during the acute infection phase, a response to the infection. This leads to a decrease in viral load from a high level to some lower “set point” (Weiss et al, 2004). The activated HIV-specific cells are targets for infection and destruction by the HIV. Without treatment, infection destroys the immune system progressively designed to control it. This HIV accumulation eventually results in the destruction of lymph node architecture and the release of the virus and other previously entrapped contents of the lymphoid tissue, like bacteria and fungi, into the circulation. Although studies have proven that HIV infection typically takes 10 to 12 years from initial infection to death, this period varies considerable between individuals. There are ‘rapid progressors’ and ‘long term non-progressors’ in adults.

Rapid progressors show a decline in CD4 cell counts and non-cytolitic CD8 suppressor activity over 2-3 years whereas the non progressors show no such decline. The contribution of immunological, virological and genetic factors may have significant roles in this difference in progression. In children however, the HIV infection generally progresses faster than in adults and the clinical presentation is variable. Bartlet, (2005, p.13), stresses that there is no significant difference in progression rates based on sex, race or risk category.

2.4.4 HIV in treated patients

Successful treatment suppresses HIV to very low levels preventing the destruction of CD4 cells. The advent of the therapy has dramatically decreased mortality and morbidity among HIV-infected persons throughout the developed world (Palella, Delaney, Moorman, Loveless, Fuhrer, Satten, et al, 1998, p.856). Hospitalisation rates for HIV related complications have decreased, AIDS incidence has decreased and there is restoration of hope and opportunity to live long (The Foundation for Professional Development, 2001, p.7). The synergistic use of at least three agents produces a potent and sustained reduction of viral load, and a CD4 lymphocyte count increase. If treatment is stopped, viral rebound occurs quickly because of latently infected CD4 reservoirs.

The above discussion demonstrates that the principles of anti-retroviral therapy and especially the basis for treatment are emphasised in the understanding of the pathogenesis of the HIV virus. The principles of HIV treatment will be discussed in detail next.

2.5 Principles of anti-retroviral therapy

HIV treatment is part of a comprehensive care programme, with guiding principles in the management of the condition. It is internationally recommended that patients should not be started on ART too soon when the CD4 cell count is normal or too late when the immune system is irreversibly damaged. Secondly, the initial regimen should consist of a potent combination with proven efficacy, tolerable side effect profile, and ease of administration. Regimen complexity is the most frequently cited determinant of adherence across a range of chronic medical illness (Meichenbaum & Turk, 1987, p.55) hence simple regimens must be used. Regimen complexity includes the number of pills (pill burden), the frequency and timing of doses, regimen-related dietary requirements, the number of different pills and pill size (Clinical Care options, 2007, p.7). Barlett, DeMasi, and Quinn, (2000) explain that when food restrictions are associated with a regimen, patients are 50 % less likely to adhere optimally and that a lower pill burden has been strongly associated with better virologic outcome.

Thirdly, considerations of affordability and availability of medicines and drug combinations should be of paramount importance, especially in resource-constrained countries like Namibia. An effective supply chain management system should be in place from procurement internally or internationally to the facility or end user level. This requires co-coordinated efforts from the stakeholders involved in the different levels of the comprehensive care programme and effective feedback mechanisms to ensure a constant supply of routinely used medicines and recently approved medicines. Rabkin et al, (2005, p.26) further recommend that patients should be made to understand where, when and how to obtain medicines and providing on-site pharmacies helps patients to ensure easy access to an uninterrupted supply of medicines. In line with this, in September 2007 Oshakati piloted a nationally approved outreach programme in a health centre to ensure that patients access their medicines nearer to their homes.

The fourth principle is the patient's readiness to be initiated on HAART (Mudiayi, 2007, p.11). Starting on ART from a public health point of view is not an emergency, and providers should take time to adequately prepare patients/caregivers before commencement of treatment. Such preparation includes discussions about the medicines, the need for lifelong therapy, the implications of suboptimal adherence and ongoing care. In most settings an assessment phase of prophylactic treatment is prescribed for a period of 2 weeks or more to ensure patient's readiness to start on ART. In this phase patient characteristics and behaviours with either positive or negative effects can be ascertained and interventions tailor made for that patient implemented (Paterson, Swindells & Mohr, 2000, p.133). For HAART, relatively high levels of adherence are desirable for optimal viral suppression.

There is a consistently demonstrated strong association between adherence and virologic response. Early studies by Paterson, et al, (2000, p.21), found that more than 95 % adherence was necessary to achieve undetectable virus with protease inhibitors. Recent studies on patients taking non nucleoside reverse transcriptase inhibitors based regimens show that moderate levels of adherence are needed to achieve the same goal as the protease inhibitors (Bangsberg, 2006, p.939). In general, the goal for viral suppression can be attained with adherence levels of 70 % to 80 %. These levels are very high and adherence decreases over time. This phenomenon of treatment fatigue with chronic treatment results from the sense that treatment has ‘taken over the patient’s life’ and requires exhausting levels of concentration to follow (Rodriguez-Rosado, Jimenez-Nacher, Soriano & Gonzalez-Lahoz, 1998, p.1112).

2.6 Treatment outcome

Effective Treatment

Outcomes of antiretroviral therapy are mainly determined using the CD4 lymphocyte cell count, viral load and clinical features. CD4 lymphocyte counts are one of the most useful and reliable markers for assessing readiness to start treatment and its effectiveness. The Namibian Guidelines (MoHSS, 2006) state that, an increase of more than 100 CD4 cells/ml in the first 6-12 months is typically seen in ARV naïve, adherent patients. Plasma viral load assay is also a major determinant of disease progression and also a predictor of effectiveness of therapy. Viral load levels are likely to reach levels of less than 50 copies/ml by 6 months of therapy in fully adherent patients (MoHSS, 2006). High costs and unavailability at some health facilities make these assays very difficult to use routinely.

Treatment Failure

Treatment failure is defined as a combination of immunological, virological and clinical failure. In virological failure there is a sustained increase of viral load of greater than 0.6 log from its lowest point or a return to 50 % of the pre-treatment value. This happens when there is no effective viral suppression and the viral levels increase. Clinical evidence of failure is indicated by HIV disease progression, for example, new opportunistic infections. Failure by immunological evaluation is a fall in the CD4 count by more than 50 % from its peak or a return to the pre-treatment value (MoHSS, 2003, p.10).

The above discussion on the positive and negative treatment outcomes demonstrates the necessity for good adherence and also the need to identify defaulters as soon as possible to avoid the consequences of defaulting.

2.7 Exploration of the meaning of the term "Defaulters"

The Oxford Dictionary, (2006, p.34) defines to default as "failure to do something that one is legally bound to do". An agreement binding the person to the terms or guidelines prescribed is entered to which the patient must adhere. In most chronic treatment protocols patients are prescribed scheduled visits for medicine refills and routine monitoring. Therefore, to default in this context is failure to attend these visits. Any patient who misses two consecutive clinic visits resulting in a break in ARV treatment owing to an insufficient supply of medicine is labelled a defaulter according to the MoHSS, (2003, 7). In this model a patient is expected to fulfil a scheduled visit for medicine refills at a prescribed interval, for example, after twenty eight days. A monthly refill has enough medicines to last for 30 days giving extra quantities for two days. These extra quantities can accumulate after each visit.

The practice in Oshakati was to balance the quantities when the extras exceeded a week supply. In view of this, an allowance of days was given to each patient outside the prescribed date of visit depending on the extra medicines they were expected to possess at a given time. If a patient missed the first month but eventually presented him/herself within the allowance period he/she was considered to have missed his/her appointment date but was adherent to treatment, if medicines balanced.

If a patient missed the first month and eventually presented to the clinic outside the allowance period, he/she had missed follow-up and was non-adherent. When the patient missed two consecutive appointments and had not obtained medicines elsewhere within that time then he/she was labelled a defaulter. Treatment would have been interrupted as there were not enough medicines for administration and this will render the patient at risk of resistance and viral progression.

2.8 Potential risks of defaulting HIV treatment

HAART interruption entails important potential risks including viral rebound, decrease in number of CD4+ T-lymphocytes, and increased resistance to drugs (Deeks, 2001, p.413). Disease progression is currently monitored through immunological, clinical and virological means. If the immunity of an infected person drops and the viral load increases there is disease progression. "Development of resistance is based on the high rate of errors with reverse transcription resulting in an average of one mutation for each HIV genome transcribed, coupled with a high replication rate that results in infection of 10^6 – 10^8 lymphoid cells per day," (Clavel & Hance, 2004, p.350).

These mutations confer specific resistance to different ART drugs, reducing their sensitivity and ultimately rendering them ineffective. For both the individual and community this is a serious situation, as the emergence of these mutated viruses could lead to their transmission and subsequent failure of the ART programme. Limitations to alternative antiretroviral regimens with documented efficacy might also make it difficult to make changes in therapy, should the need arise. Therefore careful monitoring of patients is essential to avoid the emergence of such problems.

There is growing evidence that defaulting on HAART is associated with virological failure, as most patients who default HAART do not introduce any drugs into their bodies for viruses to mutate. However, good adherence in the absence of complete viral suppression is associated with increased rates of drug resistance (Bangsberg, 2003, p. 1925). HIV has a very high replication and mutation rate. If drug doses are intermittently missed, the virus quickly begins to replicate. This supports the evidence that with defaulters, the major challenge is virological failure and disease progression. When there are low drug concentrations (in non-adherent patients), viral mutations that confer drug resistance thrive (Anderson, 2000, p.139-140). According to Clavel & Hance, (2004, p. 350), this is based on the high rate of errors with reverse transcription resulting in an average of one mutation for each HIV genome transcribed. Nevertheless, non-adherent patients are likely defaulters of most treatment protocols and the threat of a plethora of consequences such as virological failure and resistance delay achievement of goals for HIV/AIDS treatment worldwide.

Disease progression spread of resistant viral strains, and introduction of salvage treatment regimens are consequences likely to result when patients default on HAART programmes. Many second-line ART drugs remain too costly for use in many countries and this might prove an ongoing obstacle to expanding treatment access to vulnerable populations (UNAIDS, 2006a, p.13). Expanding momentum in treatment scale-up demands the monitoring of key barriers to HIV management, which include adherence and defaulter measurement. Furthermore, it is necessary to understand the reasons for default after initiation of treatment for planning strategies to reduce default and increase successful treatment outcome.

2.9 Defaulting treatment as a complex phenomenon

Despite time spent on counselling new patients, on physical examinations, and on stressing the importance of adherence, a significant number of patients still do not keep their follow-up appointments at various stages of their treatment (Bartholomew, 2004). Barriers to adherence to ART vary from setting to setting; some researchers consider non-adherence to be a biosocial and dynamic phenomenon (Castro, 2005, p.338). This is a major concern throughout the world as it seriously affects the treatment of HIV/AIDS and the success of intervention programmes in containing the spread of the disease.

Studies on defaulters in different parts of the world have identified many factors associated with defaulting. Geography, ethnicity and programmatic differences also compound the quest for the reasons why people default on treatment. Studies carried out by Deribe, Hailekiros, Biadgilign, Amberbir & Beyene, (2006) and Kwong-Leung, Chih-Cheng, Wang, Chao-Sung, Makombe, Schouten, et al, (2007) clearly show that there is a common agreement of categories for a majority of factors that lead to patients defaulting but in both studies some factors could not have a common classification and these were dependent on the study site in question. Be that as it may, there is always agreement that the consequences of defaulting are potentially harmful to the patient and the community at large.

Interruption of HAART entails significant risks such as viral rebound and decrease in number of CD4+ T-lymphocytes (Deeks, 2001, p.413). Patients discontinuing HAART usually develop rapid viral rebound and loss of CD4 cells (Papasavvas Ortiz, Gross, Sun, Moore, Heymann, et al, 2000). Optimal adherence levels needed to achieve and maintain suppression of viral replication are 95 % level of anti-retroviral drug dosing. Therefore, despite a clear cut understanding on the reasons for patients defaulting, it is important to identify, describe and deal with those factors associated with long-term defaulting in patients taking HAART (Deribe et al, 2006).

2.10 Good practices in reducing defaulters to treatment

Strategies to ensure that patients on chronic treatment religiously take their medicines have evolved and improved significantly from other similar programmes that have been previously implemented. Examples that come to mind include the TB, diabetic, cancer and hypertension programmes. Lessons learnt from these programmes can be applied to HIV/AIDS programmes to reduce the default rate of patients.

In Kenya a modified directly observed treatment (DOT) plan called directly administered anti-retroviral therapy (DAART) was implemented at a health facility to promote adherence. The plan ensured that patients were consistent in their follow-up schedules. In the DAART strategy a patient takes one dose of medication in the presence of a health worker during the visit to the facility (Sarna, Munyao, Luchters, Geibel, Shikely, Mandaliya, Kaai, Hawken, van Dam & Temmerman, 2005, p.2). This strategy can be employed in Namibia during the monthly medicine collection visits by patients. Fischl (2001) supports such a strategy and explains in his study that DAART as compared to HAART proved that compliance correlated with better therapeutic success than self- administered therapy.

“Health education provides knowledge and information, and helps people to develop the necessary skills so that they can make informed choices,” (Naidoo & Willis, 2000, p.97). It is the cornerstone of imparting knowledge and skill. However, under provision of counselling services serves as a drawback to anti-retroviral therapy programmes (KwaZulu-Natal Department of Health, 2005, p.4). The counselling offered to patients tested for CD4 count is mainly limited to patients diagnosed with CD4 count less than 200copies/ml of blood and eligible for HAART. Extending this education to the community and HIV positive patients waiting to be eligible for HAART may be necessary if people are to know more about the goals for anti-retroviral therapy. This will serve as a gentle reminder to the patients as well as the community of the essence of treatment and compliance with the prescribed regimen and follow up.

2.11 Summary

The literature review has given an understanding of anti-retroviral therapy explained as the principles. Through the principles, the need to adhere to treatment protocols for sustained viral replication and attainment of treatment goals is highlighted. The complexity of understanding the anatomy of defaulting has been shown through previous studies which make remedial approaches difficult to standardise and apply in different ethnographic settings.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

The next chapter focuses on the research design and method, target group and the criteria which used for the selection of the respondents, sampling procedure and how data was generated. It also gives an indication of where the study took place, highlights different strategies used to ensure that the study is of good quality, how data was analysed and the ethical considerations involved in the study

The research was conducted in two phases:

- Phase one - which was a quantitative approach
- Phase two - which was a qualitative approach

3.2 Phase 1: Quantitative study

3.2.1 Study design

A descriptive, explorative design with a quantitative approach was used in the initial phase of this study. This type of approach was most appropriate for this study because, apart from knowing that defaulters existed, little was known about the specific factors that apply to patients who default on HAART. Therefore, an in-depth exploration and description of the factors was essential to understand the nature of the problem (Varkevisser, Pathmanathan & Brownlee, 1995, p.121).

Descriptive design

The researcher wanted to describe the factors contributing to patients defaulting on treatment in Oshakati. "The major purpose of scientific studies is to describe situations and events", (Babbie & Mouton, 2001, p.80). Therefore, in the study descriptive statistics were extensively used.

Exploratory design

Exploratory research means that hardly anything is known about the matter at the outset of the project. The research normally begins with a rather vague impression of what should be studied and normally begins with phenomenon of interest and as much information is gathered first on the object of study and definite models or concepts is precisely developed with time (Polit & Hungler, 1997). Limited studies have been done which the focus solely on defaulters, most researchers have committed substantial time and study on non-adherent patients who keep to their regular follow-up schedules and do not interrupt treatment indefinitely. Therefore the researcher explored information that also considered defaulters to chronic treatment and addressed the objectives of the study.

Quantitative data

"Quantitative data is that information which is numerically measured or analysed. This usually involves computerisation of statistical measures and tests of significance. Quantitative research methods allow for easy comparisons and reproduction of results," (Brink & Wood 2001, p. 120). In this study quantitative descriptive statistical methods were used. Graphs, tables and pie charts were used to present the data and the Statistical Programme for Social Studies (SPSS) was used to analyse the data.

3.2.2 Study site

The study was carried out among patients who had registered for, and had started, the ART programme in the CDC at Oshakati State Hospital but had defaulted on treatment.

3.2.3 Study population and sampling

3.2.3.1 Study population

The study unit was defaulters on HAART in Oshakati who were willing to participate and had been on treatment for at least three months before defaulting. The number was dependant on the defaulter list generated by the dispensing tool.

The computer generated a list of 80 defaulters during the month of July 2007. Although the study did not exclude children as patients, no children were interviewed. The guidelines stipulated that children should be in the exclusive care of guardians and parents. Therefore guardians and parents of children on HAART were considered in the study.

Inclusion Criteria

- Patients initiated in ART programme for at least 3 months prior to defaulting.
- Patients identified, tracked who had given informed consent.
- Patients willing to re-initiate therapy if they qualified.

3.2.3.2 Study sample

Sample size

The sample was a compromise between what was desirable and what was feasible given the fact that for explorative studies a large sample size is required to reflect important variations in the population (Varkevisser et al, 1995, p.122). The researcher included all the people in the population since the population size was very small.

3.2.4 Methods of conducting the survey

Research instrument

A questionnaire with both open-ended and closed questions was used. It was completed independently by the respondents or was completed by the researcher in case of literacy and accessibility problems. This method was employed because:

- It has a high response rate.
- It allows for all questions to be answered.
- It provides a chance for a researcher to clarify questions.

Questionnaire design

An extensive literature review on studies done on defaulters to follow-up and treatment of chronic ailments including HIV/AIDS was conducted. The questionnaire format and sections was adapted with modifications from a defaulter study on Tuberculosis treatment in South Africa (Finlay, van der Walt, Holtz, Thorpe, Wells, & Weyer, 2004). This was done to integrate factors outlined from the health promotion model into the questionnaire. A statistician and an epidemiologist were consulted to check for consistency and statistical applicability of the instrument.

A questionnaire review meeting involving health personnel at the ART clinic and the researcher was held before finalisation of questionnaires to refine the content. During these discussions the group identified reasons patients had previously reported as barriers to good adherence and honouring scheduled visits to the clinic. These reasons were considered in the compilation of questions and also with reference to the conceptual framework.

Contents of Questionnaire

Section A	Demographic characteristics
Section B	Socio-economic related factors
Section C	Health Service related factors
Section D	Socio-cultural related factors
Section E	Clinical/Medical related factors

3.2.5 Validity

According to De Vos, (2002) validity refers to the degree to which an instrument is measuring what it intends to measure. There are different types of validity such as content validity, face validity, criterion validity and construct validity. In this study face and content validity were used.

Face Validity

In face validity one focuses on the operationalisation to see at “face value” that the instrument is a good translation of the construct. In assessing face validity the instrument should be sent to a carefully selected sample of experts who can report back with the judgement that the measure appears to be a good measure of the construct (Trochim, 2008). In this study the researcher ensured face validity by submitting the instrument to three expert researchers, colleagues and supervisors, who assessed whether the instrument was representative of the purpose of the study. Modifications were made accordingly.

Content Validity

In content validity one essentially checks the operationalisation against the relevant content domain for the construct (Trochim, 2008). Content validity was firstly ensured by the researcher through a comprehensive literature review on variables or fields to be used for the instrument construction. Secondly, in developing the questionnaire the guidance of experts was sought. These experts included supervisors, an epidemiologist, and a statistician.

3.2.6 Reliability

Reliability has to do with the quality of measurement. In its every day sense, reliability is the consistency or repeatability of a measure (Trochim, 2008). Tests of reliability focus on stability, internal consistency and equivalence. The choice of a test depended on the nature and intended purpose of the instrument (DePoy & Gitlin, 1998, p.203). In this study equivalence was used as a test for reliability. The researcher administered a questionnaire on two different occasions to the same 5 individuals under study in the pilot phase. Agreement of responses from the two ratings was scored as a percentage to indicate the reliability of the instrument. According to DePoy & Gitlin, (1998, p.203), a score of 80 % or higher is desirable.

3.2.7 Pilot study

A pilot test was carried out as a preliminary study on a small scale, which incorporated the entire research procedure. The aim of the test was to identify potential, unforeseen problems which could arise in the full study and thus facilitate appropriate revisions. The pilot study was conducted with five respondents at the Oshakati clinic in the Oshana region. The same individuals were given the questionnaires on their second visit (after 1 month) to test for the reliability of the instrument and consistency of responses.

Four (4) out of 5 patients managed to fill the same responses on the two occasions that they were given the questionnaire to fill. One (n=1) respondent filled correctly and consistently the scaled responses on the questionnaire, and Part 1 of the questionnaire with the demographic data section. That one respondent had inconsistent responses on the open ended questions, which are questions 22, 37 and 38. On average it took respondents 15-20 minutes to fill in the questionnaire which was considered an acceptable amount of time by the respondents.

3.2.8 Data collection process

Permission to Proceed

The following were asked to consent to the study: the Ministry of Health and Social Services research committee, Oshakati State Hospital Directorate, and the individuals who were respondents in this study. Ethical issues were also considered in the study and these are discussed later.

Data collection techniques

The researcher and a data clerk did a record study of the existing demographic and medical information of patients. This involved carefully examining appointment schedules mid-monthly from the pharmacy dispensing tool and Epi Info. A defaulter list was then generated.

The researcher with the help of the Oshana TB co-coordinator traced individuals by telephone and contacted some defaulters. Certain individuals who were traced were willing to recommence treatment and appointments were made with them so that they could fill in the questionnaires on their visit to the clinic. Traced defaulters conforming to the inclusion criteria of the study were interviewed and a questionnaire completed independently by the participants or by the researcher in cases of literacy and accessibility problems. An informed consent form was signed by participants who were interviewed face to face and those who filled the questionnaires independently.

Data Handling

Data collected was checked for accuracy, completeness and consistency. At the time of the interview the questionnaires were numbered for ease of sorting and storage. All the records were stored at the Oshakati CDC data clerk's office in a locked cabinet and were only accessible to the researcher, staff of the clinic and authorized persons. All the records were stored in a sequence determined by the number allocated to the document concerned.

3.2.9 Ethical consideration

Before data collection from participants, the purpose of the study was explained to the respondents, who were asked to give their informed consent so that their participation was voluntary. The participants were free to withdraw from the study at any time and were not be penalized for doing so. To assure confidentiality all questionnaires were anonymous and information collected was stored in a locked cabinet at the clinic and only accessed by the researcher, investigator, and members of staff and authorized personnel as explained above.

3.2.10Data analysis of quantitative data

Sorting Data

Questionnaires were sorted in categorical order, namely D1, D2, D3 etc standing for Defaulter 1, Defaulter 2, Defaulter 3 respectively. Questionnaires were checked for completeness and internal consistency. Because missing data might affect the validity of the study, it was necessary to ask for clarification. Variables collected without categorisation were categorised and expert advice sought prior to questionnaire design and entry of data. SPSS was used for data entry. Descriptive statistics were utilized. The analysis was performed using SPSS. Information was presented in the form of central tendencies and it was supported by frequency tables.

3.3 Phase 2: Qualitative study

A second qualitative study was carried out towards the completion of the quantitative study on defaulters in Oshakati. The purpose was to seek an in-depth understanding of the factors that had influenced the patients to default on treatment and to provide suggestions for improving the return rates of the patients. The method used was a focus group discussion.

A focus group discussion is defined as a “carefully planned discussion designed to obtain perceptions in a defined area of interest in a permissive, non-threatening environment” (Kreuger, 1998, p.20). The key element here is the involvement of people where their disclosures are encouraged in a nurturing environment. It taps into human tendencies where attitudes and perceptions are developed through interaction with other people. As such, during a group discussion, individuals may shift opinions owing to the effect of comments from others or opinions may be held with certainty.

3.3.1 Sampling and group composition

Recruitment and sampling

The sample population was taken from a pre-existing cluster of 72 defaulters who had previously been respondent at the first phase of the study. Convenience sampling was employed in the recruitment process to come up with members of the group. Most of the respondents had been re-initiated on treatment and it was relatively easy to come up with a group. Appointments schedules were synchronised for group members so that the focus group discussion could be held on their following appointment.

Sample size

The size of the group was 12 conveniently sampled people. Kreuger (1998, p.94) suggests that a smaller group of people are preferable when the participants have a great deal to share about a topic on which they have lengthy experience.

3.3.2 Data collection

A guide with open ended questions was developed in collaboration with the staff at the Oshakati ART clinic that served to provide direction and set the agenda for the discussion, see annexure 4. The questions were developed from the research question that gave the impetus to the research. The focus group explored and described the different factors that had contributed to the patients defaulting on treatment, and attempt was made to categorise them according to the different characteristics they revealed during the group discussion. The group also explored possible strategies that could be implemented to curb the problem of defaulters. The researcher assumed the role of moderator and Chief Rapporteur for the group and was assisted in the translation from Oshiwambo to English and vice versa by a pharmacist assistant. A registered nurse at the clinic assumed the role of the second Rapporteur. Verbatim notes on all the conversation were recorded in English and field notes where kept to increase the validity of the study.

Location and time of the discussion

The focus group discussions were conducted in one of the secure counselling room in the Oshakati ART clinic. The time was chosen to coincide with the date of follow up appointments and was organised so that all the respondents could attend on the 28 May 2008.

Questions for the participants

1. Please introduce yourself. What is your age and, where do you come from?
2. Why did you stop your ART?
3. How can this problem be solved?
4. What are your opinions about the healthcare providers in Oshakati ART clinic?

3.3.3 Data analysis of the qualitative data

The qualitative data was analysed according to the method of Tesch (cited in Creswell 1994, p.155). The 8 steps appear below:

Step 1: Read through all the transcripts and make notes of ideas as they come to mind.

Step 2: Pick the shortest or most interesting interview and find the underlying meaning. Write your notes in the margin.

Step 3: Follow this procedure for a few participants. Make a list of all the topics which arise and cluster similar topics together. Arrange the topics in column of major topics, unique topics and other topics.

Step 4: Give those topics codes and write the codes next to the appropriate segment of the next sentence, and see if new categories and codes emerge.

Step 5: Find the most descriptive words for the topics and turn them into categories. Try to reduce the total list of categories by grouping topics that are related together.

Step 6: Make a decision on the abbreviation of categories and alphabetise these codes.

Step 7: Bring the data material belonging to each category together in one place and perform a preliminary analysis.

Step 8: Re-code the data if necessary.

A literature control was carried out to verify the results and to place them in the context of an established body of knowledge.

The participants' comments were first read to obtain a general overview. The most interesting anecdote or comment was then evaluated. Patterns were established and these were later grouped together as themes.

3.3.4 Quality and credibility of the qualitative research

The following protocols were applied to the qualitative phase of the research to ensure reliability and validity of the data collected and analysed: trustworthiness (dependability, confirmability, transferability and credibility) and methodological triangulation was used to enhance or improve trustworthiness.

Dependability

According to Strauss & Myburgh, (2000), dependability means that if any other researcher goes through the raw data collected from the focus group discussion in a particular study, they should come to the same conclusions or findings. Literature control was used to substantiate the findings in this study.

A clear description of the research methodology was also provided so that other researchers can follow the same process accurately. Therefore, in this study a dense description of the steps followed in conducting the focus group discussion was provided.

Lincoln & Guba, (1985, p.221), suggests that, “a single audit of the research can enhance the dependability of the project.” This was done continuously by the supervisors and a qualitative independent coder with specialisation in qualitative data analysis. General consensus and discussions were held after each audit stage.

Confirmability

Another aspect in ensuring rigour in qualitative data is confirmability, which is the consistency and repeatability of the decision making about the process of data collection and data analysis (MacNee & McCabe, 2008, p. 170-171). Criteria that can be used to ensure confirmability include confirmability audit, triangulation and reflexivity (Lincoln & Guba, 1985).

An adequate confirmability trail should be left to enable the auditor to determine if the conclusions, interpretations, and recommendations can be traced to their sources and if they are supported by the inquiry. Lincoln & Guba, (1985) suggest six classes of raw record data to be reviewed and the researcher kept a record of such data.

1. **Raw Data**: included recorded written field notes, documents, focus group discussion results.
2. **Data Reduction and Analysis Products**: these included write-ups of field notes, summaries and condensed notes, theoretical notes such as working hypotheses, concepts, and hunches.
3. **Data Reconstruction and Synthesis Products**: these were themes that were developed, findings and conclusions and the final report
4. **Process Notes**: which included methodological notes, trustworthiness notes, and audit trail notes.
5. **Material Relating to Intentions and Dispositions**: This included inquiry proposal, personal notes and expectations.
6. **Instrument Development Information**: this included the preliminary findings from the phase 1 study.

Methodological triangulation was used to enhance the confirmability and confidence of findings in the whole study. Two methods were used in the data collection process. Quantitative data were obtained in the first phase of the research and focus group discussions were held after preliminary findings from the first phase to validate the findings by a process of cross checking. This method is referred to as *methodological triangulation* (Padgett, as cited in de Vos, Strydom, Fouche & Delport, 2004).

Reflexivity involves the realisation that the researcher is part of the social world he/she studies and that this realisation is part of an honest examination of the values and interest that may impinge on research work (Davies & Dodd, 2002, p.281). Throughout the study the researcher examined the impact of his presence and entries related to this are found in the field diary. Researcher prejudices and biases are documented in this discussion.

Transferability

The third aspect of rigour in qualitative research is the transferability of the concepts, themes or dimensions identified (MacNee & McCabe, 2008). It is essentially the extent to which the results can be applied to a similar context. The criteria that have to be met to address this strategy must look at the nominated sample, comparison of sample to demographic data, time sample and dense description.

Convenience sampling was employed in this research. Defaulters to HIV treatment were conveniently selected for this study to gain insight on their experiences and to obtain the reasons why they had defaulted on treatment. A complete in-depth description of the results was made supported by verbal quotes from the group discussion, field notes were analysed and interpreted and a literature control was undertaken.

Credibility

The fourth aspect in ensuring rigour in qualitative research is credibility, which is the accountability (Strauss et al, 2000) or the truth value of the whole research. The term credibility also refers to “the description or interpretation of a person’s experience that remains truthful to the story that has been told or an idea which is defensible” (Johnson, 1997, p.282). It includes actions in preparation for the field, establishing researcher authority, keeping a reflexive (field) journal, member checking (MacNee & McCabe, 2008), triangulation and peer group examination.

In this study, a guide with open-ended questions was used in the focus group discussions, a field (journal) notes was kept and literature control was utilised in the preparation of the guide and for the field visit. The researcher established authority by assuming the role of moderator and Chief Rapporteur during the discussions.

Member checks mean that “the data and findings from data analysis are brought back to the original participants to seek their input concerning the accuracy, completeness, and interpretation of the data” (MacNee & McCabe, 2008, p. 172). In this study member checking was done after the focus group discussion to confirm the preliminary findings with the participants.

Peer examination “involves the researcher’s discussing the research process and findings with impartial colleagues who have experience with qualitative methods” (Lincoln & Guba, 1985, p.219). Peer examination of the study was done by discussing the findings of the study with an expert in qualitative research and with two supervisors of the research.

3.3.5 Ethical consideration

Before the group discussion, the purpose of the study was explained to the respondents, who were asked to give their informed consent so that their participation was voluntary. The participants were free to withdraw from the study at any time and were not be penalized for doing so. To assure confidentiality all data including notebooks remain stored in a locked cabinet at the clinic and only accessed by the researcher, investigator, and members of staff and authorized personnel. Because of the sensitivity of the data being collected, a group code of conduct was agreed upon before proceeding with the focus group discussion.

3.4 Summary

This chapter addressed the way in which the study of factors contributing to patients on anti-retroviral therapy to default treatment was carried out. The steps of the research process that was followed were highlighted. The methods and strategies employed in selecting the population and sample relevant to the study, the development of the data collecting instrument and the collection of information were discussed. In the next chapter the data analysis of the results will be discussed.

CHAPTER FOUR

DATA ANALYSIS

4.1 Introduction

In this chapter, data analysis will be discussed in detail. A total of seventy six respondents (N=76) participated in Phase 1 and twelve (N=12) respondents participated in focus group discussions in Phase 2 of the study. In the quantitative phase of the study, data was collected by using a questionnaire (see annexure D) which contained open and close ended questions and in the qualitative phase of the study a focus group discussion was held and a guide was used to facilitate the discussion (see annexure E). Statistics were calculated using descriptive statistics for quantitative data and the themes where identified from qualitative data using the method of Tesch as described in Chapter 3. In some cases figures are presented to illustrate the statistics. The results from Phase 1 of the study will be discussed first.

4.2 Results from Phase 1 of the study

4.2.1 Pattern of ART use among HIV positive individuals in Oshakati Hospital

During the period of register review, 2640 patients were registered on the ART register. Of the 2640 patients, 2057 were active ART users coming for their refills monthly. Of the 2057 active ART users 1360 were female and 608 were younger than 13 years of age. A total of 583 (22.1 %) had missed two or more consecutive clinical appointments, and these comprised 20 (0.8 %) dead, 483 (18.3 %) transferred out to other facilities and 80 (3.0 %) defaulted. A graphic presentation of these figures is given in table 4.1 below.

Table 4.1 Pattern of ART use among HIV positive individuals in Oshakati Hospital, July 2007

Status	Number (N)	Percent (%)
Active refills	2057	77.9
Defaulted	80	3.0
Transferred Out	483	18.3
Died	20	0.8
Total	2640	100

Of the total defaulters 76 (95 %) were traced and responded to the questionnaire.

The defaulter rate in Oshakati (3 %) is slightly lower than reported in Malawi (5 %) (Kwong-Leung et al, 2007). Other studies have reported a defaulter rate of between 1.3 % - 13.1 % (Quarva-Jones & Barthlomew, 2004). Almost all patients (95 %) who were active and defaulted HAART were traced. The reason for not tracing the other

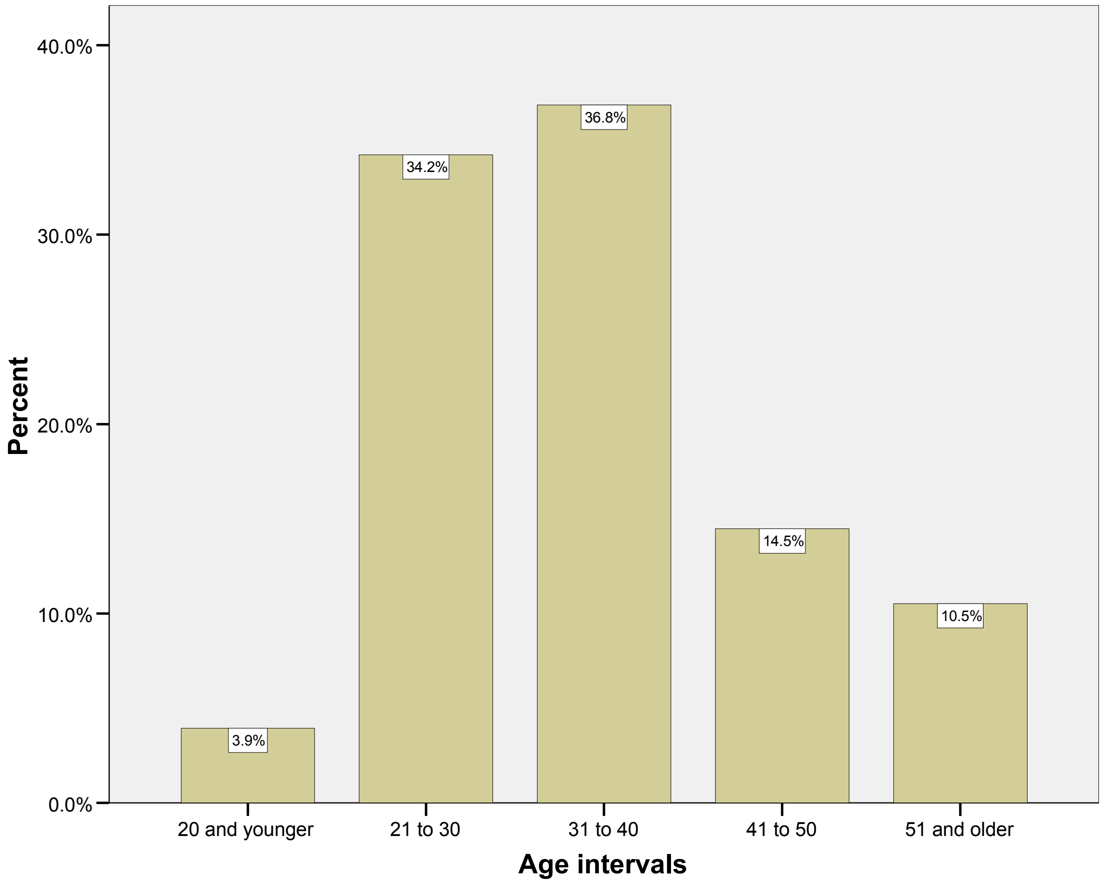
5 % of the patients was not clear, it could have been that patients gave incorrect contact details or the clinic staff erroneously entered incorrect details.

In what follows results are presented and discussed as they appeared on the questionnaire, as demographic, socio-economic, socio-cultural, service-related and medical factors.

4.2.2 Demographic data

4.2.2.1 Distribution of Defaulters by Age

Fig 4.1 Distribution of defaulters by age interval



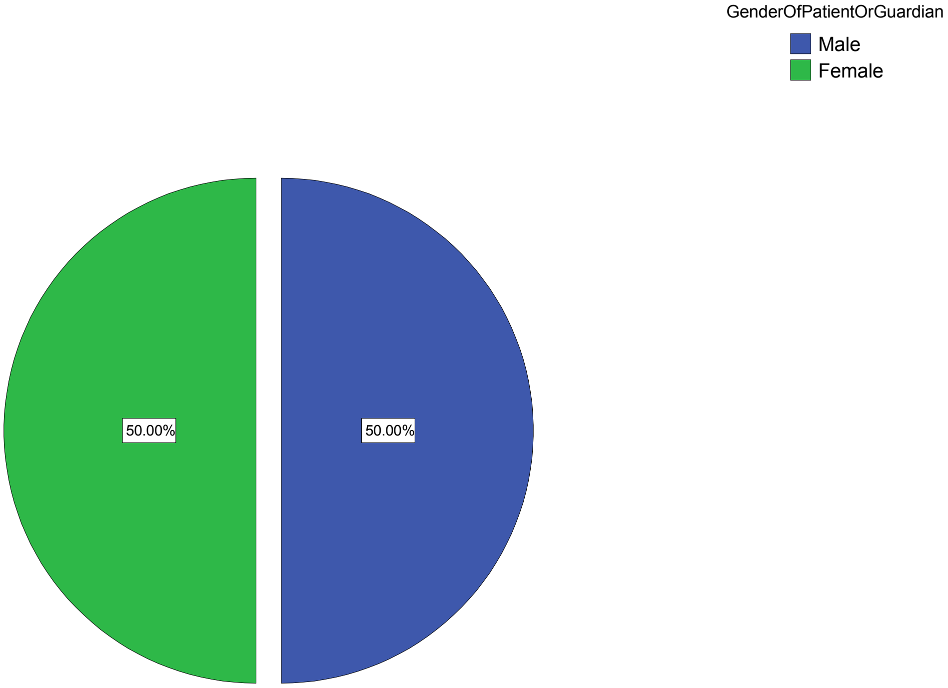
Three (3.9 %) respondents were younger than 21 years of age. The majority of the respondents were in the age groups 21- 30 years and 31- 40 years with twenty six (34.2 %) and twenty eight (36.8 %) respectively. The average age of the respondents was thirty five (mean=35, median=35 years). The minimum age of respondents was

16 years and the maximum was 80 years. The range was 64 years. The majority of the respondents are in the economically active group, of 21 years to 40 years.

These results support findings from the HIV Sentinel Survey (MoHSS, 2005) that most patients who are HIV/AIDS positive fall within the same age range. The people in this age range have other responsibilities as well, such as employment, children and often need to move and change their places of residence. Being on treatment may cause a strain to meet these commitments and defaulting on treatment may be the only way to fulfil these obligations (Thuy, Shah, Anh, Nghia, Thom, Linh et al, 2007).

4.2.2.2 Distribution of defaulters by Gender

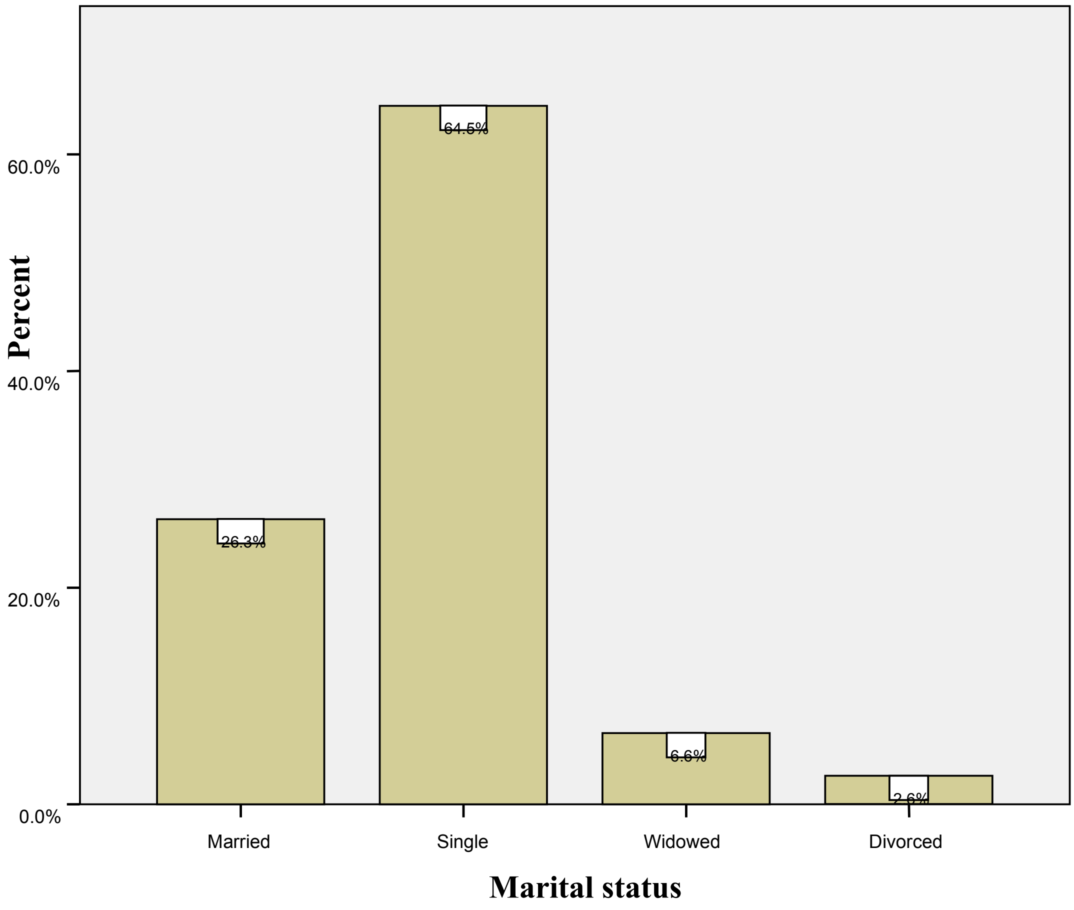
Fig 4.2 Distribution of defaulters by gender



The number of male participants in the study was the same as the number of female participants since there were 38 (50.0 %) of both sex.

4.2.2.3 Marital status of Respondents

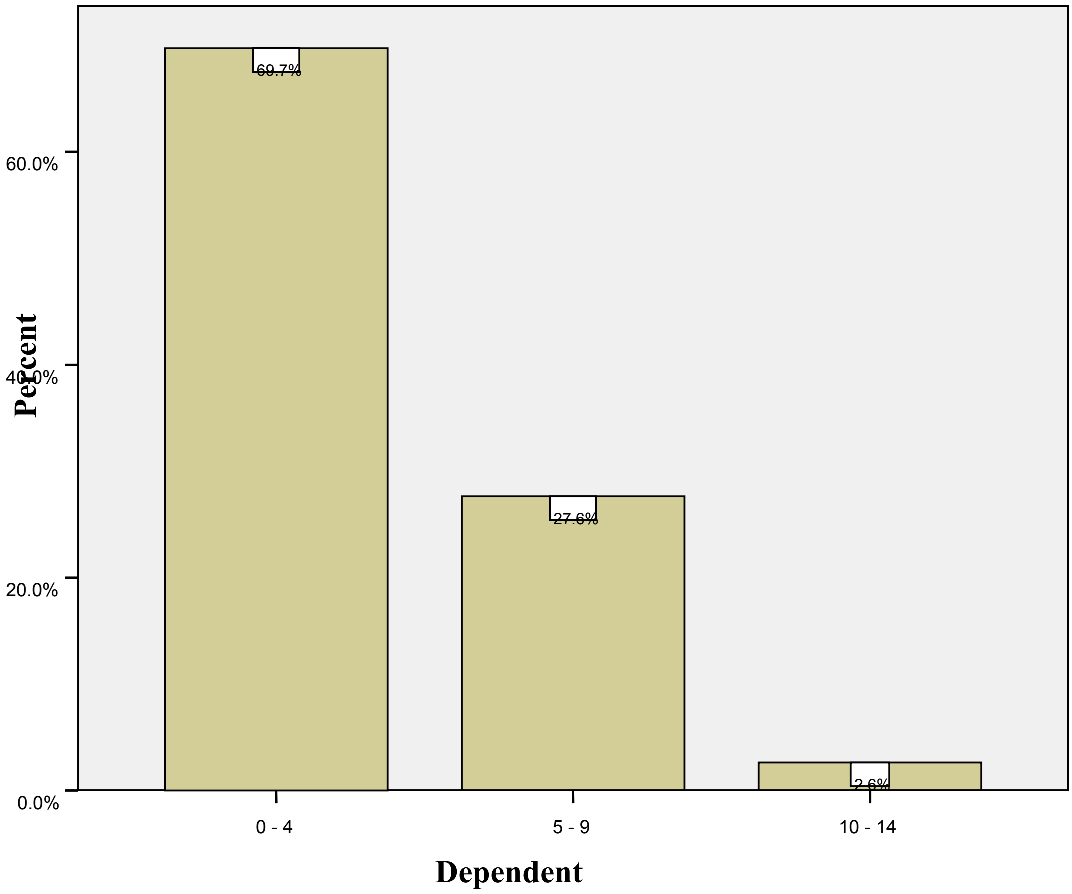
Fig 4.3 Distribution of defaulters by marital status



Forty nine of the defaulters (64.5 %) were single, twenty were married (26.3 %), two were divorced (2.6 %) and five were widowed (6.6 %). The National Consensus results in 2001 showed that fifty six percent of those older than 15 years in Namibia had never been married (Central Bureau of Statistics, 2003, p.4). However this reason can not be attributed to patients defaulting on treatment since there was no case controlled study to compare these findings with patients who were on treatment.

4.2.2.4 Level of dependants of defaulters

Fig 4.4 Level of dependants of defaulters



The majority of the respondents namely fifty three (69.7 %) had fewer than five dependants. Twenty one (27.6 %) had between 5 and 9 dependants and two (2.6 %) of the respondents had between 10 and 14 dependants. Family burden was viewed as a barrier to attending clinic visits. With more dependants, the competition in prioritising financial resources becomes harder (Kipp, Tindyebwa, Karangi & Rubaale, 2006).

4.2.2.5 Level of Education

Table 4.2 Distribution of defaulters by level of education

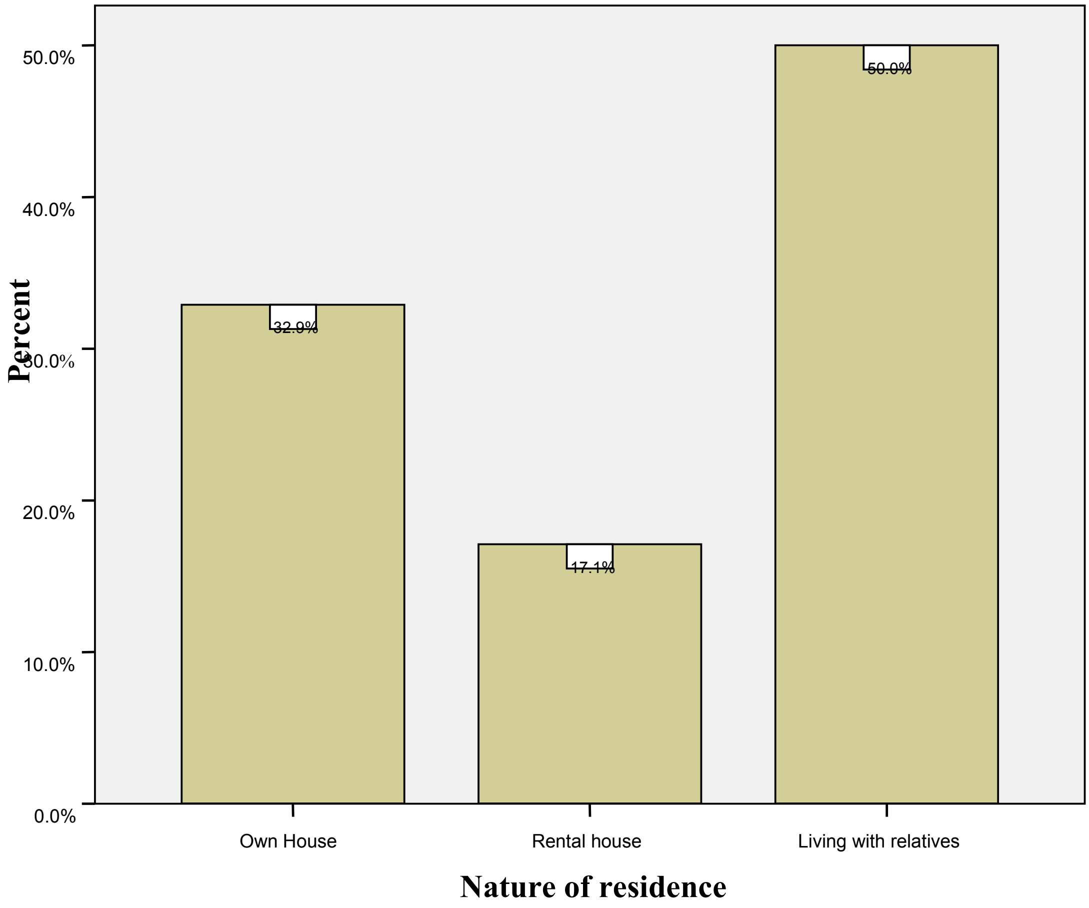
	Frequency	Percent	Valid Percent	Cumulative Percent
Not been to school	5	6.6	6.6	6.6
Primary School	31	40.8	40.8	47.4
Secondary School	34	44.7	44.7	92.1
Tertiary Education	6	7.9	7.9	
Total	76	100.0	100.0	100.0

Most of the participants, namely thirty four (44.7 %), attended school up to secondary level, thirty one (40.8 %) reached primary school, six (7.9 %) reached tertiary level and five (6.6 %) had never attended school. The level of education of a patient directly affects their interpersonal influences and cognitions concerning their beliefs (Grol & Wensing, 2004). However, in this study it appeared that most defaulters were patients with post basic education.

4.2.3 Socio-economic data

4.2.3.1 Nature of Residence

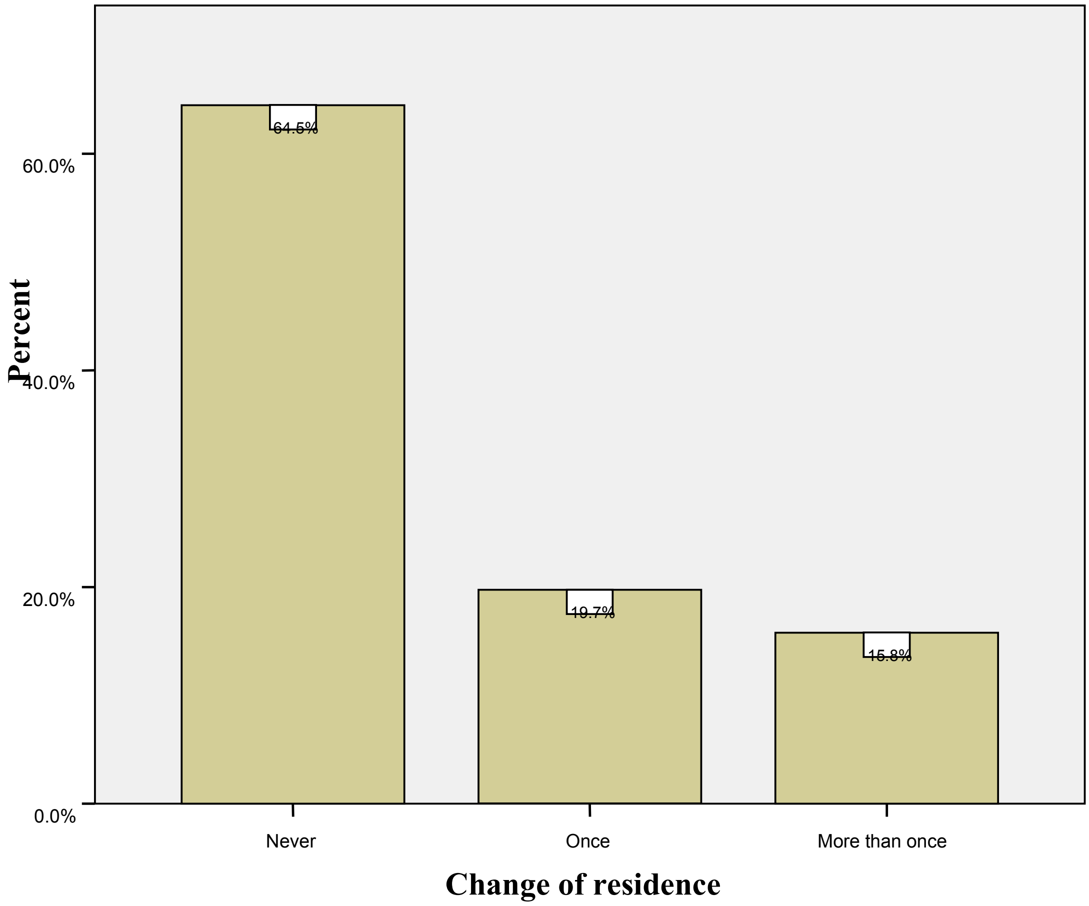
Fig 4.5 Nature of residence of defaulters



The number of respondents that were staying with relatives at the time of participating in the survey was thirty eight (50.0 %), the number of respondents who owned houses was twenty five (32.9 %) and the number of respondents who were renting a house was thirteen (17.1 %). Ownership of a house is a strong indicator for socio-economic well being of a community (Shargie & Lindtjorn, 2007). However, most people in the Oshana region stay in the rural areas with relatives (Central Bureau of Statistics, 2003).

4.2.3.2 Rate of change in residence at the time of participating in the survey from the time they started treatment

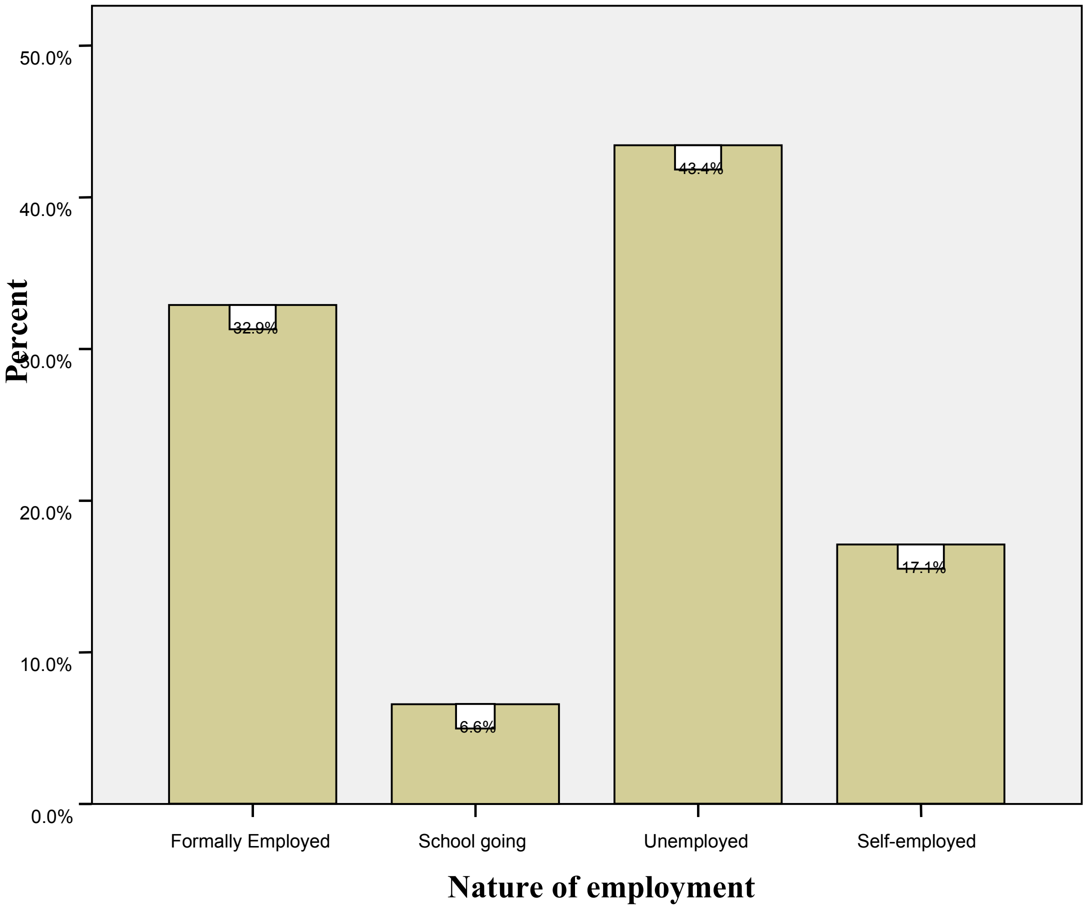
Fig 4.6 Rate of change in place of residence for the defaulters



Forty nine respondents (64.5 %) had never changed their place of residence after starting treatment, fifteen (19.7 %) had changed once and twelve (15.8 %) had changed more than once. Migration also shows an unstable socio-economic standing of a community (Shargie & Lindtjorn, 2007). This shows that most of the defaulters were stable dwellers and had not changed residences. Probably they live in the villages where they stay as families.

4.2.3.3 Nature of employment

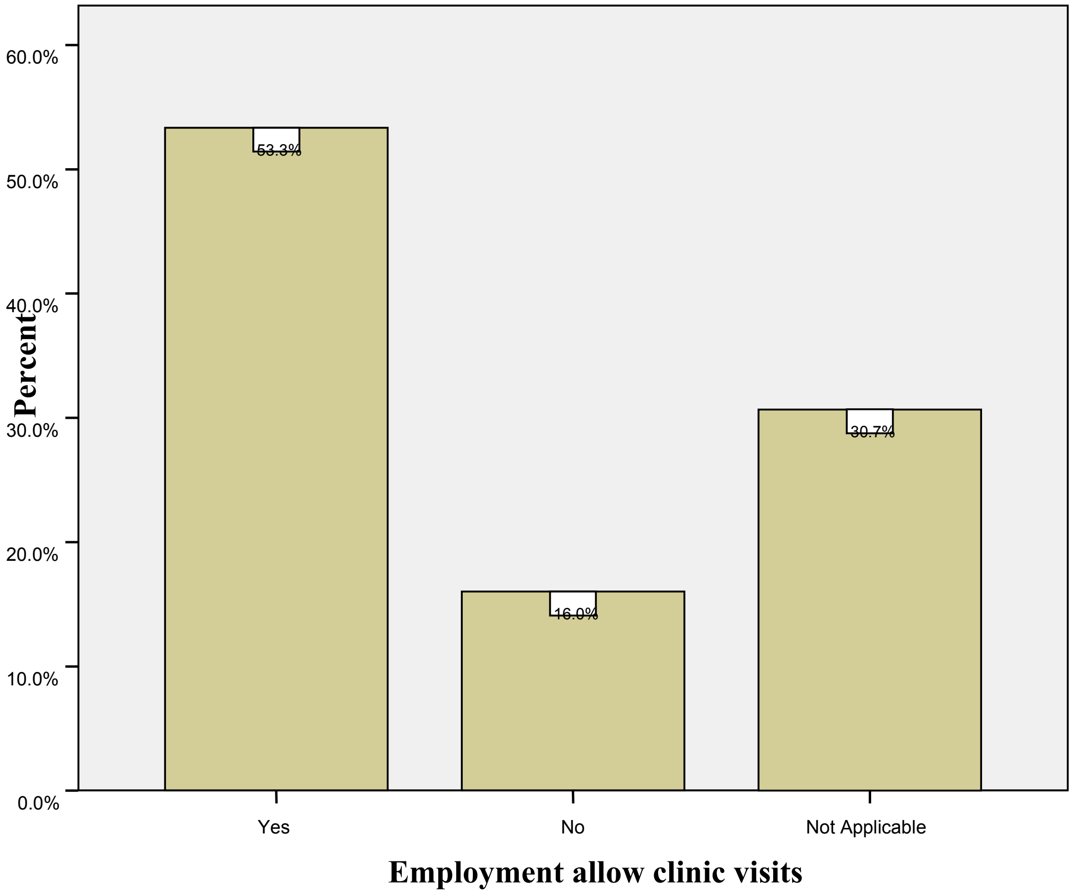
Fig 4.7 Nature of employment of the defaulters



Most of the respondents, namely thirty three (43.4 %) were unemployed. The number of respondents who were formally employed at the time of the survey was twenty five (32.9 %), those who were self employed were thirteen (17.1 %) and five (6.6 %) of the respondents were at school. The number of people who do not have any form of employment was the same as those who had some form of employment. Employment serves a source of income that enables a patient to afford food, transport and hospital fees. Lack of employment therefore, is a barrier to affording these items.

4.2.3.4 Illustration of whether employment of respondents permitted them to attend clinic visits

Fig 4.8 Illustration of whether employment allowed clinical visits for the defaulters



Literature shows that in some settings commitment to work can result in patients interrupting their treatment. In a study carried out in Ethiopia, Sagbakken, Frich and

Bjune, (2008, p.11) state, “People who are daily labourers or work in the private sector, they can’t get any kind of leave and they face more problems. Many of them interrupt treatment because they don’t want to lose their jobs”.

The researcher wanted to find out how many defaulters were not able to attend clinic visits because of work commitments. A majority of the respondents, namely forty (52.6 %), agreed that their work or nature of employment allowed them to attend clinic visits, twelve (15.8 %) disagreed, twenty three (30.3 %) were neutral and one (1.3 %) person did not answer. Therefore most defaulters were not prevented from attending clinic visits by their employer.

Mode of transport used by the respondents to the health facility

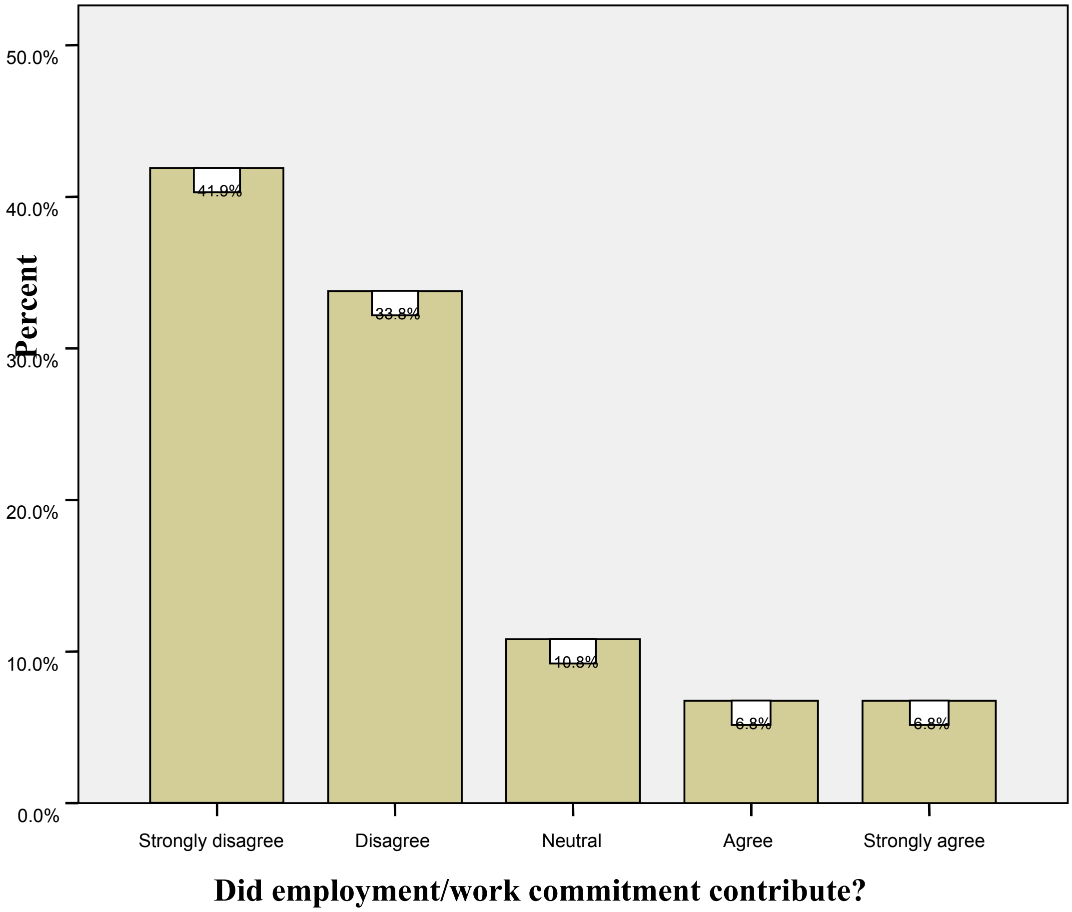
Fig 4.9 Mode of transport used by the defaulters to the health facility

The mode of transport used by patients may give an indication of whether the treatment facility is physically far from the patient's place of residence. In this study twenty seven patients (35.5 %) used public transport such as taxis to get to the clinic for any scheduled visits, twenty six (34.2 %) used a lift, fifteen (19.7 %) of the respondents walked to the clinic and eight (10.5 %) respondent used their own car to get to the clinic.

This indicates that most patients could not walk to the treatment facility and had to use other means of transport which they would have to pay for. This included public transport and also lifts from other people.

Contribution of employment/work commitment to defaulting

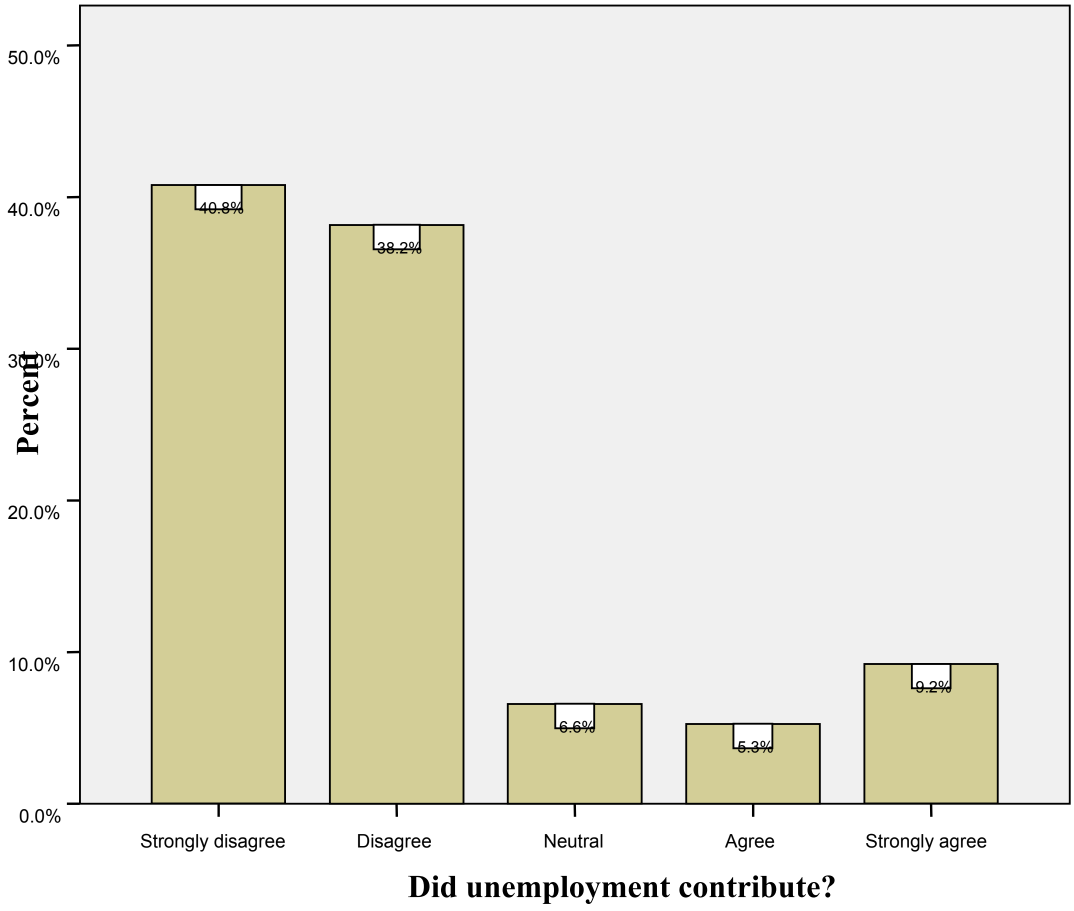
Fig 4.10 Illustration of whether employment/work commitment contributed to the patients defaulting



Five (6.6 %) agreed and five (6.6 %) totally agreed that work commitment contributed to their defaulting to make a total of ten (13.2 %) respondents that affirmed. Most patients disagreed that work commitments contributed and this supports the findings in 4.4.5 that most people could attend their clinic visits regularly without any interference from their work.

4.2.3.7 Contribution of unemployment to their defaulting

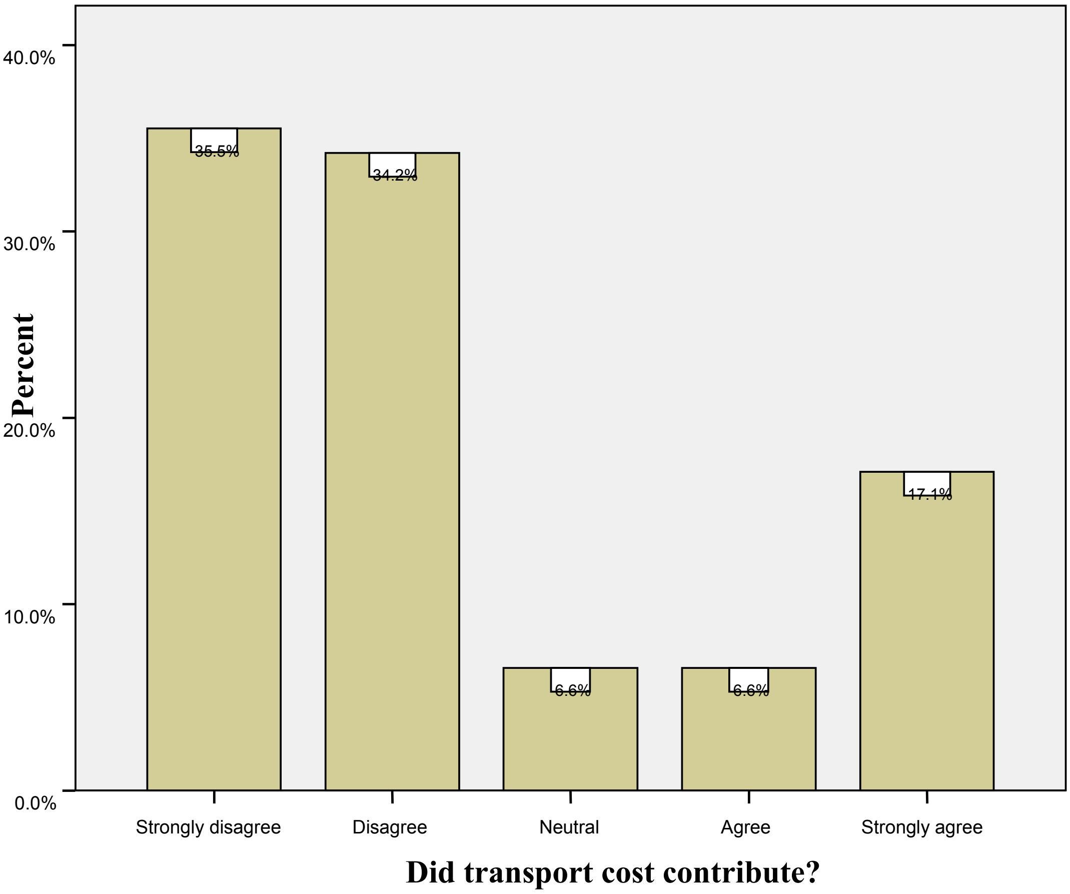
Fig 4.11 An illustration of whether unemployment contributed to patients defaulting



A total of eleven (14.5 %) respondents were in agreement that being unemployed had a bearing to their defaulting, five (6.6 %) were neutral. Most of the respondents disagreed. Even though 50 % of the respondents were unemployed as indicated in 4.4.3, most people disagreed that being unemployed contributed to their defaulting.

4.2.3.8 Contribution of transport costs to the clinic to their defaulting

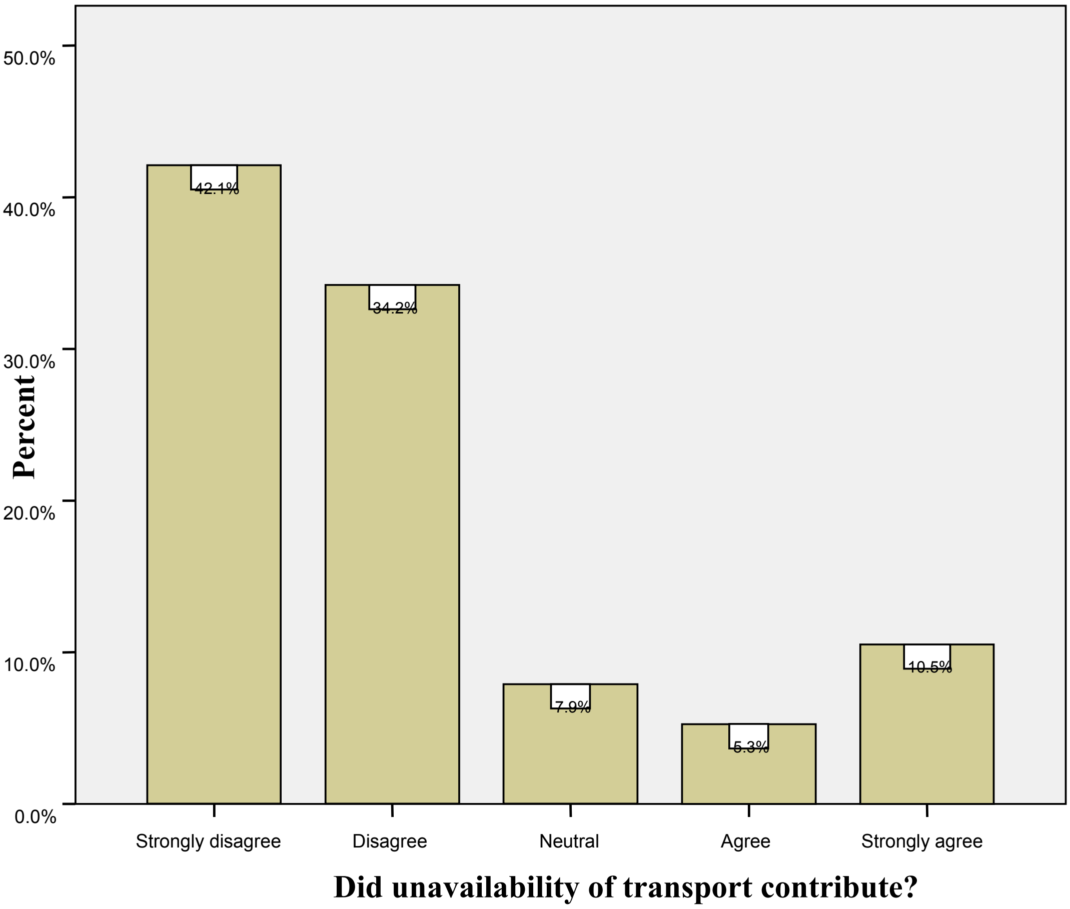
Fig 4.12 An illustration of whether transport costs contributed to patients defaulting



Thirteen (17.1 %) of the respondents strongly agreed that transport contributed to their defaulting, five (6.6 %) agreed to make a total of eighteen (23.7 %) respondents who were in agreement. Despite a large number (69.7 %) of people who used public transport or lifts from other people in item 4.4.5 the majority of the defaulters disagreed that transport costs led them to default on treatment.

4.2.3.9 Contribution of unavailability of transport to their defaulting.

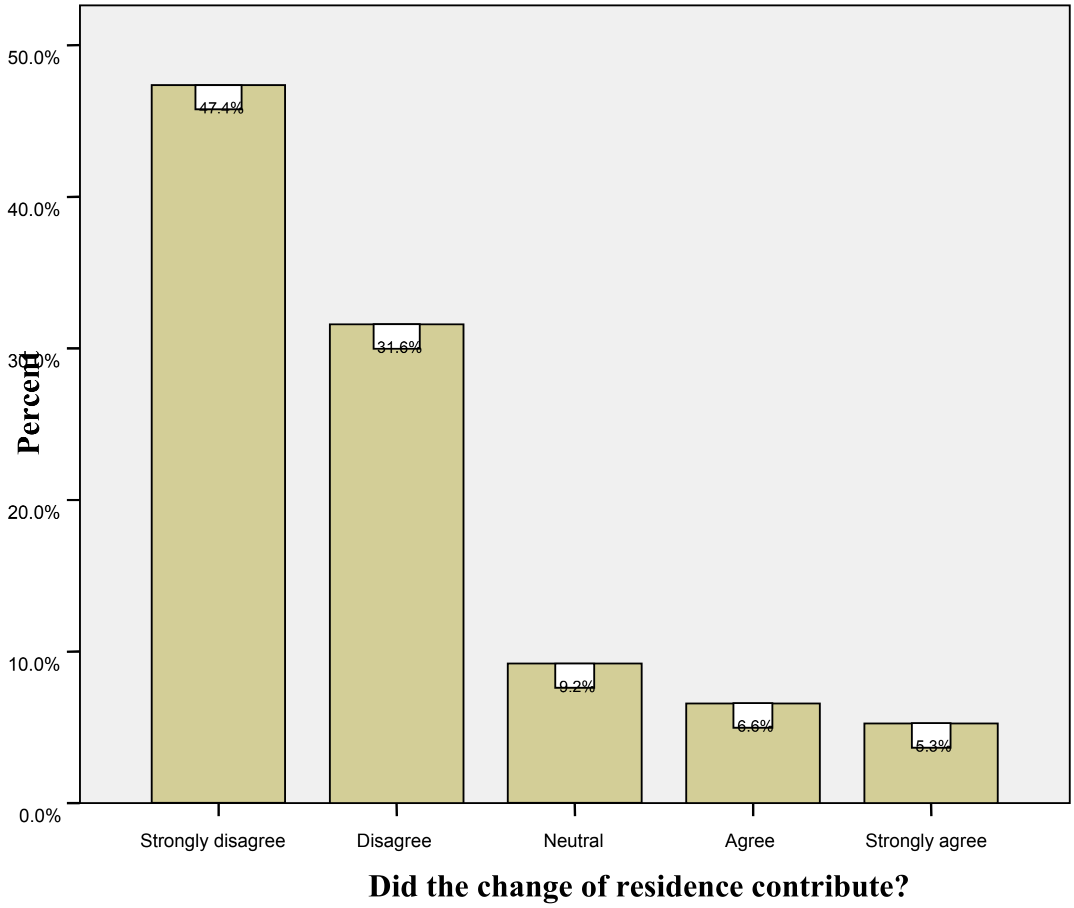
Fig 4.13 An illustration of whether unavailability of transport contributed to patients defaulting



A total of twelve (15.8 %) were in agreement that unavailability of transport contributed to them defaulting. The majority of the respondents (74.3 %) disagreed, transport is usually available in the regions Oshana surrounding and there is always a taxi to take a person from one point to the other (G. Nakathingo, personal communication, July 29, 2007).

4.2.3.10 Contribution of change of residence during the course of taking treatment to patients defaulting on treatment

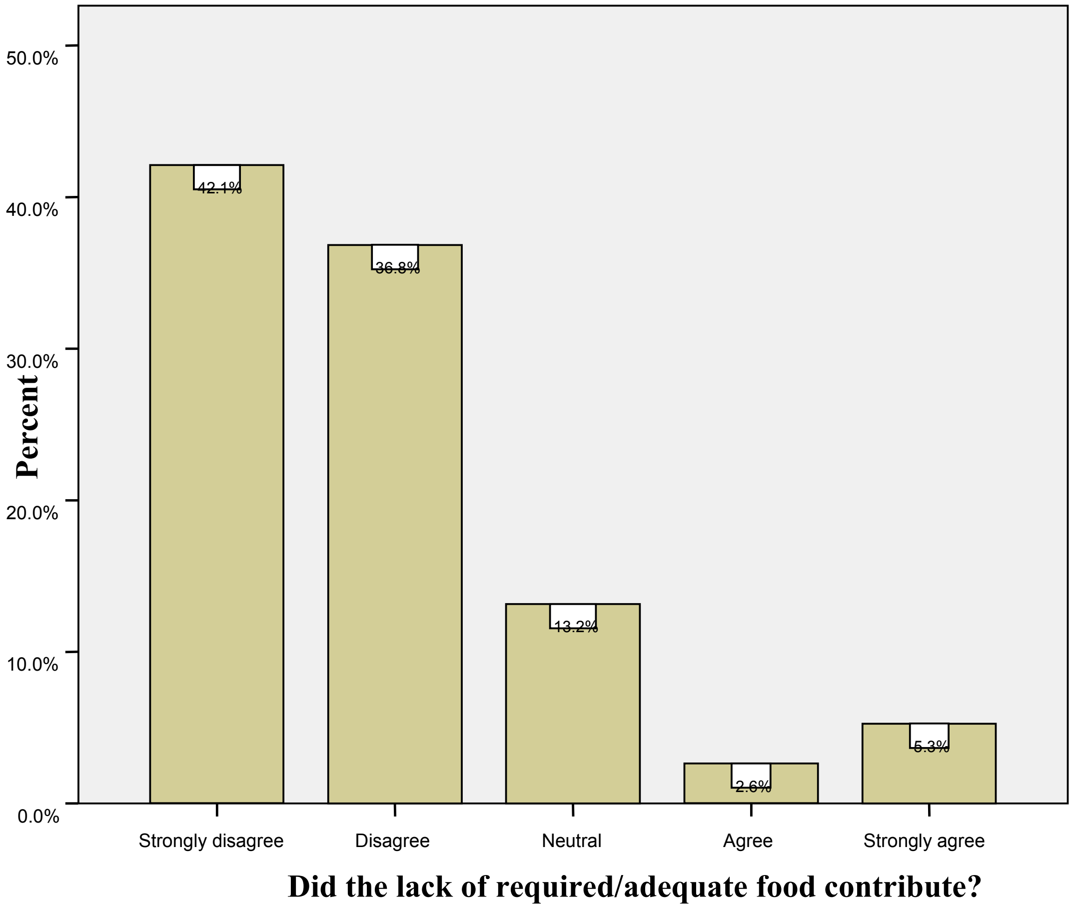
Fig 4.14 An illustration of whether change in the place of residence contributed to patients defaulting



Four (5.3 %) totally agreed that change of residence contributed to their defaulting, five (6.6 %) agreed. The total of the respondents who were in agreement was nine (11.9 %). In item 4.4.2 , most defaulters had never changed their place of residence since initiating their treatment, therefore most respondents were likely to disagree that change of residence could have led them to default on their treatment. Sixty five (89.1 %) respondents therefore did not agree.

4.2.3.11 Contribution of inadequacy of food to their defaulting

Fig 4.15 An illustration of whether lack of/inadequate food contributed to patients defaulting on treatment

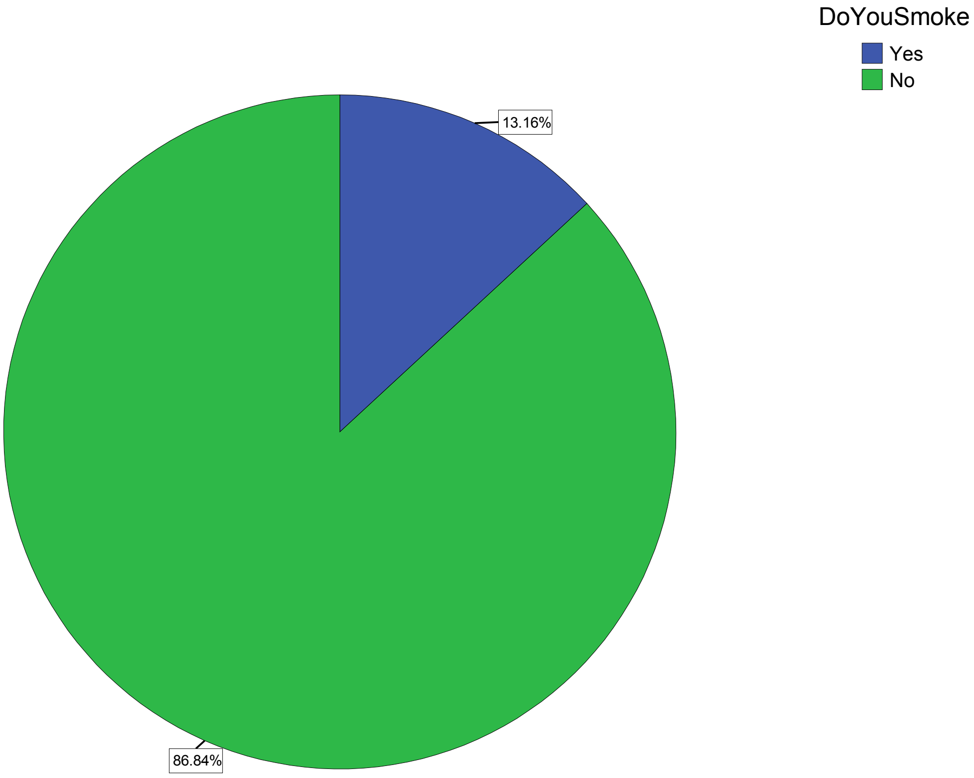


Food security is particularly important for people affected by HIV (UNAIDS, 2008) and lack of food may lead to poor nutrition and undermine adherence and response to antiretroviral therapy (Gillespie & Kadiyala, 2005). The majority of the respondents in this phase of the study disagreed that lack of food contributed to their defaulting. A total of six (7.9 %) were in agreement that inadequacy of food contributed to them defaulting and ten (13.2 %) were neutral, whilst two (2.6 %) agreed and four (5.3 %) strongly agreed.

4.2.4 Socio-cultural factors

4.2.4.1 Smoking status of the respondents

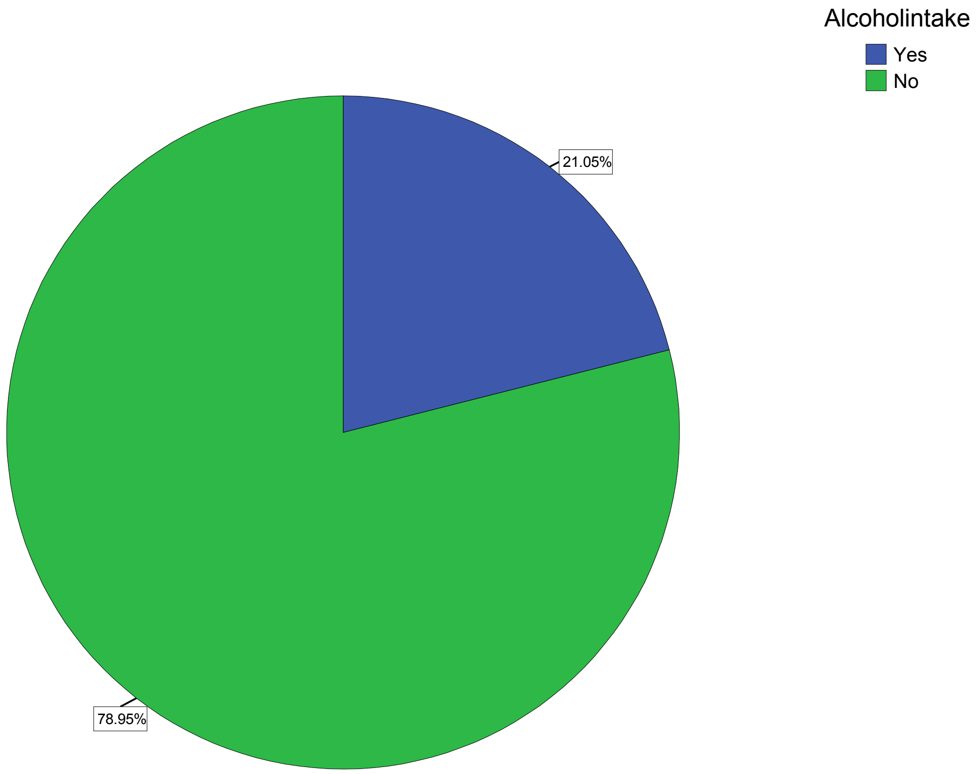
Fig 4.16 Pie Chart showing smoking status of defaulters



A majority of the respondents did not smoke namely sixty six (86.8 %) and only ten (13.2 %) did smoke.

4.2.4.2 Alcohol intake status of respondents at the time of filling the questionnaire

Fig 4.17 Pie Chart showing alcohol intake of defaulters

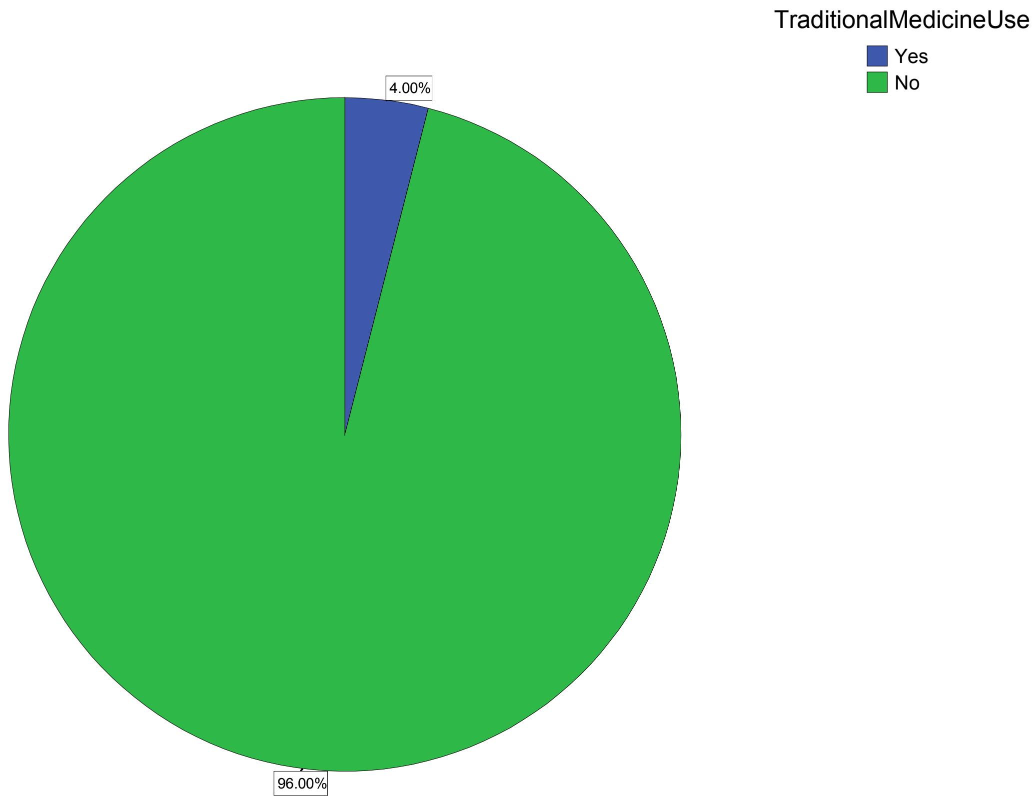


Sixty (78.9 %) respondents reported not taking alcohol at the time of participating in the survey and sixteen (21.1 %) took alcohol.

Drug abuse may impair judgement and the ability to adopt and maintain routine medication usage (Deribe et al, 2006). For item 4.5.1 and 4.5.2, the researcher wanted to screen the defaulters for smoking and alcohol use. However, most patients reported that they had never used either of these substances.

4.2.4.3 Use of traditional medicines during the course of patients' taking ARV treatment

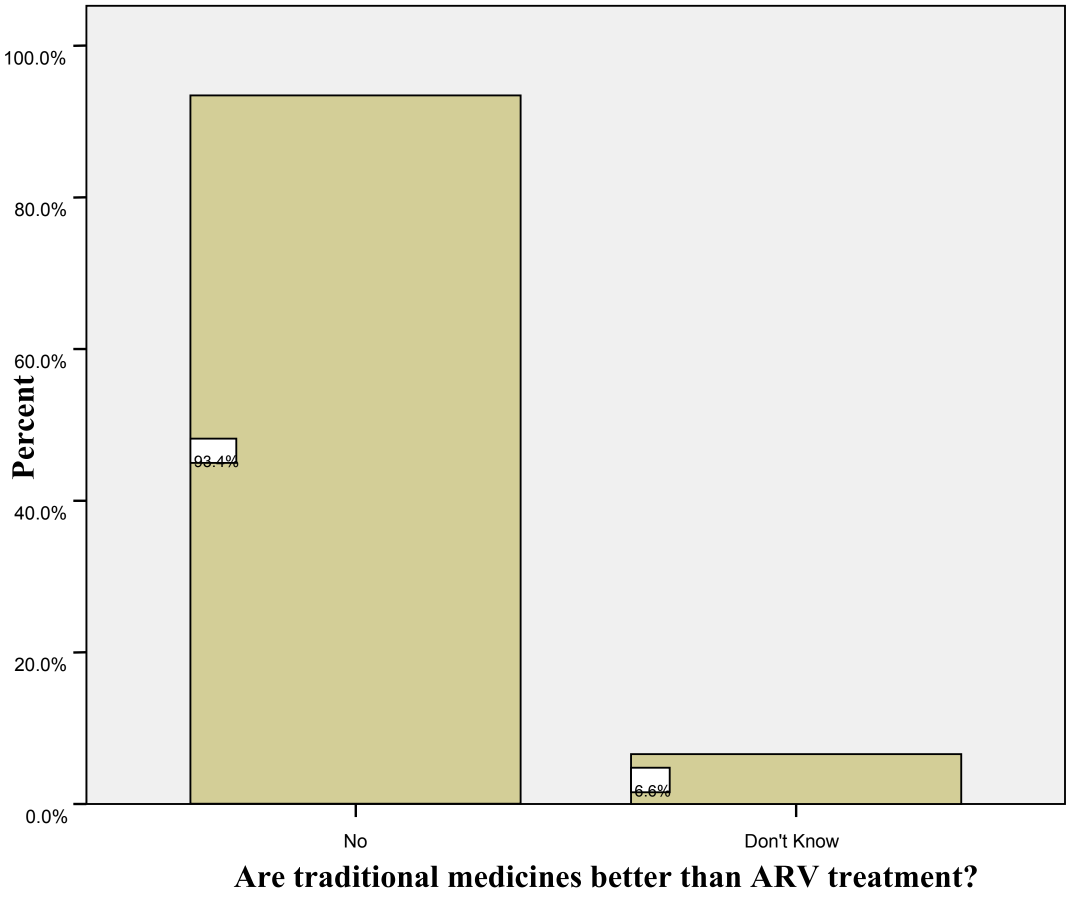
Fig 4.18 A pie chart illustrating use of traditional medicine among defaulters



There are traditional claims to cure HIV and many people have fallen prey to these claims because orthodox HIV treatment only slows the progress of the disease and does not cure it. Consequently, people might abandon ART or combine it with traditional medicines, causing interference in drug level (Rowe, Makhubele, Hargreaves, Porter, Hausler & Pronyk, 2005) and this may lead to exacerbated adverse effects (Hoffman, Rockstroh & Kamps, 2005). Most of the respondents namely seventy two (94.7 %) reported that they did not use any traditional medicines and only three (3.9 %) did use traditional medicines.

4.2.4.4 Beliefs in the efficacy of traditional medicines compared to orthodox ARV treatment

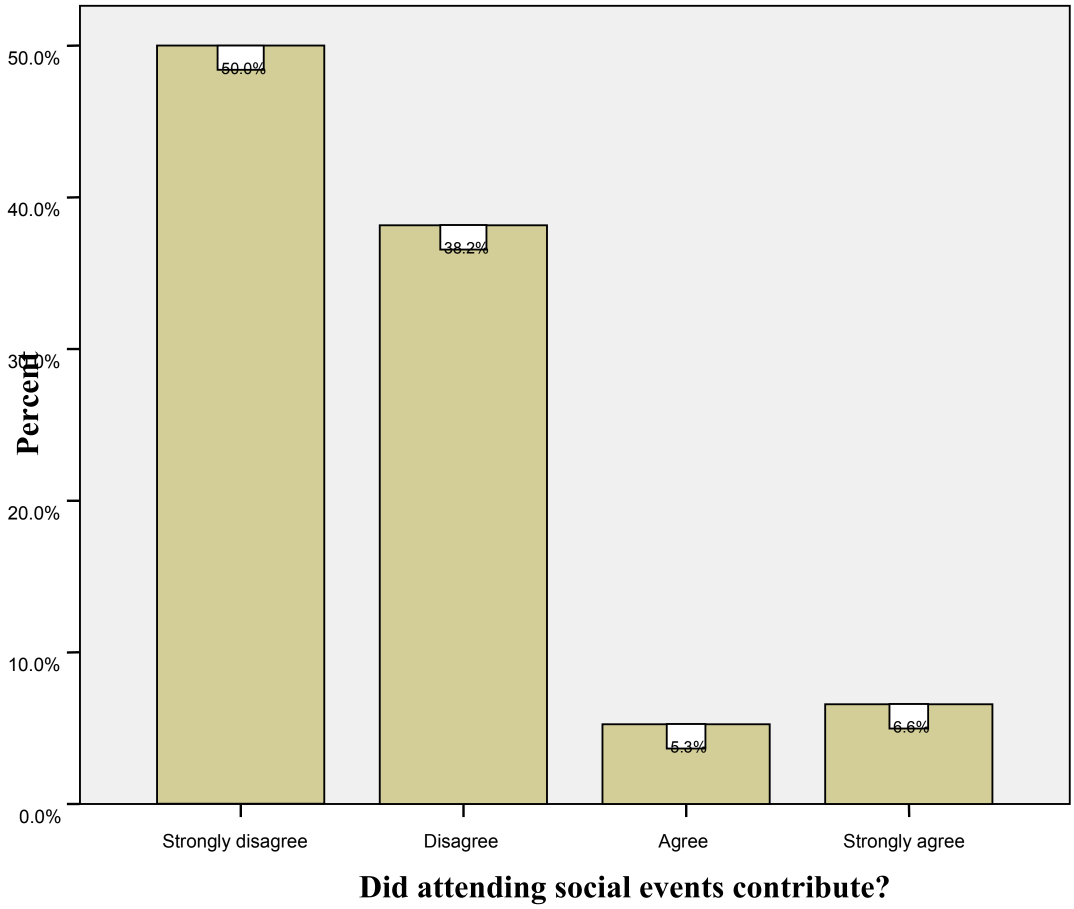
Fig 4.19 An illustration on defaulters' beliefs about the efficacy of traditional medicines



Seventy one respondents (93.4 %) reported that traditional medicines were not better than the orthodox ARV treatment and five (6.6 %) reported that they did not know or were neutral. Although 4 % of the respondents had previously used traditional medicines no participant reported believing that it is better than orthodox HIV medicines.

4.2.4.5 Contribution of attendance to social events to defaulting therapy

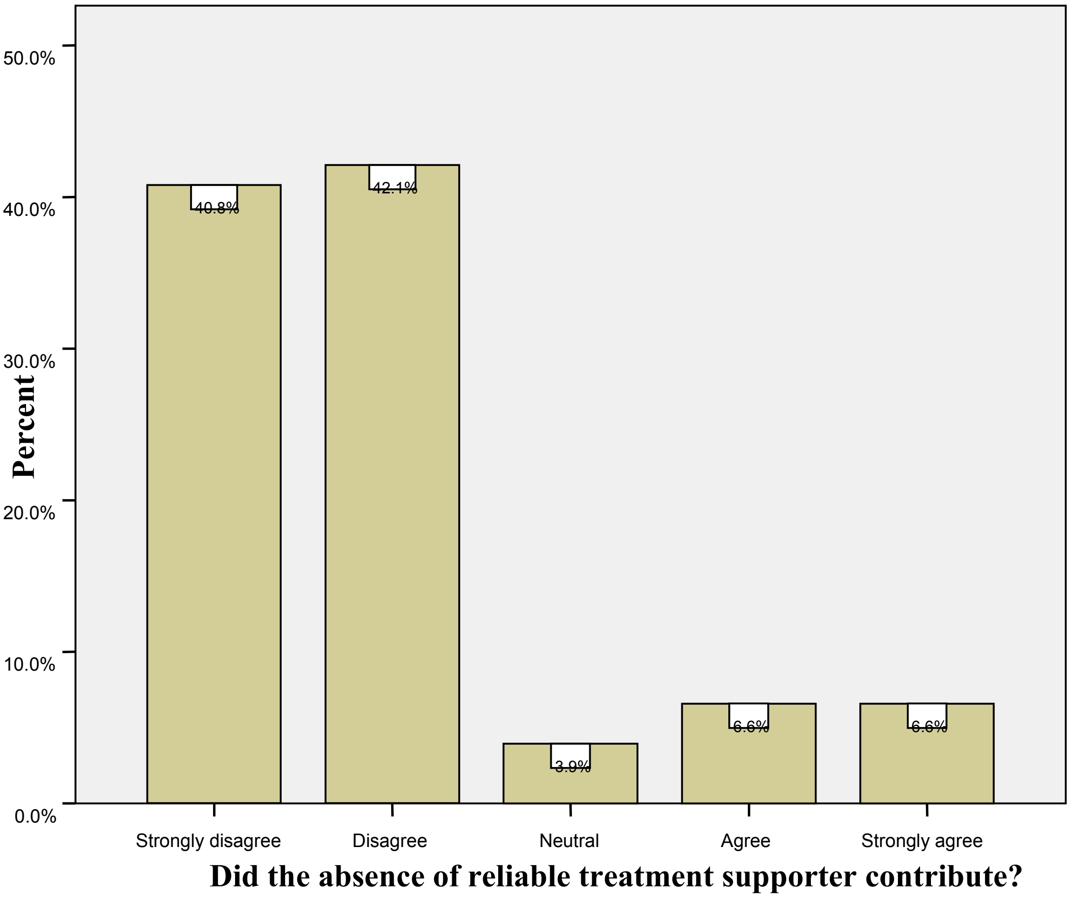
Fig 4.20 An illustration of whether attending social events contributed to patients defaulting



From the experience in dealing with defaulters to treatment in Oshakati hospital, the researcher had noted that most patients would state that they had attended a funeral, wedding, graduation, baptism and other social events as a reason for not adhering to the stipulated dates on their health passports. During the instrument construction the researcher and the focus team as mentioned in Chapter 3 wanted to measure if attending these events contributed to patients defaulting. However, only nine (11.9 %) of the respondents agreed that attending social events contributed to them defaulting namely, five (6.6 %) agreed and four (5.3 %) strongly agreed. The majority did not agree.

4.2.4.6 Contribution of the absence of a reliable treatment supporter to defaulting therapy

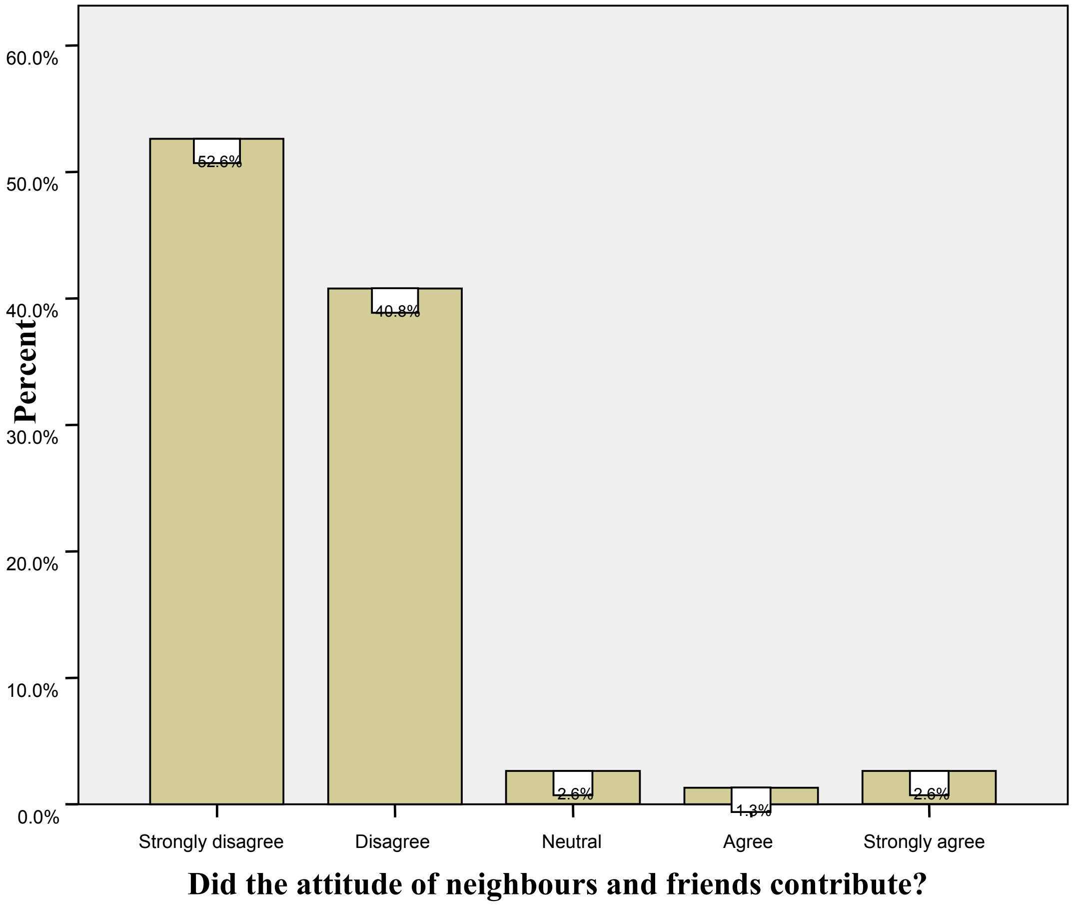
Fig 4.21 An illustration of whether the absence of a treatment supporter contributed to patients defaulting



Treatment supporters are a valuable source of support for most patients on HIV treatment often reminding patients to take their medicines (Aspeling & van Wyk, 2008). Support is essential for successful adherence to a medication schedule (UNAIDS, 2006b). Five (6.6 %) respondents agreed that the absence of a reliable treatment supporter contributed to their defaulting treatment and five (6.6 %) strongly agreed to make a total of ten (13.2 %) respondents who affirmed.

4.2.4.7 Contribution of the attitudes of friends and neighbours to defaulting on treatment

Fig 4.22 An illustration of whether the attitude of neighbours and friends contributed to patients defaulting



Most patients fear discrimination if they disclose their status or when people find out they are taking HIV medicines; however, few participants normally alter their levels of adherence because of this fear (Aspeling & van Wyk, 2008). Also in this study very few people agreed that the discriminatory attitudes of neighbours and friends contributed to their defaulting.

4.2.5 Service related factors

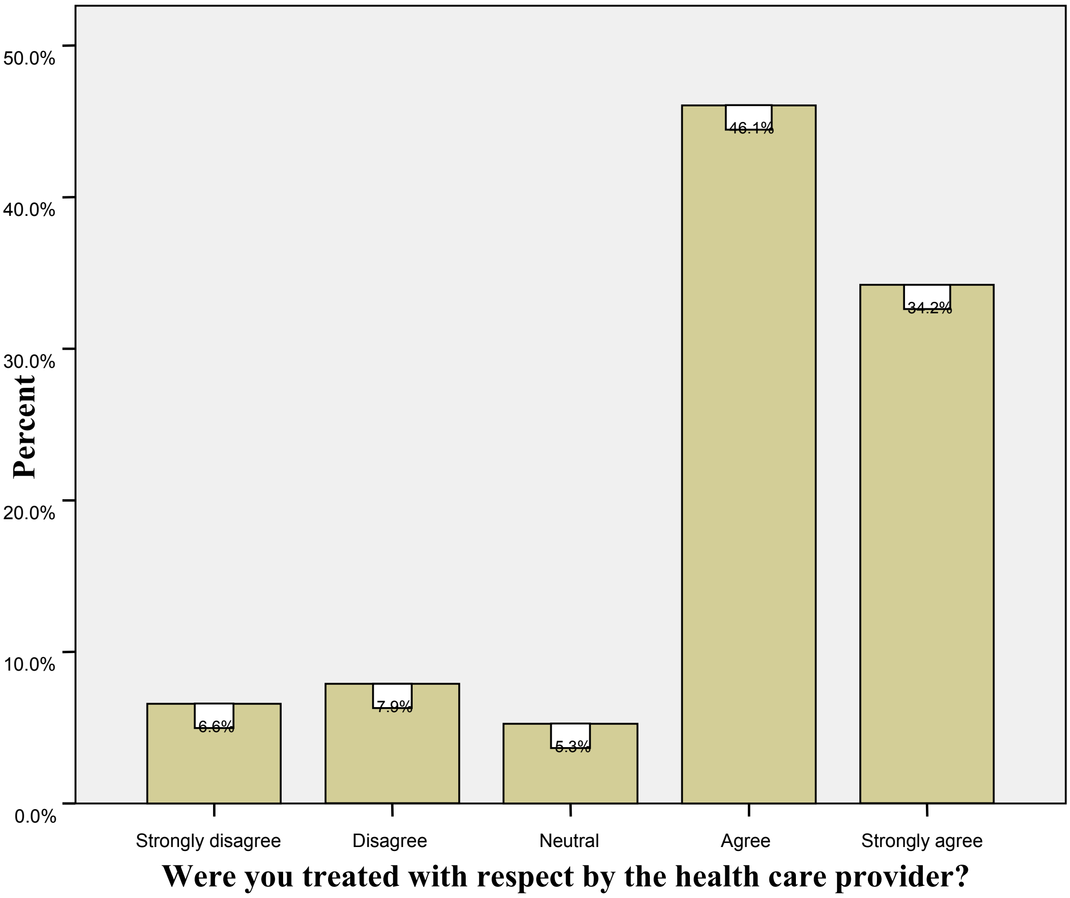
From the literature review, the researcher gained the impression that the perceived factors on the health system and the type of care offered have a bearing on the patients' particular behaviour to default on their treatment. These may be viewed as perceived barriers to health promoting behaviour. It has been demonstrated that health care restructuring and health care service limitations also play a role in causing patients not to be adherent to their treatment protocols (Driver, Matus, Bayuga, Winters & Munsiff, 2005; WHO, 2003; Vermiere, Hearnshaw, Van Royen & Denekens, 2001; Lerner, 1997 & Sumartojo, 1993).

Most people on HIV treatment would prefer a health care provider who is available, confidential, competent, approachable, non-judgmental and supportive and where patient provider relationships are based on trust. Discourteous treatment of patients often results in them interrupting treatment (Aspeling & van Wyk, 2008).

The opinions about the health care provider (respect, support by listening, adequately counsels and attitude) and the health care system (frequency of clinic visits and patient waiting time) will be discussed in this sub section.

4.2.5.1 Opinion about the health care provider

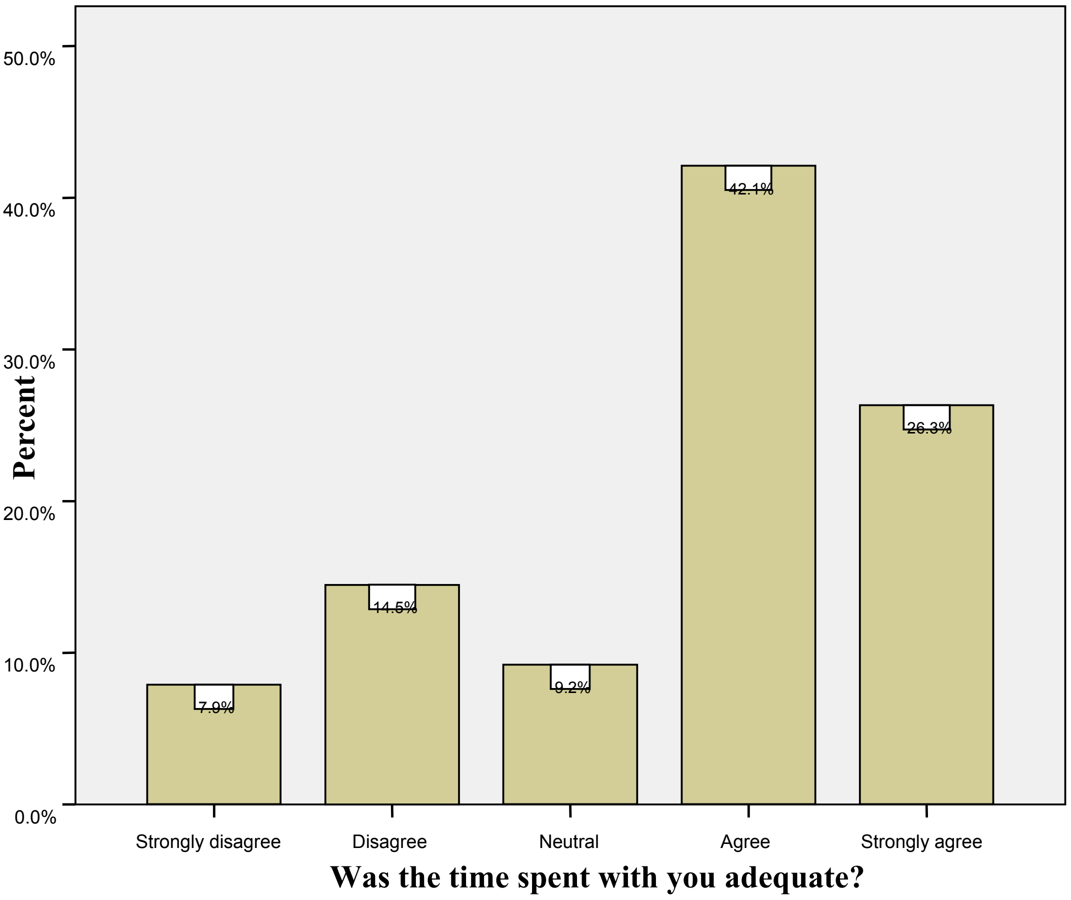
Fig. 4.23 An illustration of whether defaulters were treated with respect on their scheduled visits



Most of the respondents, namely twenty six (34.2 %) strongly agreed that they were treated with respect and thirty five (46.1 %) agreed. Five (6.6 %) of the respondents strongly disagreed, six (7.9 %) disagreed and four (5.3 %) were neutral.

4.2.5.2 Adequacy of time spent by the respondent with the health care provider

Fig 4.24 An illustration on whether defaulters were given adequate time for consultations at the facility



Fifty nine (77.6 %) respondents were in agreement namely, twenty (26.3 %) respondents strongly agreed, thirty two (42.1 %) agreed. Seven (9.2 %) were neutral, eleven (14.5 %) of the respondents disagreed that enough time was spent on them during the clinic visits and six (7.9 %) strongly disagreed.

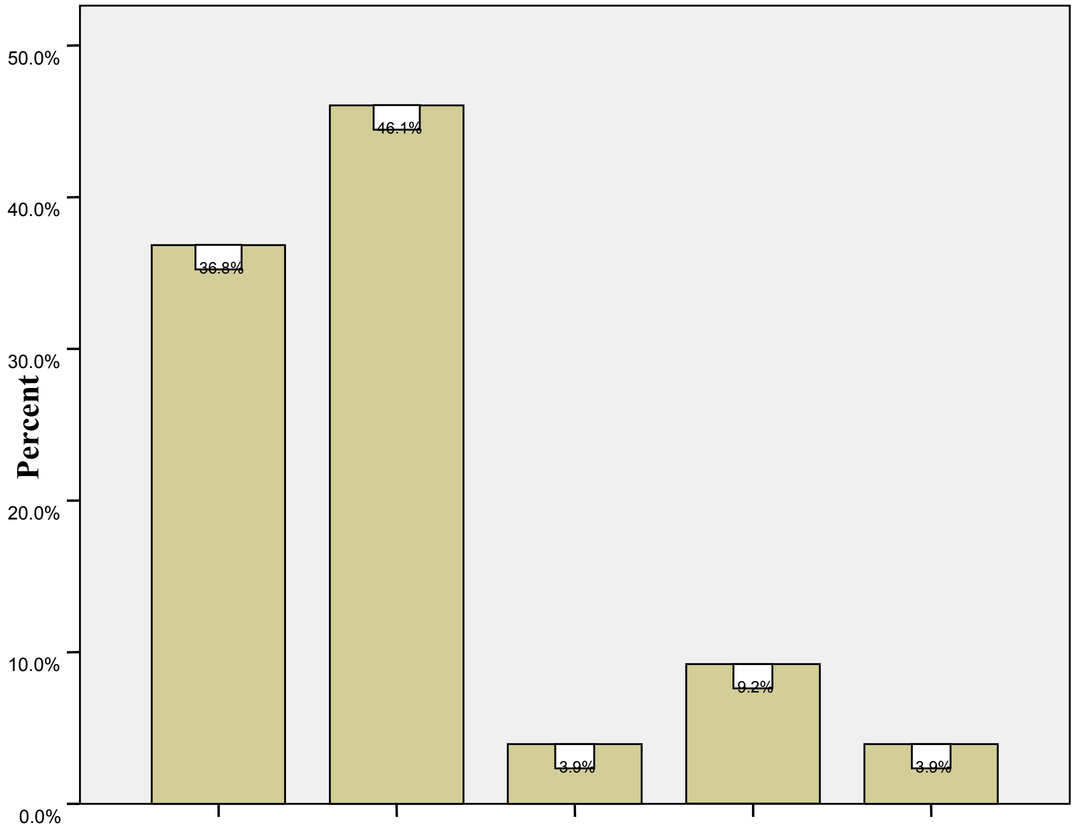
4.2.5.3 Appropriateness of counselling at the facility

Fig 4.25 An illustration of whether defaulters received appropriate counselling during clinic visits

A majority of the respondents agreed that the counselling was appropriate, namely twenty seven (35.5 %) strongly disagreed and thirty two (42.1 %) agreed. Seven (9.2 %) were neutral, five (6.6 %) strongly disagreed and four (5.3 %) simply disagreed.

4.2.5.4 Contribution of the frequency of the visits to the ARV facility contributed to defaulting treatment

Fig 4.26 An illustration of whether frequency of visits to the clinic contributed to patients defaulting

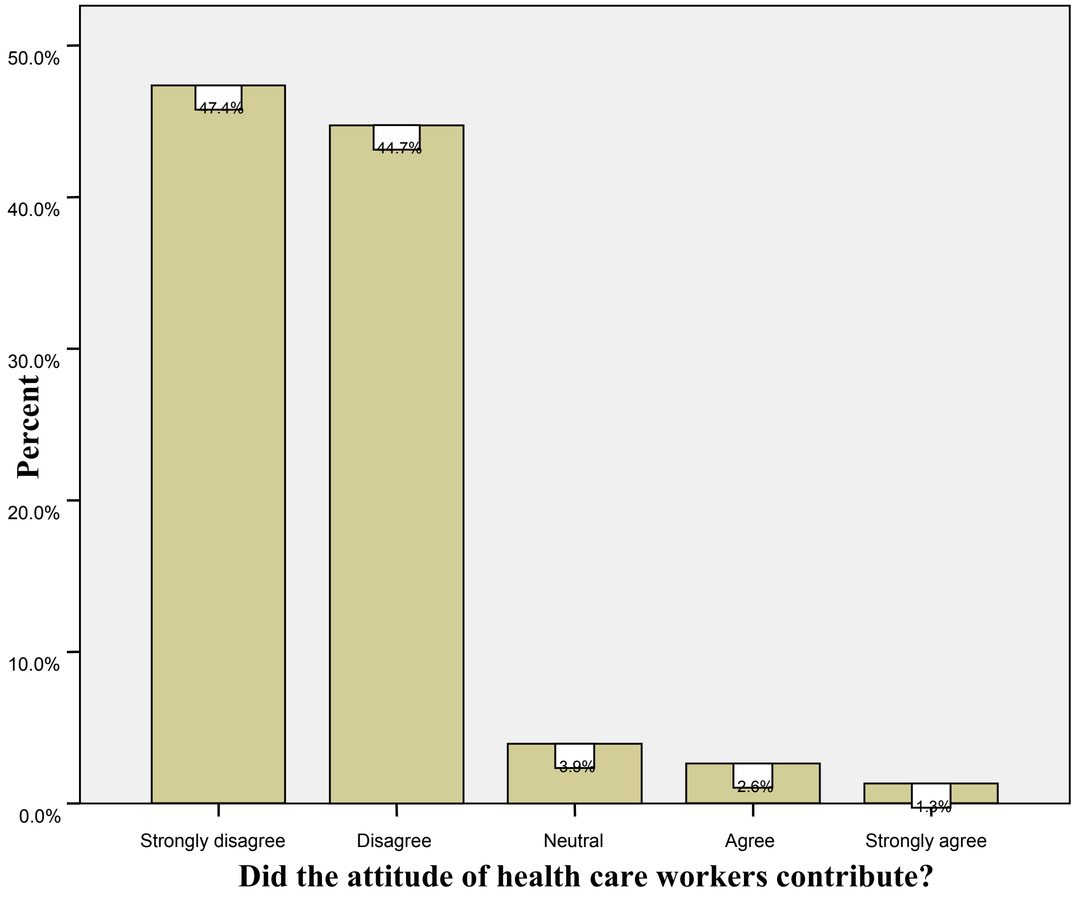


Did the frequency of visits contribute?

Ten (13.2 %) respondents were in agreement namely, three (3.9 %) respondents strongly agreed and seven (9.2 %) agreed. But most strongly disagreed namely twenty eight (36.8 %), thirty five disagreed (46.1 %) whilst three (3.9 %) were neutral.

4.2.5.5 Contribution of the attitude of health workers towards the patients defaulting on treatment

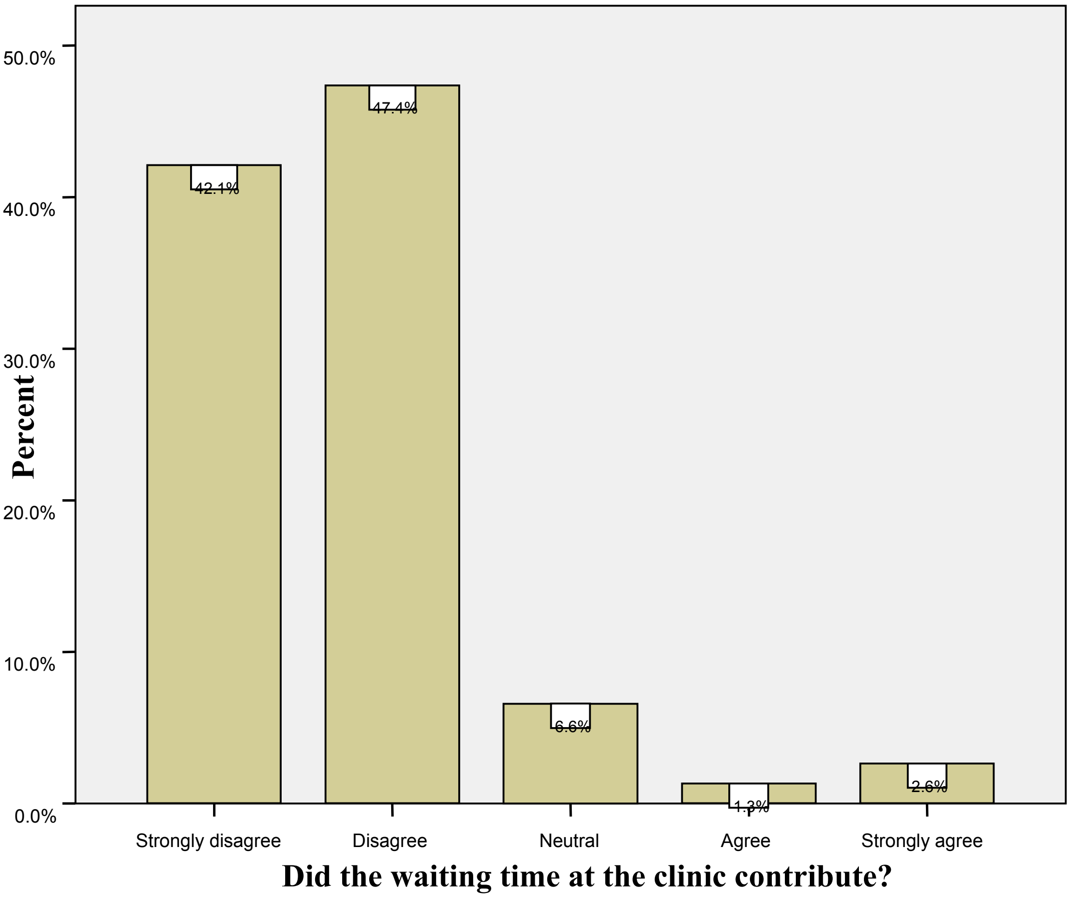
Fig 4.27 An illustration of defaulters' rating on the attitudes of health workers at the facility



A total of three (3.9 %) the respondents agreed that the attitude of health workers towards the patient contributed to them defaulting, namely one (1.3 %) strongly disagreed and two (2.6 %) agreed. As shown in items 4.6.1, 4.6.2 and 4.6.3, most respondents were happy with the treatment that they received from the facility and therefore disagreed that the attitude of health workers could have led them to default their treatment.

4.2.5.6 Contribution of waiting time at the clinic to patients defaulting on treatment

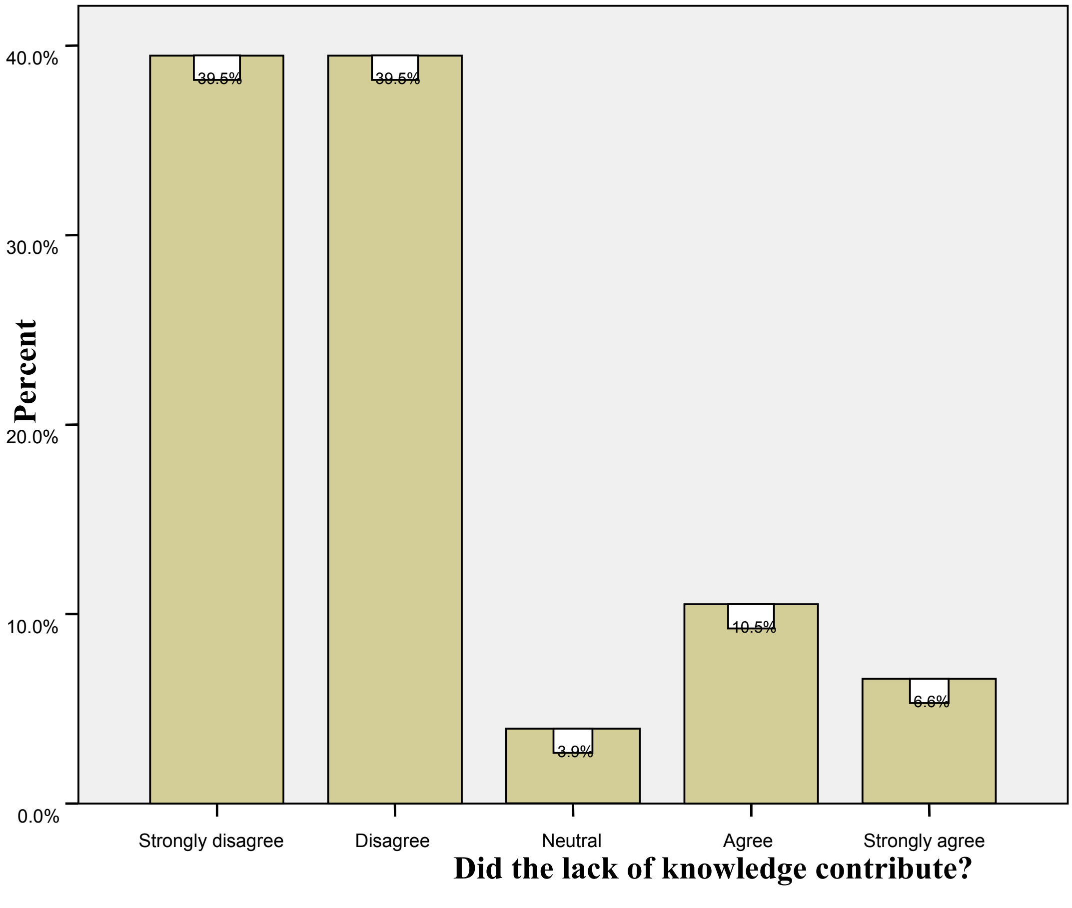
Fig 4.28 An illustration of whether waiting time contributed to patients defaulting



A total of three (3.9 %) the respondents agreed that the waiting time at the clinic contributed to them defaulting, namely two (2.6 %) strongly disagreed and one (1.3 %) agreed.

4.2.5.7 Contribution of the lack of knowledge about treatment and its outcomes to patients defaulting treatment

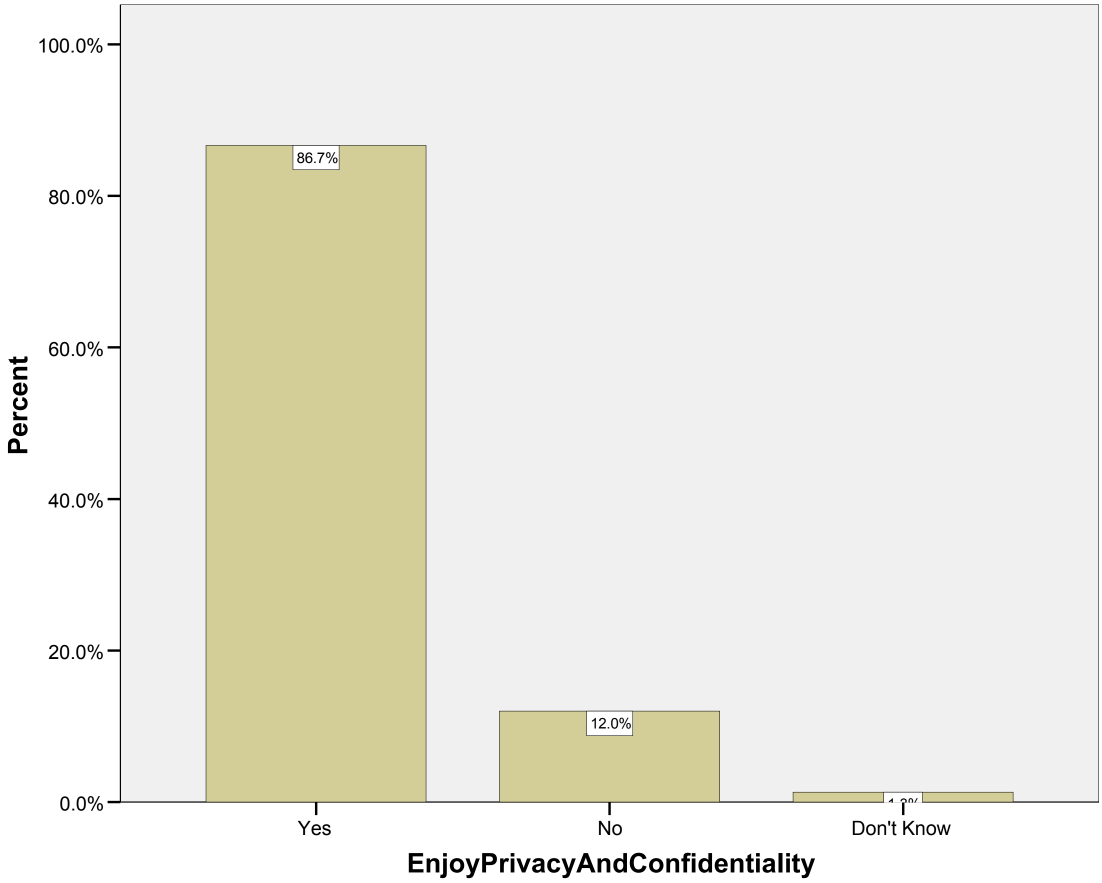
Fig 4.29 An illustration of whether the lack of knowledge on treatment outcome contributed to patients defaulting



Thirteen (17.1 %) respondents were in agreement namely, five (6.6 %) respondents strongly agreed and eight (10.5 %) agreed whilst twenty five (39.5 %) strongly disagreed and twenty five (39.5 %) also disagreed. The patients agreed to being adequately counselled and also receiving appropriate counselling and therefore most of them disagreed that lack of knowledge about the treatment contributed to their defaulting.

4.2.5.8 Opinion on whether privacy and confidentiality was respected and accorded at the clinic

Fig 4.30 An illustration showing defaulters' opinions on privacy and confidentiality at the clinic

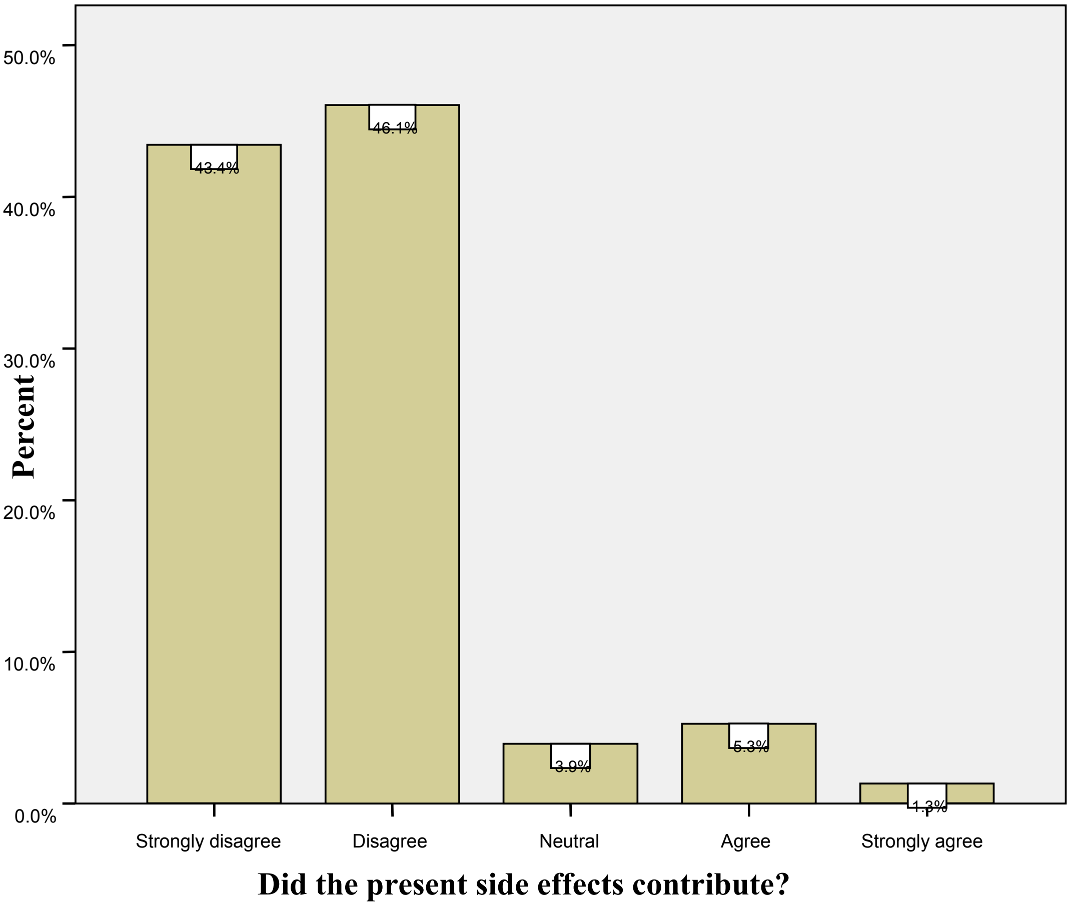


Sixty five (86.7 %) agreed that they enjoyed privacy and confidentiality at the clinic, nine (12 %) said they did not and one (1.3 %) did not know. One (1.3 %) did not respond.

4.2.6 Medical Characteristics

4.2.6.1 Contribution of side effects to the medicine administered to patients defaulting treatment

Fig 4.31 An illustration of whether side effects contributed to patients defaulting

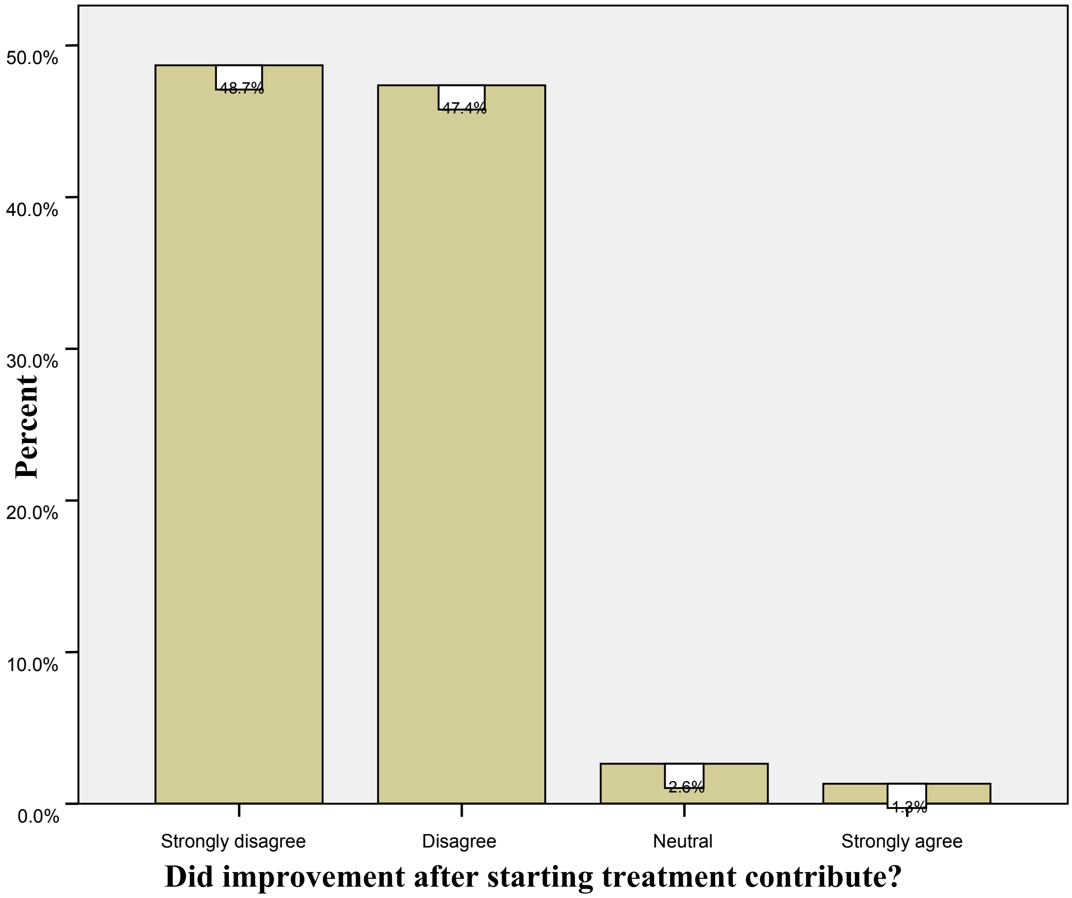


Side-effects might interfere with adherence. Most patients will tolerate adverse effects from medicines when informed. Uncomfortable side effects may cause patients to adjust their medication or discontinue their treatment (Aspeling & van

Wyk, 2008). Most of the respondents disagreed that side effects contributed to their defaulting on treatment. Only a total of five (6.6 %) respondents were in agreement, namely one (1.3 %) strongly agreed and four (5.3 %) agreed.

4.2.6.2 Contribution of the immediacy of improvement after initiation of HAART to patients defaulting on treatment

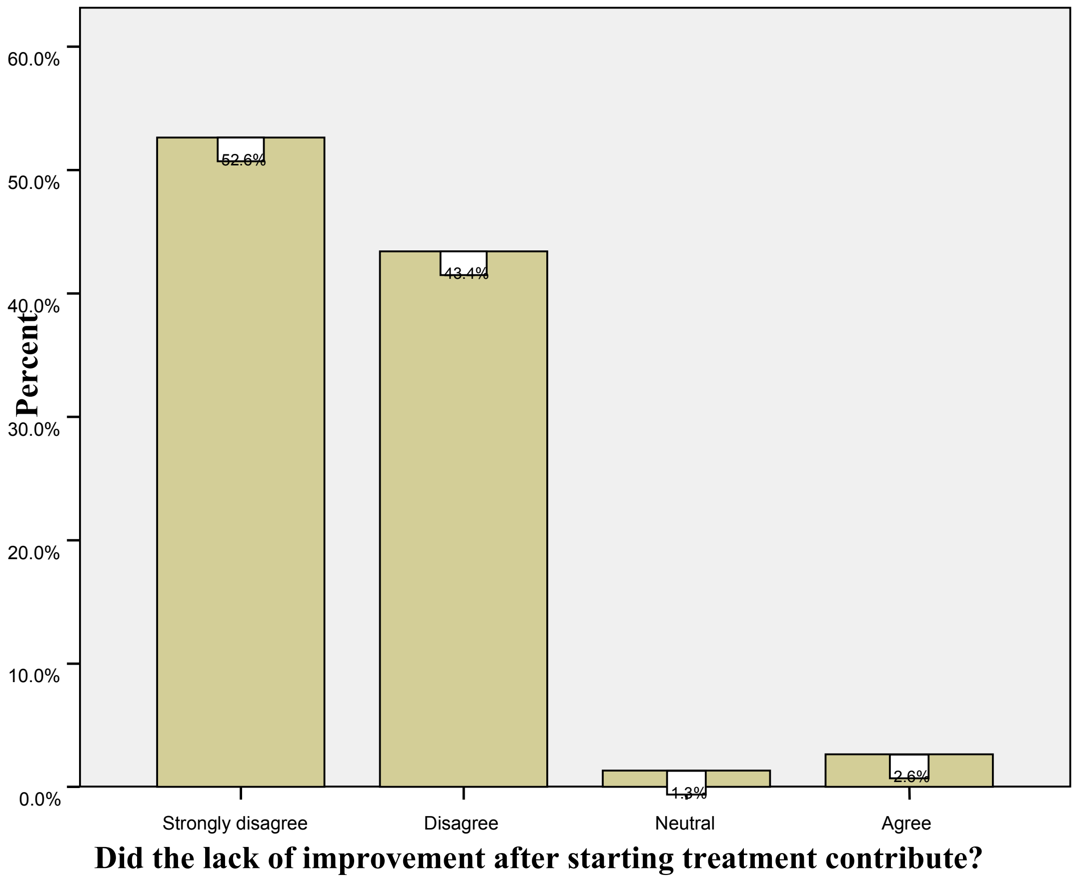
Fig 4.32 An illustration of whether immediacy of beneficial effects contributed to patients defaulting



Literature review on defaulters to treatment shows that most of them stop treatment as a result of getting better after a few courses of their treatment (Tissera, 2003; Kwong-Leung, et al; Aspeling & van Wyk, 2008). However, in this study only one (1.3 %) respondent was in agreement that the improvement initially led to their defaulting.

4.2.6.3 Contribution of the absence of improvement after initiation of HAART to patients defaulting treatment

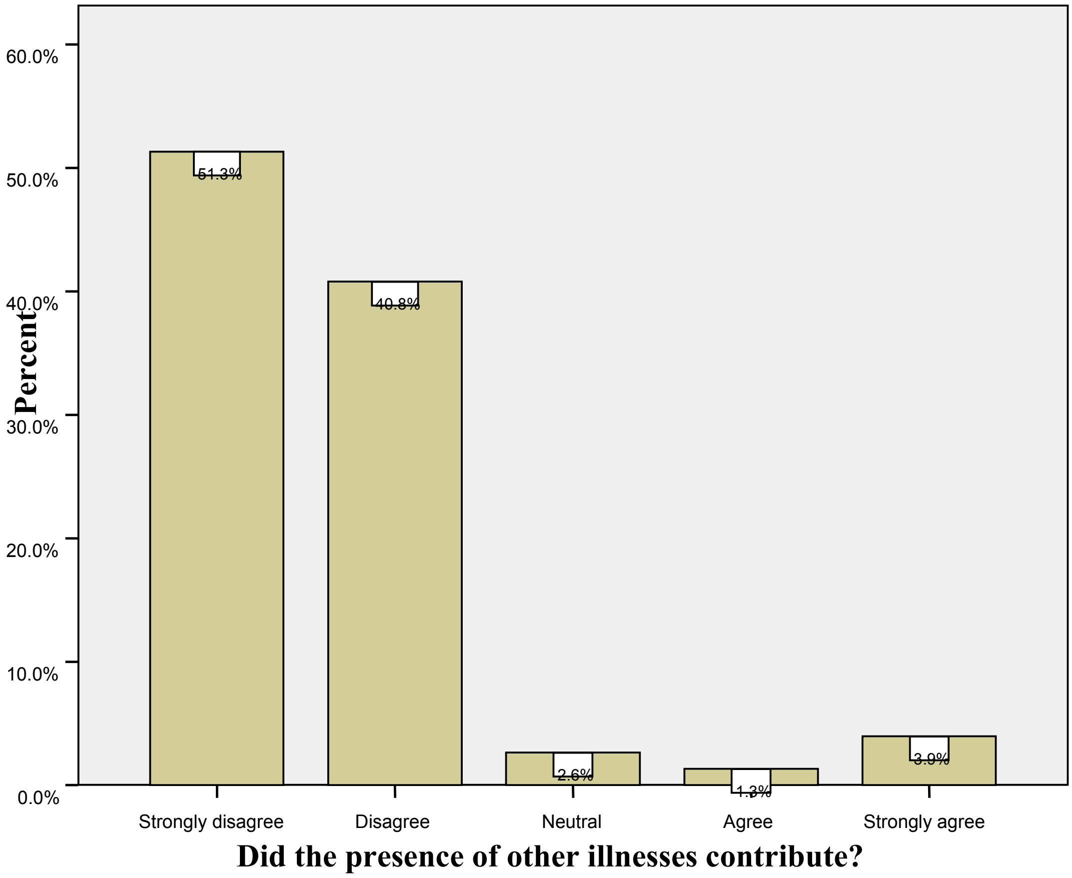
Fig 4.33 An illustration whether immediacy of harmful effects contributed to patients defaulting



Chatterjee, Banerjee, Dutt, Pati and Mullick (2003) noted that negative treatment outcome, on the other hand, also led some patients on chronic treatment to default. This could be as a result of anticipated or real side effects after initiation of treatment. In this study only two (2.6 %) respondents were in agreement that the absence of improvement led to them defaulting.

4.2.6.4 Contribution of co-morbidities to patients defaulting on treatment

Fig 4.34 An illustration of whether presence of other illnesses contributed to patients defaulting



Over 50 % of patients infected with HIV have other co-morbidities normally associated with immunosupression (WHO, 2005). These co-infections have been associated with reduced quality of life and death in a large proportion of co-infected patients (Finlay et al, 2004). This may lead to treatment interruption in some patients. In this phase of the study most respondents disagreed that the presence of other infections led them to default on treatment. A total of four (5.2 %) respondents were in agreement, namely three (3.9 %) who strongly agreed and one (1.3 %) who agreed.

4.3 Summary of results from the quantitative phase of the study (Phase 1)

The results from phase 1 of the study show that a majority of the defaulters rejected the factors which were listed under the different categories had contributed to them defaulting on treatment, though a small number of respondents had agreed in each category. Other studies have demonstrated through case controlled studies (Deribe et al, 2006; Aspeling & van Wyk, 2008; Tissera, 2003) that most factors that were listed in the questionnaire were associated with defaulting in some patients. Despite patients reporting that they used public transport and "hikes" to the facility, did not own houses and were unemployed, they disagreed that these factors led them to default. Therefore, in the absence of generalisation and association of factors that led patients to default, the researcher also embarked on a qualitative study to identify the reasons. The results from the qualitative phase of the study will be analysed next.

4.4 Results from Phase 2 of the study

The results are structured around themes, patterns and actual description from the participants which were identified by the researcher and the independent coder through the analysis of the transcripts from the focus group discussion that was conducted with patients who had defaulted treatment in Oshakati. The data were collected to investigate and explore the reasons why the patients had defaulted on treatment in Oshakati.

The results are supported by exact quotations from the discussion and are substantiated by relevant literature after the description of each theme and pattern. The quotations are given word for word without correction in order to represent the experience of the participants as accurately as possible. The method of Tesch as described in Chapter 3 was used in the data analysis. Table 4.3 shows a summary of identified themes and patterns. The detailed discussion will follow this table.

Table 4.3 Summary of identified themes and patterns

Themes	**Patterns**	**Actual description**
Health care and system related factors	Complexity of treatment process	"…The visit to the clinic is also too much and the nurses collect too much blood from us..." "…to start the whole process again it was too difficult for me, that is why after coming for about 4 visits I decided to stay at home, the process was just too much for me, coming to collect medicines now and again…" "I was scared of coming after missing the follow up date many times and going to the counselling school which took most of my time."
	Poor patient-provider relation ship	"…they say there are grants but I was denied…" "…they start asking us a lot of questions…"

		"…So I stopped taking the medicines myself because the Drs there did not want to see me anymore as they said I was troublesome and maybe psychotic…" "…the staff must tell us of the follow up dates instead of writing in the passport without telling us…"
	Dissatisfaction with services provided	"…I don't want to go there their care is not good…" "…visit to the clinic is also too much…" "…coming to collect medicines now and again, and waiting, there are many people in Oshakati
Patient related factors	Socio-Economic Financial constraints	"…Oshimaliwa kapeena sha (money is not there), I have no job… "…most of us here are unemployed and the government tells us to take medicines with food…its no use taking medicines without money for food "…money is the problem to my defaulting…. I could not be able to afford buying food to take with my medicines
	Long distance to health facility	"…at that time transport to take us back home is unavailable. I don't come from Oshakati, I am from Ongandjera…" "…Pharmacy to supply medicines until the Drs follow up to reduce travelling…or at least bring the medicines to the clinics closer to our homes…" "…for me money was not a problem but the distance of coming to collect medicines now and again…"
	Employment or job commitment	"…although I stay in Okatana it's my job made me to stop coming here…"

		"…I stopped because I felt I could work…"
▪	Socio-Cultural Unavailability of support, psycho-social, emotional	"…my own family, flesh and blood neglected me when I needed them the most…" "…they say there are grants but I was denied because they said I could work with my hands…"
	Patient lack of knowledge about the disease and treatment.	"After that my mother took me to the Traditional Healer and I was given some herbs to take…. I was told to stop (ARVs) as it had caused my body to be sick…"
	Low literacy levels	"… Most of us are illiterate and we don't understand written language…." "The follow-up date even though its written, most of us can not read…"
Condition related ▪ factors ▪	Immediacy of beneficial effects	"…I started treatment and when I felt better I stopped…" "…I couldn't lose my job so I decided to stop after all I was feeling better…"
	Immediacy of harmful effects, side effects	"…My health was beginning to be worse…" "…suddenly my buttocks started being small and my weight started to fall…"
	diseases that carry a degree of stigma	"…I was feeling hateful of myself, no matter what I was told I remained so much regretful of myself and my life…" "…and I started missing some medicines because I was so angry and cursed myself all the time…"

In the group interviews, respondents expressed twelve broad interacting elements that may have contributed to their defaulting. Three themes emerged from the data analysis.

Theme one was related to the participants experience towards the health care system on how it contributed to their defaulting treatment. They indicated that factors related to the demanding process of accessing treatment and care, client–provider relationship and dissatisfaction with services played a role in their decision to stop treatment.

Theme two was related to the participants' personal feelings and experiences and how that affected their opinions and views about continuing on treatment. These factors are also referred to as patient related factors and include patient knowledge and beliefs about their illness, self efficacy, expectancies regarding the outcome of treatment and the consequences of defaulting, socio-economic status, disclosure of illness to relatives/friends, availability of support, whether financial, psycho-social and emotional.

Theme three was related to the participants' view of their health condition on how it contributed to their defaulting treatment. They indicated factors related to the symptoms they experienced, severity and rate of progression of the disease and side-effects experienced from taking their medication. The detailed discussion of the themes identified is discussed in the next section.

4.5 Discussion of the results

The themes and categories identified in the results will be discussed in this section and in the order listed in table 4.3 of the summary of the findings.

4.5.1 Influences of Health care and system related factors on patients defaulting on treatment

The researcher gained the impression that the perceived factors on the health system and the type of care offered have a bearing on the patients' particular behaviour in defaulting on their treatment. These may be viewed as perceived barriers to health promoting behaviour. In this study these factors are categorised as the complexity of the treatment process, dissatisfaction with the services provided and poor patient–health provider relationship. It has been demonstrated that health care restructuring and health care service limitations also play a role in causing patients not to adhere to their treatment protocols (Driver et al, 2005; WHO, 2003; Vermiere et al, 2001; Lerner, 1997; Sumartojo, 1993).

Complexity of the treatment process

In the guidelines for the management of HIV/AIDS, a patient undergoes a series of steps before being initiated on treatment. This process takes about a month before a "qualified" patient can take home anti-retroviral medicines (taking into account 2 – 4 week's preparatory phase before initiation). In the initiation phase the patient has to undergo counselling and has to visit the clinic fortnightly within the first month of initiation. Thereafter the patient has to adhere to regular follow-ups for monitoring as indicated in the introduction. Should a patient miss follow-up or default on their treatment and there is sufficient evidence that they interrupted their medicine intake then the patient has to undergo the same process as a treatment naïve patient.

The researcher gained the impression that the patient's perception about the intangible services provided had a direct effect on the rating of the services. This determined whether patients continued to use the services at the Oshakati hospital. These findings were corroborated from comments such as those that appear below.

"…the visit to the clinic is also too much and the nurses collect too much blood from us…"

" to start the whole process again it was too difficult for me, that is why after coming for about four visits I decided to stay at home, the process was just too much for me, coming to collect medicines now and again…"

"I was scared of coming after missing the follow up date many times and going to the counselling school which took most of my time…"

Frequent visits to the clinic, inconveniencing scheduled activities and uncomfortable conditions in the service delivery methods contributed to some patients defaulting on treatment. These factors may hinder or act as barriers to patients honouring their scheduled visits or using the facility for accessing their treatment. Hossain, (2002) stated that, “patients may view processes in accessing treatment as expensive, time-consuming and inconveniencing to be always attending to the facility for services to be provided to them” (p.20). These findings were supported by Halda, Sarkar, Bisoi and Mondal, 2008.

Poor Patient-Provider Relationship

Patients’ perceptions about the health system are not the only factors that contributed to their defaulting but also interpersonal relationships between the patient and the health care providers. The nature of health provider–patient relationship determines success or otherwise in any consultation process. Debra and Judith, (1991) suggested that, “provider behaviours within both the technical and socio-emotional realm inspire parallel patient behaviours” (p.185). A health care provider who is warm and friendly will inspire parallel patient attitudes in the socio-emotional domain, such as friendliness and satisfaction. However, lack of warmness, friendliness, attentiveness and above all competence which the patients need to be satisfied with services may contribute to patients not seeking services. In the study the researcher noted that poor communication between the health service provider and the patient resulted in some of them defaulting on their treatment.

“I don’t want to go there their care is not good…”

"...I stopped coming there because I think the Drs gave me the wrong medicines…… the Drs changed me to Lamistar 40 suddenly my buttocks started being small… ..when I approached him he told me it was not the medicines…I was angry with him as I knew that when I was taking Lamistar 30 I had no problems…."

"...I understood the counselling and education that was given to me but I think communication was a problem…"

Though the combination used may not have been wrong for the patient the dosage of Stavudine in the regimen was high enough to cause fat redistribution (lipodystrophy) from the arms, buttocks to other parts of the body such as the breasts.

4.5.2 Influence of patient related factors on patients defaulting treatment

Socio-Economic Factors

This was the strongest predictor of treatment interruption in the study, since interplay of related factors such as lack of transport and long distances to the facility acted together in determining patient's defaulting on treatment. Lack of financial resources to buy food, afford transport costs are some reasons respondents gave for defaulting on their treatment. Food security is particularly important for people affected by HIV (UNAIDS, 2008) and lack of food may lead to poor nutrition and undermine adherence and response to antiretroviral therapy (Gillespie & Kadiyalal, 2005; Scrimshaw & SanGiovanni, 1997; Paton, Sangeetha, Earnest, & Bellamy, 2006; Friis, 2006).

"...Money is the problem to my defaulting.... I could was not able to afford buying food to take with my medicines..."

"...Oshimaliwa kapeena sha (we don't have money), I have no job..."

"...I feel the financial pressure all the time..."

"...My pension was stopped and I could not be able to afford the transport to come and collect medicines from Oshakati hospital..."

In the quantitative phase of the study, the researcher found that the majority of the defaulters used public transport or walked to the facility. Availability of such transport and physical access to the clinic had a significant bearing on patients defaulting treatment as well. A study done in Ethiopia to identify determinants of treatment failure among smear positive pulmonary TB patients identified the need for transport to get to a facility (Shargie & Lindtjorn, 2007). Similarly patients in this study highlighted that transport at times was not available to take them home. Therefore visiting the facility could be viewed as inconveniencing as there will be no transport to carry them back to their homes.

"…That time transport to take us back home is not available. I don't come from Oshakati. I am from Ongandjera, Omathindiko…"

Physical access to the facility also posed a challenge to the patients. Namibia is a vast country with relatively long distances between towns and villages. Some participants made comments like:

"…I have no job and I travel as far as from Onesi to get my medicines…"

"…me money was not a problem but the distance of coming to collect medicines now and again…"

"…I agree with everyone it is far where we come from…"

Although some patients had problems related to finance and logistics some of the respondents had defaulted because of work-related commitments. Fear of losing employment due to regular visits to the facility, loss of income due to absence from income-generating activities among other issues. The following statements supported these findings:

"…I stopped because I felt I could work…"

"… I couldn't lose my job so I decided to stop coming…"

Socio-cultural factors

Respondents also reported that socio-cultural factors contributed to their defaulting. Factors such as unavailability of social, psychological and emotional support, lack of knowledge about HIV/AIDS and low literacy levels are some of the factors the researcher noted during the focus group discussion.

Lack of psychosocial support

Effective delivery of HIV/AIDS treatment requires more than just medicines, the presence of support systems is also an integral part of this initiative. "Psychosocial support helps with the stigma and discrimination associated with HIV/AIDS," (WHO, 2008, p.4). The researcher noted that some patients defaulted as a result of several emotions, including anger and fear that came about as a result of being neglected or not offered enough psychosocial and emotional support.

"...my own flesh and blood neglected me when I needed them the most..."

"... I was called a lazy person who did not want to work...I loved my medicines but started missing some medicines, I was so angry with myself and cursed myself all the time..."

"...for me at that time I was feeling hurtful of myself, no matter what I was told I remained so much regretful of myself and my life. So I stopped..."

UNAIDS, 2006b stresses that support from family and friends is critical to a patient's successful adherence to a medication schedule.

Lack of knowledge

The researcher realised that patients had defaulted because they lacked sufficient knowledge about the disease and the treatment. This was compounded by low levels of literacy amongst some patients.

Mills, Nachega, Bangsberg, Singh, Rachlis, Wu, et al, (2006), identified lack of understanding treatment as a barrier to good adherence. These findings were supported by Alcorn, (2007) who found that lack of information about medicines and HIV treatment aims also contribute to patients stopping treatment. In this study, respondents from the focus group discussions stopped treatment as a result of receiving accurate information from trusted figures such as traditional healers and parents.

"...after that my mother took me to the traditional healer and I was given some herbs to take...I was told to stop ARVs as it had caused my body to be weak..."

Illiteracy

Some of the defaulters indicated that they can read and write and attributed their defaulting to low levels of literacy, this also tied in with poor communication when health providers merely wrote follow-up information on patients' passports instead of communicating this with the patients verbally.

"…most of us are illiterate we do not understand written language…"

"…the follow up date even if its written in the passport, most of us can not read…"

Al-Hajjaj and Al- Khatim, (2000) stress that non-compliance may be associated with no or minimal education and their findings support the findings in this study that low literacy levels contributed to some patients defaulting on treatment.

4.5.3 Influence of condition related factors on patients defaulting treatment

Immediacy of beneficial effects

A classic notion the researcher obtained from literature review on defaulters to chronic treatment is that most of them stop treatment as a result of getting better after a few courses of their treatment. The researcher experienced that some respondents stopped treatment as a result of getting better. A number of reasons have been postulated in previous studies. Lack of accurate information, suspicion about medicines and view of medicine intake as disruptive of daily life are some of the reasons given by Alcorn, (2007).

In this study respondents gave the following reasons to support this notion as to why they defaulted.

"...I started treatment and when I felt better I stopped..."

"...I couldn't lose my job so I decided to stop after all I was feeling better..."

Immediacy of harmful effects

Negative treatment outcome, on the other hand, also led to some respondents defaulting on their treatment. Anticipated and real side effects, intolerance to medicines and temporary illness as a result of intake of HAART (also called immune reconstitution syndrome) caused defaulting in some patients.

"...my health was beginning to be worse..."

"...suddenly my buttocks started being small and my weight started to fall..."

Similar reasons were identified by Chatterjee et al. (2003) in their study on defaulters to TB treatment.

4.6 Summary

Chapter 4 described the results of the data generated from the questionnaire in the qualitative phase of the study and from the focus group discussions in the qualitative phase of the study. The results from the phase 1 study were presented under the five categories of factors identified from literature that contributed to patients defaulting in other studies. A majority of the respondents disagreed that these factors contributed to their defaulting. In the qualitative phase of the study, three themes were identified. A literature control was done during the analysis to support these findings. In chapter 5 conclusions and recommendations will be discussed.

CHAPTER FIVE

SUMMARY OF RESEARCH FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

In this chapter the research findings are summarised, discussed and conclusions are drawn. Based on these conclusions, recommendations are formulated and presented within the limitations recognised as existing within this study. These limitations will be presented and placed within a context.

The discussion of this chapter will be based on the order and focus of the macro-arguments namely the purpose and objectives of the study.

Purpose of the study

The purpose is to explore and describe factors causing patients to default on HAART in Oshakati and to propose appropriate interventions.

It has been revealed in the literature that defaulting on treatment is a complex biosocial phenomenon caused by a variety of factors. Literature also shows that tracing defaulters is not so straightforward because of the complexity of human behaviour as well. These factors were presented in the literature according to the health promotion model and discussed as patient, condition and health care and system- related factors.

Objectives

- To identify and trace defaulters of highly active anti-retroviral therapy in Oshakati.
- To describe the profile of defaulters to highly active anti-retroviral therapy.
- To determine what factors cause patients on highly active anti-retroviral therapy to default.
- To propose interventions to ensure improved return rates of anti-retroviral therapy patients.

Each objective will be discussed individually, conclusions will be drawn and recommendations made.

5.2 Summary of research findings, conclusion and recommendations with regard to Objective 1

The first objective reads as follows:

To identify and trace defaulters of highly active anti-retroviral therapy in Oshakati

During the period of register review, 2640 patients were registered on the ART register. Of the 2640 patients, 2057 were active ART users coming for their refills monthly. Of the 2057 active ART users 1360 were female and 608 were younger than 13 years of age. A total of 583 (22.1 %) had missed two or more consecutive clinical appointments, and these comprised 20 (0.8 %) dead, 483 (18.3 %) transferred out to other facilities and 80 (3.0 %) defaulted. These figures are presented in tabular form below.

Table 5.1 Pattern of ART use among HIV positive individuals in Oshakati Hospital, July 2007

Status	Number	Percent (%)
Active refills	2057	77.9
Defaulted	80	3.0
Transferred Out	483	18.3
Died	20	0.8
Total	2640	100

The number of the defaulters was generated by the ART dispensing tool. The computer generated a list of 80 defaulters for the month of July 2007. A total of seventy six respondents participated in the initial phase of the study (N=76). The remaining four patients could not be traced because of incorrect contact details for the patient and the caregiver on the patient registers.

Conclusion

The defaulter rate in Oshakati (3 %) is slightly lower than reported in Malawi (5 %) (Kwong-Leung et al, 2007). Other studies have reported a defaulter rate of between 1.3 % - 13.1 % (Quarva-Jones & Barthlomew, 2004). Almost all patients (95 %) who were active and defaulted HAART were traced. The reason for not tracing the other 5 % of the patients was not clear, it could have been that patients gave incorrect contact details or the clinic staff erroneously entered incorrect details.

Recommendations with regard to objective 1

Facilities offering HAART need to record correctly and give full addresses and contact details; this would aid in the successful tracing in case of a patient who misses an appointment. Staff should try to do contact tracing as soon as possible in the event of clinic non-attendance. Since most defaulters stay with their relatives or in rented accommodations and are likely to move, it is also crucial to regularly update patient addresses on their profiles.

A community based strategies that can be employed for successful tracing and referral to clinics is to link patients to community based support groups. According to the Health Promotion Model, interpersonal influences play a significant role in affecting an individual’s predisposition to engage in a particular behaviour (Gorin & Arnold, 1998), therefore engaging community based support groups may help patients to adhere to their treatment.

Programme managers should allocate adequate staff resources for defaulter tracing instead of solely focusing on enrolment and treatment and encourage family/community-based counselling to sensitise the community about the need for adherence. It is encouraging to note that the Ministry of Health and Social Services through a programme called Integrated Management of Adolescents/Child Illnesses (IMAI) has began establishing satellite clinics at health facilities in an effort to increase access to ARV medicines as well as provide services closer to the communities. This initiative may reduce barriers, such as physical access and personal costs in travelling, as outlined in the Health Promotion Model, to access treatment (Pender et al, 2002).

5.3 Summary of research findings, conclusion and recommendations with regard to Objective 2

The second objective reads as follows

To describe the profile of defaulters to highly active anti-retroviral therapy

With the second objective, eight variables were assessed to give a profile of the defaulters:

- Age range
- Gender

- Marital status
- Level of education
- Level of dependency
- Nature of residence
- Change of residence
- Nature of employment

Three (3.9 %) respondents were younger than 21 years. The majority of the respondents were in the age groups 21-30 years and 31-40 years with twenty six (34.2 %) being in the first group and twenty eight (36.8 %) being in the second group. The average age of the respondents was thirty five years. The number of male participants in the study was the same as the number of females.

The majority of respondents were single n=49 (64.5 %), twenty were married, two were divorced and five were widowed. The majority of respondents, namely fifty three (69.7 %), had less than five dependants. Twenty one (27.6 %) had between 5-9 children and two (2.6 %) had between 10-14 dependants.

Most of the participants, namely thirty four (44.7 %), had attended school up to the secondary level, thirty one (33.3 %) reached primary school, six (7.9 %) reached tertiary level and five (6.6 %) had never attended school. When it came to the nature of employment thirty three (43.4 %) were unemployed. The number of respondents who were formally employed at the time of the survey was twenty five (32.9 %).

The number of respondents who were self employed was thirteen (17.1 %) and only five (6.6 %) respondents were at school.

Most of the respondents n=38 (50.0 %) stayed with their relatives at the time of the survey, twenty five (32.9 %) owned houses and thirteen (17.1 %) were renting. The majority of the respondents had never changed their place of residence since initiating treatment n=49 (64.5 %). Fifteen (19.7 %) had changed residence only once and twelve (15.8 %) had changed more than once.

Conclusion

These results support the HIV Sentinel Survey (MoHSS, 2005) which shows that most patients who are HIV/AIDS positive fall within the same age range. The people in this age range have other commitments as well, such as employment, caring for children and often need to move and change their place of residence. Being on treatment may cause a strain to these commitments and defaulting on treatment may be the only option to fulfil their responsibilities. This has also been confirmed in other studies (Thuy et al, 2007; and Shargie & Lindtjorn, 2005).

Forty nine of the defaulters (64.5 %) were single, twenty were married (26.3 %), two were divorced (2.6 %) and five were widowed (6.6 %). The National Consensus results in 2001 showed that fifty six percent of the people older than 15 years in Namibia had never been married (Central Bureau of Statistics, 2003, p.4). However, this reason can not be attributed to patients defaulting on treatment as there was no case-controlled study to compare these findings with patients who were on treatment.

The number of people who did not have any form of employment was the same as those who had some form of employment. Employment serves as a source of income that enables a patient to afford food, transport and hospital fees. Lack of employment therefore, is a barrier to affording the above since poverty as a result of unemployment or lack of finance has been shown to play an important role in defaulting on treatment (Tanguis, Cayla, De Olalla, Jansa & Brugal, 2000).

With regard to level of education a majority of the respondents stated that they had gone to school, i.e. from primary school to tertiary level and only a small proportion had never been to school. This is rather contradictory since some of the respondents attributed illiteracy to their defaulting on treatment in the focus group discussion.

With regard to residential status most of the defaulters were staying with their relatives and renting; they did not own their own houses. This indicated that most of the patients were disadvantaged economically because they could not afford their own houses. However, most people in the Oshana region stay in the rural areas with relatives (Central Statistics Bureau, 2003).

With regard to migration which was measured by a change in residence, most of the defaulters had not changed residence since they started treatment, though a comparatively significant number had changed their place of residence at least once. Migration also shows the unstable socio-economic standing of a community (Shargie & Lindtjorn, 2007). This study reveals that most defaulters were stable in their places of residence and had not changed them. They probably reside in the villages where they stay as families.

Recommendations

It was difficult to make inferences from the demographic factors and associate any factors with patients' defaulting. The researcher, therefore, recommends that a case controlled study should be done to look at the risk factors associated with patients' defaulting on HAART.

5.4 Summary of research findings, conclusion and recommendations with regard to Objective 3

The third objective reads as follows:

To determine what factors cause patients on highly active anti-retroviral therapy to default.

From the quantitative phase of the study, it was unclear which reasons had caused patients to default on their treatment. A majority of the respondents disagreed with the reasons given in the questionnaire. However, through the focus group discussion the respondents outlined specific factors which were classified under three broad themes. The three themes were:

- Health care and system related factors
- Patient related factors
- Condition related factors

Three factors emerged under health care and health system theme, the complexity of the treatment process, and poor patient-provider relationship, ultimately leading to dissatisfaction with the health services provided as well as the health workers.

With regard to the second theme, respondents outlined financial constraints to be able to buy food or afford transport fees, the long distance to health facilities from their places of residence, a lack of food and loss of income as a result of unemployment or the inability to perform income generating projects. These factors were classified as socio-economic factors. The respondents gave factors that were classified as socio-cultural and these were lack of psychosocial support, illiteracy, misinformation and lack of knowledge.

With regard to the third theme, patients identified that immediacy of beneficial effects or "getting better" as well as immediacy of harmful effects or "negative treatment outcome" played a role in the defaulting on treatment of some patients.

Conclusion

These results are similar to those found in other studies given in the literature review and the conclusion of the researcher is that these results are associated with patients' defaulting on treatment and also that the factors identified in the results always interact and interrelate in contributing to patients defaulting on HIV treatment.

With regard to health care system level factors, several authors have cited multiple layers of factors as contributing to defaulting treatment and these include patient dissatisfaction with Health Care Workers, and poor patient-provider relationship (Holtz, Lancaster, Laserson, Wells, Thorpe & Weyer, 2006; Nuwaha, 1999; Tekle, Mariam & Ali, 2002). Long waiting hours at the facility (Elshabrawy, 1992) and many consecutive dates for follow-up appointments with brief intervals in between (Hardon, 2007) also contributed to patients defaulting on their treatment plan.

With regard to patient related factors, studies have demonstrated that lack of money for food (Deribe et al, 2006) and unaffordable transport costs (Tissera, 2003) contribute to patients discontinuing treatment. Long distances and a need to use public transport for ambulatory care between residential places and the health facility has also been demonstrated to work together with financial constraints to influence patients defaulting on treatment (Shargie & Lindtjorn, 2007). Fear of losing employment and income caused by absence from income-generating activities was also linked to socio-economic factors which could have contributed to patients defaulting on treatment.

It can also be concluded that socio-cultural factors such as lack of knowledge about treatment and outcomes (Mills et al, 2006), and receiving inaccurate information from trusted figures (Murray & Semrau, 2007) play a role in defaulting on treatment.

This is further complicated by low levels of literacy amongst most of the patients. Low levels of literacy mean that patients are not able to read more about the disease but rely on information from other people. Absence of support groups and systems that give not only accurate information but also emotional and psychosocial support cause patients to be confused and to have several emotions that may include anger and fear about the disease.

Some of the reasons why patients defaulted are linked to the condition, i.e. positive and/ or negative outcome after initiating treatment. This was also confirmed in studies that looked at defaulters to HIV treatment (Deribe et al, 2006) and other chronic conditions (Santha, Garg & Frieden, 2002).

Recommendations with regard to objective 3

Options to be considered to improve patient adherence and minimize or eliminate defaulter rates will be recommended based on the conclusions drawn above and also based on the context of the study. The researcher is aware that many other factors could be important as contributing factors to patients defaulting on treatment.

The decentralisation of treatment follow-up to community health clinics and health centres could be explored to bring services closer to the people and minimise structural barriers such as physical access to treatment. Past studies have demonstrated that removing these structural barriers reduces default to treatment (Farmer, Robin, Ramilus, & Kim, 1992). In an effort to reduce the access gap to treatment, the Ministry of Health and Social Services started out-reach programmes to designated health centres and clinics. Immediate steps should be taken to minimise delays in the clinic, i.e. identifying bottle necks in the system and making attempts to address them.

There has to be improved patient-provider communication on treatment duration, outcomes and expectations in order to deal with the preconceived ideas patients have prior to initiating treatment. After all, the onus to reverse these ideas is upon the care provider. Peer encouragement mechanisms such as “social / treatment clubs’ have also been effective community-based approach in enhancing adherence to treatment. Furthermore the importance of good rapport between patients and care providers in proper treatment adherence needs to be emphasised.

Recurrent costs to users such as transport fees and hospital fees should be minimised. “This can be done by providing 3 month worth of medicines patients instead of 1 month once optimal adherence levels have been achieved,” (Hardon, 2007, p.4). Programme managers need to understand that changing residence or location is also an identifier of unstable socio-economic position as many patients migrate from one place to another in search of work. Migrating patients should not be treated with undue suspicion, a comprehensive review of their past medical history is essential but hurdles to treatment access for these groups should be identified and minimised.

Every clinic and health centre visit or health care worker contact should be treated as an opportunity to check and re-enforce adherence, pill counting and appointment-keeping.

A better understanding of treatment default in patients may help programme managers to better plan ahead so as to reduce this problem. Future research in this area should address the complex interplay between such factors and explore possible interventions to improve treatment adherence.

5.5 Limitations of the study

The study focused on one health facility in the country and the results can not be generalised to the broader region or the country.

A case-controlled study would have given more meaningful results in the quantitative phase of this study.

5.6 Summary

In this chapter the method of identifying and tracing defaulters, the profile of defaulters and factors that were considered to be associated with ART patients defaulting treatment were analysed, conclusions drawn and recommendations made.

From the findings, it is clear that the quantitative approach to this study was not ideal as more meaningful data was obtained through qualitative inquiry.

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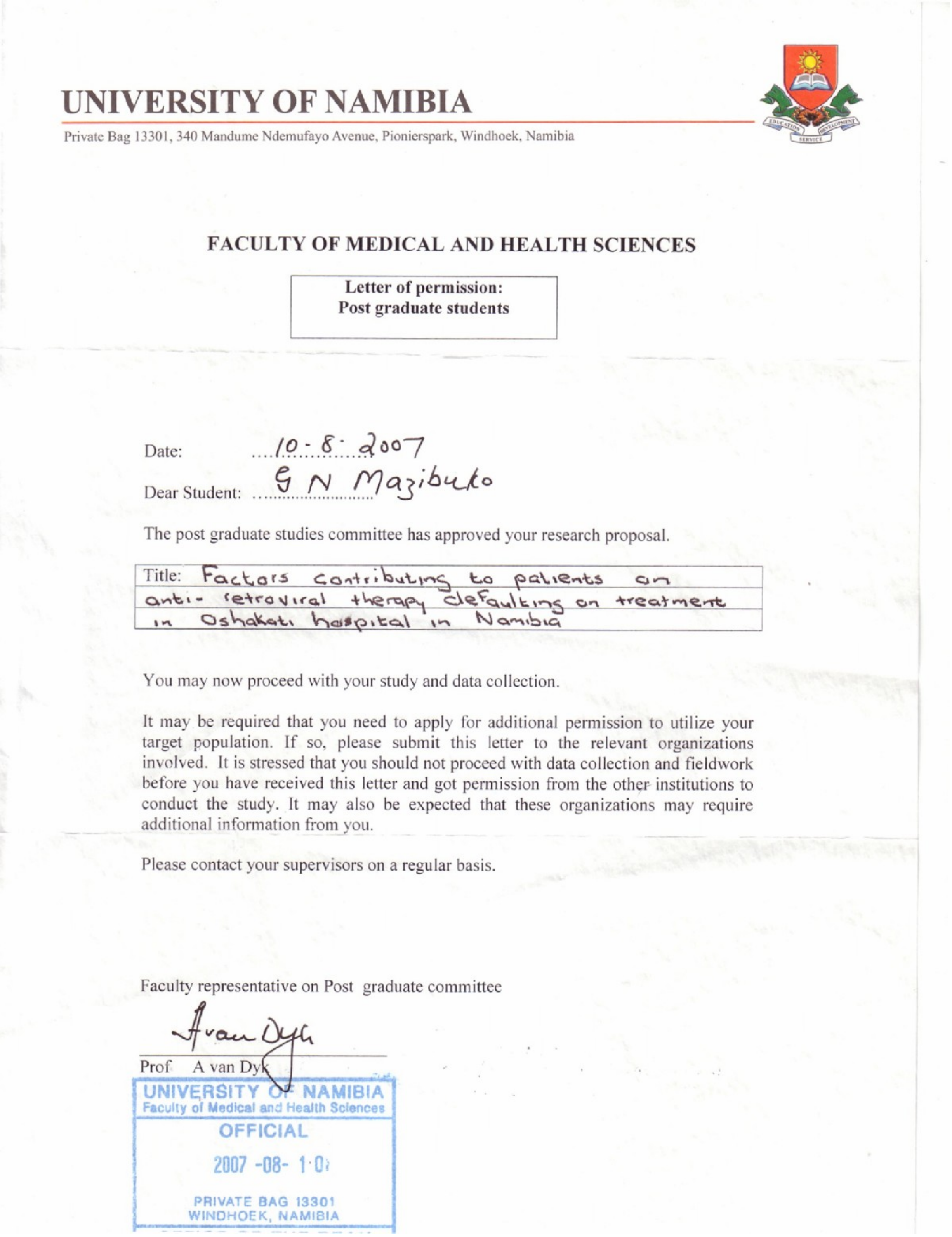
Annexure A: Release letter from UNAM



UNIVERSITY OF NAMIBIA
Private Bag 13301, 340 Mandume Ndemufayo Avenue, Pionierspark, Windhoek, Namibia

FACULTY OF MEDICAL AND HEALTH SCIENCES

Letter of permission:
Post graduate students

Date: 10-8-2007

Dear Student: G N Mazibuko

The post graduate studies committee has approved your research proposal.

Title: Factors contributing to patients on
anti-retroviral therapy defaulting on treatment
in Oshakati hospital in Namibia

You may now proceed with your study and data collection.

It may be required that you need to apply for additional permission to utilize your target population. If so, please submit this letter to the relevant organizations involved. It is stressed that you should not proceed with data collection and fieldwork before you have received this letter and got permission from the other institutions to conduct the study. It may also be expected that these organizations may require additional information from you.

Please contact your supervisors on a regular basis.

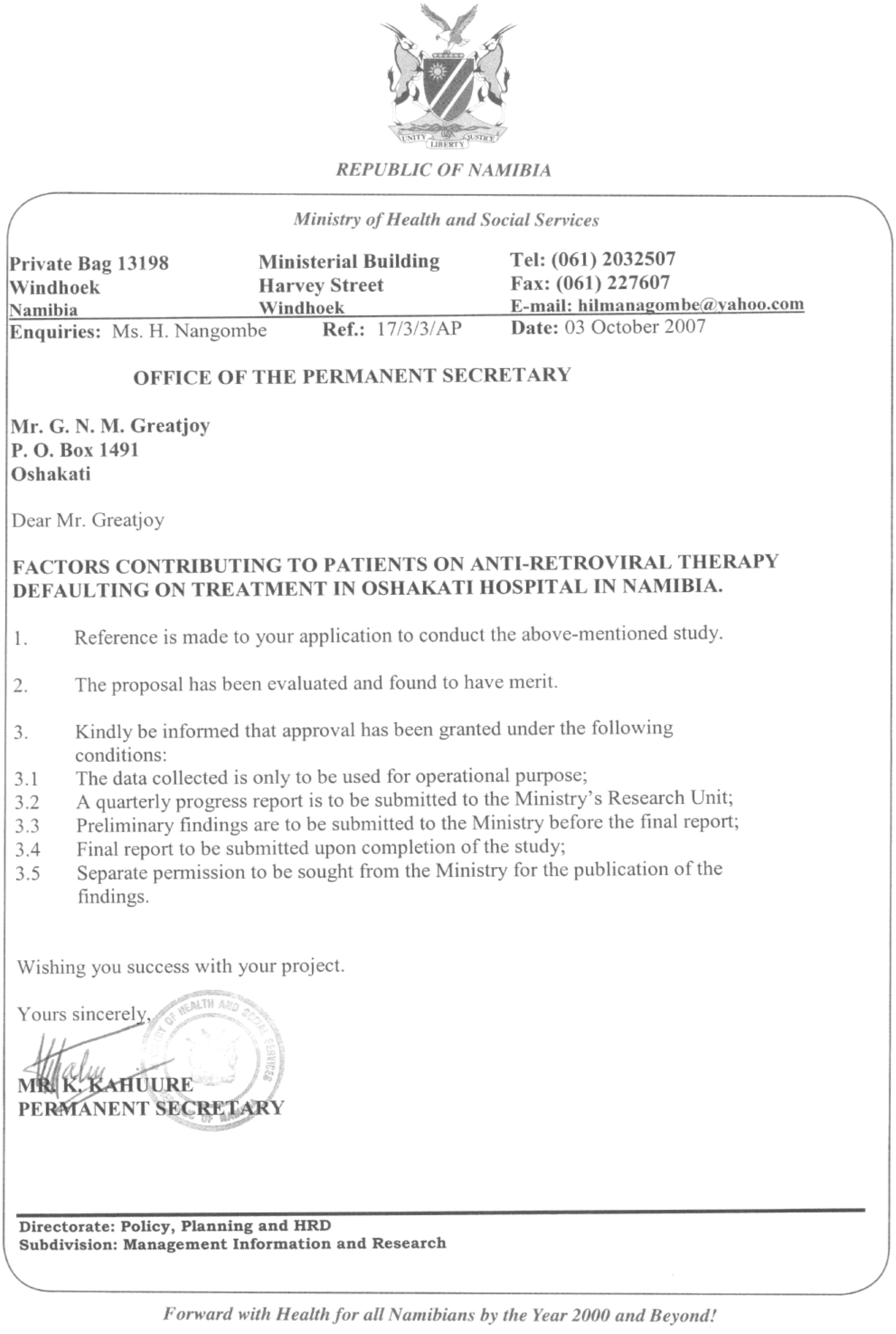
Faculty representative on Post graduate committee

Avan Dyk

Prof A van Dyk

UNIVERSITY OF NAMIBIA
Faculty of Medical and Health Sciences
OFFICIAL
2007 -08- 10
PRIVATE BAG 13301
WINDHOEK, NAMIBIA

Annexure B: Release letter from the Ministry of Health and Social Services



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: (061) 2032507
Fax: (061) 227607
E-mail: hilmanagombe@yahoo.com

Enquiries: Ms. H. Nangombe **Ref.:** 17/3/3/AP **Date:** 03 October 2007

OFFICE OF THE PERMANENT SECRETARY

Mr. G. N. M. Greatjoy
P. O. Box 1491
Oshakati

Dear Mr. Greatjoy

FACTORS CONTRIBUTING TO PATIENTS ON ANTI-RETROVIRAL THERAPY DEFAULTING ON TREATMENT IN OSHAKATI HOSPITAL IN NAMIBIA.

1. Reference is made to your application to conduct the above-mentioned study.

2. The proposal has been evaluated and found to have merit.

3. Kindly be informed that approval has been granted under the following conditions:

3.1 The data collected is only to be used for operational purpose;
3.2 A quarterly progress report is to be submitted to the Ministry's Research Unit;
3.3 Preliminary findings are to be submitted to the Ministry before the final report;
3.4 Final report to be submitted upon completion of the study;
3.5 Separate permission to be sought from the Ministry for the publication of the findings.

Wishing you success with your project.

Yours sincerely,

MR. K. KAHUURE
PERMANENT SECRETARY

Directorate: Policy, Planning and HRD
Subdivision: Management Information and Research

Forward with Health for all Namibians by the Year 2000 and Beyond!

Annexure C: Cover note for the questionnaire

Dear Respondent

RE: Factors contributing to patients anti-retroviral therapy defaulting on treatment in Oshakati Hospital in Namibia

I am in the process of completing the Master of Public Health degree at the University of Namibia (UNAM). As partial fulfilment of the requirements of the University, I have to submit a research thesis on the above mentioned topic.

The purpose of the study to explore and describe factors causing patients to default HAART in Oshakati. The data will enable to identify information that could be useful in addressing the problems of defaulting through this study and future studies and to propose appropriate interventions in this regard.

It would be greatly appreciated if you complete the attached questionnaire. All information will be treated confidentially and all data will be grouped and processed, thus ensuring anonymity. You may at any stage, without prejudice, withdraw your consent and participation in the study. Permission to conduct the study has been granted by the Ministry of Health and Social Services, University of Namibia and the Oshakati State Hospital management. Before you complete the questionnaire, complete the informed consent form and return it to the researcher. The questionnaire should take approximately 20 minutes to complete.

In case of any doubt, question, query or input, please do not hesitate to contact me on the following numbers: Work telephone 0652233268, Cell phone 0811496526, Work address Oshakati State Hospital, Communicable Disease’s Clinic, Oshakati.

Thank you for your participation. As a result of your co-operation, recommendations can be made about reducing the incidence of defaulters and strengthen management strategies in this regard.

Annexure D: Questionnaire

FACTORS CONTRIBUTING TO PATIENTS ON ANTI-RETROVIRAL THERAPY DEFAULTING ON TREATMENT IN OSHAKATI HOSPITAL IN NAMIBIA

PATIENT / GUARDIAN QUESTIONNAIRE

In the case of a minor (patients less than 13 years of age) a guardian should be the respondent.

Please answer all questions and tick your appropriate answer in the boxes

SECTION A DEMOGRAPHIC DATA

Demographic profile of patient

1. Gender of patient/ guardian: Male ☐ Female ☐

2. Age of patient/guardian (if minor) in Years_______

3. Marital Status
Married ☐ Single ☐
Widow/Widower ☐ Divorced ☐

4. Number of Dependant Children _________

5. Level of Education

Not Been to School ☐ Primary School ☐ Secondary School ☐
Tertiary Education ☐

SECTION B SOCIO-ECONOMIC CHARACTERISTICS

Socio-economic profile of patient

6. Nature of Residence

Own House ☐ Renting ☐ Living with relatives ☐

7. How many times did you change residence after starting treatment?

Never ☐ Once ☐ More than once ☐

8. Nature of Employment

Formally Employed ☐ School going ☐ Unemployed ☐ Self Employed ☐

9. Does your employment allow you to attend clinic visits anytime?

Yes ☐ No ☐

10. How do you get to the ARV Health Facility?

Public Transport ☐ Lift ☐ Own transport ☐ Walk ☐

Contribution of Socio-economic factors to defaulting treatment

Rate the contribution of the following factors / situations to you defaulting treatment.

A rating of: **5 indicates that you strongly agree**
4 indicates that you agree
3 indicates that you are neutral
2 indicates that you disagree
1 indicates that you strongly disagree

	1	2	3	4	5	
11. Did your employment/ work commitment contribute to defaulting?						
12. Did unemployment contribute to defaulting?						
13. Did transport cost to the ARV health facility contribute to defaulting?						
14. Did unavailability of transport contribute to defaulting?						
15. Did changing residence during the course of treatment contribute to defaulting?						
16. Did the lack of required/adequate food supply contribute to defaulting?						

SECTION C SOCIO-CULTURAL CHARACTERISTICS

17. Do you smoke? Yes ☐ No ☐

18. Do you take alcohol? Yes ☐ No ☐

19. Did you use traditional medicine during your ARV treatment? Yes ☐ No ☐

20. Do you believe that traditional medicine is better that ARV treatment?
Yes ☐ No ☐ Don’t Know ☐

Rate the contribution of the following factors /situations to you defaulting treatment.

A rating of: **5 indicates that you strongly agree**
4 indicates that you agree
3 indicates that you are neutral
2 indicates that you disagree
1 indicates that you strongly disagree

21. Did attending social events for example wedding, funeral contribute to defaulting?						

22. State any event you attended that might have contributed to defaulting if no stated in question 21____

Rate the contribution of the following factors /situations to you defaulting treatment.

A rating of: **5 indicates that you strongly agree**
4 indicates that you agree
3 indicates that you are neutral
2 indicates that you disagree
1 indicates that you strongly disagree

	1	2	3	4	5	
23. Did the absence of reliable treatment supporter contribute to defaulting?						
24. Did the attitude of neighbours & friends contribute to defaulting?						

SECTION D SERVICE RELATED CHARACTERISTICS

Opinion about health care provider

Indicate how you would rate the approach of the healthcare worker towards you.

A rating of: **5 indicates that you strongly agree**
4 indicates that you agree
3 indicates that you are neutral
2 indicates that you disagree
1 indicates that you strongly disagree

	1	2	3	4	5	
25. Did the health worker treat you with respect?						
26. Was the time spent with you enough to listen to all your problems?						
27. Was the counselling appropriate for you?						

Contribution of service related factors on defaulting treatment

Rate the contribution of the following factors / situations to you defaulting treatment

A rating of: **5 indicates that you strongly agree**
4 indicates that you agree
3 indicates that you are neutral
2 indicates that you disagree
1 indicates that you strongly disagree

	1	2	3	4	5	
28. Did the frequency of visits to the ARV health facility contribute to defaulting?						
29. Did the attitudes of healthcare provider towards you contribute to defaulting?						
30. Did the waiting time at the facility contribute to defaulting?						
31. Did the lack of knowledge about treatment and outcomes contribute to defaulting?						

32. Did you enjoy privacy and confidentiality at the ARV clinic?

Yes ☐ No ☐ Don’t know ☐

SECTION E MEDICAL CHARACTERISTICS

Contribution of medical related factors on defaulting treatment

Rate the contribution of the following factors / situations to you defaulting treatment.

A rating of: **5 indicates that you strongly agree**
4 indicates that you agree

3 indicates that you are neutral

2 indicates that you disagree

1 indicates that you strongly disagree

	1	2	3	4	5	
33. Did side effects from HIV treatment contribute to defaulting?						
34. Did the presence of improvement/recovery after treatment contribute to defaulting?						
35. Did the absence improvement after starting treatment contribute to defaulting?						
36. Did the presence of illness such as TB/Hepatitis/Meningitis contribute to defaulting?						

SECTION F GENERAL INFORMATION

37. State in your own words, any other reasons that may have contributed to you defaulting on treatment?

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38. State in your own words, what could be done to reduce people defaulting treatment?

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Annexure E Focus group Questions/Guide

FOCUS GROUP DISCUSSION

Introduction

The first phase of this study sought to obtain factors contributing to patients to default treatment in Oshakati Hospital using a structured questionnaire bearing factors that have been postulated in other studies. Preliminary findings from the analysis of the data showed that most of the respondents did not agree that those factors contributed to them defaulting. Therefore the researcher thought it was important to revisit a conveniently random selected group consisting of 12 people to explore in depth the reasons why people default treatment.

Aim: This focus group discussion is to explore in depth the reasons patients default treatment in Oshakati Hospital.

Rules of the Group

What is said in the room is confidential. Do not talk about what is said here with your peers and relatives. Reflect, try and share your opinions, experiences and testimonies as much as possible. Everyone is important.

Questions for the participants

1. Ask the participant to introduce themselves; introduction must include age, where they are from?
2. What are the reasons why patients default on ART in Oshakati specifically?
3. How can this problem be solved?
4. What are your opinions about the healthcare providers in Oshakati ART clinic?