

**An investigation of the factors associated with default of scheduled drug pick-ups and clinic visits by patients on antiretroviral therapy at Murchison Hospital, Kwa Zulu Natal Province in South Africa**

**By**

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## DECLARATION

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## ABSTRACT

The fact that patients on Highly Active Antiretroviral Therapy (HAART) default scheduled drug pick-ups and clinic visits requires attention, because the long-term effect is non-adherence to prescribed regimens and the development of drug resistance, as indicated in the report of the Fourteenth Conference on Retroviruses and Opportunistic Infections held in November 2007 in Los Angeles.

A cross-sectional survey and observational qualitative study was done to identify key factors associated with the fact that patients on antiretroviral therapy fail to pick up drugs and keep scheduled clinic appointments, with a view to suggesting intervention measures. The study focused on Murchison Hospital in Ugu District, Kwa Zulu Natal Province.

Data were collected from patient records, telephonic interviews with patients, or patients' caregivers, treatment supporters and family members of a patient who did not return for follow-up at the clinic, as well as from face-to-face interviews with healthcare workers to understand the reason for default. Observation checklists were used to collect data from systems, structures and processes used in services provision. Thereafter data were analyzed through the various stages of coding and writing up of notes and reported.

Of 638 defaulters identified, 205 were contactable, and only 95 patients were reached. The key factors associated with default identified were death (49.5%) and logistics and cost (15%). Other additional factors were travel and migration, religious beliefs, hospitalization, side effects, work schedules and commitments, imprisonment and visiting private practices. Poor relationships with healthcare workers, patients' financial difficulties and termination of disability grants added to the problem.

A significant proportion of patients, care givers, patients' supporters and healthcare workers suggested that in order to reduce default, antiretroviral therapy services should be decentralized, poverty reduction programmes especially for people living HIV and AIDS should be targeted, there should be a home based treatment option and HIV treatment capacity building intervention should be prioritized.

## OPSOMMING

Die feit dat pasiënte op Hoogs Aktiewe Retrovirale Terapie (HAART) in gebreke bly om hulle medikasie af te haal of om hulle afspraak by die kliniek na te kom, vereis aandag omdat die lang termyn effek is dat hulle afwyk van die voorgeskrewe medikasie en weerstand teen die voorgeskrewe middels opbou. Hierdie probleem is ook in die verslag van die Veertiende Konferensie oor Retroviruses en Oportunistiese Infeksies wat in November 2007 in Los Angeles gehou is aangespreek.

‘n Oorsig en kwalitatiewe studie is gedoen om die sleutel faktore wat assosieer word met die nie-nakom van skeduleerde kliniekafsprake deur pasiënte op antiretrovirale terapie te identifiseer en om intervensies voor te stel. Die studie is gedoen by die Murchiston Hospitaal in die Ugo Distrik, Kwa-Zulu Natal.

Data is ingesamel vanaf die verslae van pasiënte, telefoniese onderhoude met pasiënte, oppassers, ondersteuners en gesinslede van pasiënte wat nie afspraak nagekom het nie, asook van onderhoude met gesondheidsorgwerkers. Die doel was om die redes waarom afspraak nie nagekom is nie, te verstaan. Observasie lyste is gebruik om data in verband met sisteme, strukture en prosesse wat vir dienslewering gebruik is, te versamel. Die data is toe ontleed en daar is verslag gedoen.

Pasiënte (638) wat nie afspraak nakom nie, is geïdentifiseer. Van hulle was net 205 kontakbaar en is daar uiteindelik met 95 telefonies onderhoud gevoer. Die hoofredes wat aangevoer is vir die wat in gebreke bly om afspraak na te kom, was die dood (49, 5%) en logistiek en koste (15%). Bykomende faktore was reis en migrasie, godsdiens, hospitalisasie, nuwe-effekte van medikasie, werkskedules en pligte, gevangenisstraf, die besoek van privaatdokters, swak verhoudings met gesondheidswerkers, finansiële probleme, en die opskorting van ongeskiktheidspensioene. ‘n Beduidende persentasie van die pasiënte, hulle oppassers en gesinslede, asook die gesondheidswerkers, maak voorstelle wat kan help dat pasiënte meer gereeld hulle medikasie afhaal en kliniekafsprake nakom. Hierdie voorstelle sluit in beter armoede-verligting programme veral vir mense met MIV-VIGS en tuisbehandeling as ‘n opsie.

## **ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral
BBC	British Broadcasting Corporation
DoH	Department of Health
HIV	Human Immunodeficiency
PWA	People (living) With AIDS
SOP	Standard Operation Procedures
TB	Tuberculosis
STDs	Sexually Transmitted Diseases
UNAIDS	United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme

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## **Chapter 1: Introduction**

### **1.1 Background information**

According to the 2008 report on the global AIDS epidemic, 33.2 million people were living with the AIDS virus globally at the end of 2007, with 2.5 million people newly infected during the year. The report also highlighted that approximately 5.5 million people were living with the AIDS virus in South Africa, making it the country with the highest numbers and fastest growing HIV-infected population in the world. This AIDS global epidemic report has resulted in an unprecedented global effort to roll-out ART (antiretroviral therapy) in every country threatened by the pandemic (AVERT, 2008).

British Broadcasting Corporation Health News (2008) reported that just 31% of people in need of treatment in low and middle-income countries had access to ART in 2007. The report by the Joint United Nations programme on AIDS and HIV, said an extra 950,000 people in these countries received the drugs in 2007, leaving an estimated 6.7 million people unable to access potentially life-saving drugs. Though shockingly small, this figure represents a great advance since 2003, when only 400,000 were receiving treatment globally. In addition to that, antiretroviral therapy has already dramatically cut the rate of AIDS diagnosed cases and death in Western countries where treatment has been provided since the mid 1990s (AVERT, 2008).

Health, well-being and survival of most people receiving ART in poor rural setting has improved and this has brought hope to millions who are living with HIV and AIDS, their families and communities (UNAIDS, 2008). However, failure to keep scheduled drug pick-ups and clinic visits pose serious challenges to this endeavour, because the long-term effect is non-adherence to prescribed regimens and the development of drug resistance, as indicated in the report of the Fourteenth Conference on Retroviruses and Opportunistic Infections held in November 2007 in Los Angeles.

As South Africa increases access to ART in all public health facilities, it is important to understand key associated factors which have led patients on ART to miss scheduled drug pick-ups and clinic visits in order to design appropriate interventions.

## **1.2 Study Objectives**

This study was designed to investigate key factors associated with failure to pick-up drugs and non adherence to scheduled clinic visits by patients on antiretroviral therapy, with a view to suggesting intervention measures. The study focused on Murchison hospital in the Ugu district, Kwa Zulu Natal province.

## **1.3 Specific Objectives**

The study aims during the study were to:

- Assess the quality of operating structures, processes and systems used in the provision of ART services to patients attending the selected site in order to understand whether they contributed toward missed scheduled drug pick-ups and clinic visits.
- Identify the reasons for default from experience of antiretroviral therapy users who missed scheduled drug pick-ups and clinic visits.
- Identify reasons that led patients on ART to miss scheduled drug pick-ups and clinic visit from patients' care givers, patients' treatment supporters, and patients' family members or healthcare workers' experience.
- Document suggestions and proposals from patients on antiretroviral therapy, patients' care givers, patients' treatment supporters, healthcare workers' and patients' family members to improve patients' compliance with scheduled drug pick-ups and clinic visits.

## **Chapter 2: Literature review**

A literature review serves as a study framework that guides the study project. It tells whether the identified research problem has been researched and the reason for replicating it is if a similar study has been conducted (Christensen, 2004). This literature review aims to provide an overview of some key factors associated with default to scheduled drug pick-ups and clinic visits in South Africa and other parts of the world.

In a study by Maskew et al. (2007) it is reported that patients with financial difficulties are likely to default on follow-up appointments at St Helen's Hospital in Johannesburg, South Africa. In addition to that, the unreported death and migration of patients adds to the problem. Another study conducted at Jimma Hospital in Ethiopia found that poverty and lack of money for transport was a major cause of default to antiretroviral therapy. Other factors like lack of food, mental illness, and having a partner with HIV negative status or unknown status were also associated with default (Deribe et al. 2008). It has been argued that because of the gender dimension on poverty, poor women are generally likely to be less compliant to treatment plans than their male counterparts (Skhosana et al. 2006). An experience from Haiti shows that administration of ARV to poor patients has been a challenge regardless of the treatment being free, because of other associated costs (Fitzgerald & Krain, 2005).

Neglecting cultural specificities in Africa and elsewhere in the world has negatively impacted on antiretroviral therapy treatment outcomes because of lack of involvement of all health actors, for instance the traditional health practitioners (Fitzgerald & Krain, 2005). Some defaulting patterns of patients on antiretroviral therapy were the result of patients visiting traditional healers or using traditional medicine (Worley, 2007). Chopra et al. (2006) highlight the challenges to the responses of the introduction of ART in South Africa that, antiretroviral therapies are being introduced into an environment where they are competing with a multitude of alternative treatments and those alternatives are traditional African therapies. It is reported that providers (traditional healers) of these traditional African therapies are ubiquitous throughout sub-Saharan Africa and outnumber biomedical health professionals by a hundred-fold or more (Homsy et al. 2004).

Patients feeling too ill, the resolution of symptoms, forgetting or confusion regarding appointment dates and time lead to antiretroviral therapy default in general practices in Leeds, United Kingdom (Cosgrove, 1990). Other factors like migration or travel, stigma, and side effects constrained patients on antiretroviral therapy from sticking to agreed-to treatment plans in Botswana, although the principal factor was financial problems (Weiser et al., 2003). Hasker et al. (2008) conclude that factors such as unemployment, being a pensioner, alcoholism and homelessness have been a major cause of defaulting among tuberculosis patients in Tashkent, Uzbekistan. Excessive consumption of alcohol and hard drugs like cocaine and cannabis have also been associated with defaulting among patients on antiretroviral therapy at Jimma Hospital in Ethiopia (Deride et al., 2008).

Smart (2007) reported that the need to take time off from work to travel great distances to clinics and wait for the service all day long discouraged patients to come back for drug pick-up and clinical appointments. Also, he reports that with increasing numbers of patients joining the programme, it is becoming more difficult to give the needed attention to each patient for appropriate symptoms and opportunistic infection diagnosis and management. This creates a serious risk that many patients fall in the cracks or do not receive the adequate support to keep them in care partly because human resources limit the clinic's ability to follow-up patients and bring them for treatment.

Krain & Fitzgerald (2005), Skhosana et al, (2006), Deribe et al. (2008) report that social demographic and psychosocial issues have great potential impact on patients continuing with treatment. For instance, family and community support and religious beliefs about illness and medication might influence patients to discontinue antiretroviral therapy. Issues of disclosure and broader community-hospital based response have been found to have serious implications for patients regarding the continuing of treatment in South Africa (Smart, 2007).

A study by Fitzgerald & Krain (2005) conducted in Haiti highlights that lack of trained healthcare workers negatively impacted on patients' continuation with antiretroviral treatment. Attitudes and quality of care of the health care staff, seriousness of disease, adverse drug reaction and side effects, lack of appropriate counselling, long waiting hours, communication barriers, healthcare workers' burn-out and poor patient knowledge and information on HIV and illiteracy

had a negative influence on patients continuing with treatment in Tanzania (Hardon et al., 2006). A cordial relationship between patients and healthcare workers was reported to be the main motivating factor and reason for TB patients' completion of treatment at Effia-Nkwanta Regional Hospital in Sekondi, Ghana (Afenyadu & Dodor, 2005). Quality of health services was highlighted by 56% of tuberculosis patients as being a reason for initial default of treatment at Desmond Tutu TB centre in Cape Town, South Africa (Botha et al., 2008).

Afenyadu & Dodor (2005) report that decentralization of tuberculosis treatment to points more easily reached in Sekondi, Ghana significantly improved the patients' adherence, retention and treatment outcome. Improved tuberculosis patient-address records to assist patient follow-ups together with improved counselling, contributed to improved patient retention in Pradesh, India (Sai Babu et al., 2008). In a different study on defaulting partners of patients on a leprosy control programme in Mozambique showed that patients tend to default treatment early rather than late (Griffiths & Ready, 2001). Regarding this finding, Griffiths & Ready (2001) suggest that a comprehensive strategy to reduce default is needed rather than a single or specific strategy.

Skhosana et al., (2006), Hardon et al. (2006) report that factors such as disclosure, patient lifestyle, and proper treatment literacy have shown to increase the number of patients sticking to a treatment plan. Also in the same study it was suggested that the provision of several months' supply of medicines per visit would help to reduce transport costs and minimize patient expenditure and defaulting incidence. Deribe et al., (2008), Malta et al. (2004) conclude that, in order to improve compliance to treatment plans for patients on antiretroviral therapy, programmes and efforts should address illicit drugs and excessive alcohol use. In addition to that, decentralization of antiretroviral services, institution of home-based treatment options for patients that are seriously ill and bedridden, and improved integration of different health actors should be a prioritized.

## **Chapter 3: Research Methodology**

### **3.1 Study design**

This study was based on a cross-sectional survey and observational design to collect qualitative data. Cross-sectional survey design is a non-experimental, descriptive research method used to gather information or probe into a given state of affairs that exists in a population at a single point in time (Babbie, 1973). This research design was used as it allows for the gathering of information from individuals whose characteristics, behaviours and attitudes are relevant to the investigation (Christensen, 2004).

### **3.2 Study population**

The study population consisted of:

- 14 healthcare workers based at the ARV clinic and involved in the provision of ART services;
- All patients who had contact details in their files, started ART therapy at the facility but missed their last scheduled drug pick-ups and clinic visits for a period of more than three days;
- Patients' treatment supporters, care givers of minors and family members participated in cases where patients could not be reached by phone calls.

### **Inclusion and exclusion criteria of interviewees**

#### **Inclusion criteria:**

Patients, treatment supporters, caregivers and family members:

- All adult patients on antiretroviral therapy who defaulted their last scheduled drug pick-ups and clinic visits for over three days and who agreed to participate in the study;
- All care givers or parents of minors on antiretroviral therapy who defaulted on their last scheduled drug pick-ups and clinic visits and who agreed to participate in the study;
- All patient supporters or treatment-buddies or family members registered in a patient file who agreed to participate in the study.

Healthcare workers

- Healthcare staff who had worked at least for the past six months at the antiretroviral therapy clinic and who were well-informed about antiretroviral therapy use and who agreed to participate in the study.

**Exclusion criteria:**

Patients, treatment supporters, caregivers and family members:

- All patients who defaulted on their last scheduled drug pick-ups and clinic visits but didn't want to participate, patients not on antiretroviral therapy and all minor patients on antiretroviral therapy.

Healthcare workers:

- All healthcare workers who didn't work with patients on antiretroviral therapy and who were not well informed about antiretroviral therapy use.

**3.3 Data collection**

Data collection commenced on the 25th of March 2008 to the 12th of April 2008. The date and time of interviews with healthcare workers was arranged by the ARV clinic manager to suit each ARV clinic employee so as to avoid inconvenience. Telephonic semi-structured interviews were conducted with patients without pre-arrangement. Permission was asked by the data collector from the participant to conduct an interview.

The informed consent process involved the data collector giving a verbal explanation to each potential participant on the nature of the study, its purpose, the procedures involved, the expected duration, the potential risks and benefits involved, and any discomfort it might entail. Each participant was informed that participation in the study was completely voluntary and that they could withdraw at any time, and that withdrawal of consent would not affect their subsequent treatment or relationship with the facility staff or any other person.

### **3.3.1 Data collection tools**

Surveys can use both open-ended questions and forced-choice questions (Babbie, 1793). This study used both open-ended questions and forced-choice questions and a observation checklist.

### **3.3.2 Data collection methods**

Due to the nature of the study, combinations of data collection methods were used to gather information. Methods used were telephonic semi-structured interviews, face to face semi-structured interviews and a observation checklist. Semi-structured interviews were used because they are more flexible than standardized methods and are conducted with a fairly open framework which allows for focused, conversational, two-way communication which allows for the giving and receiving of information (FAO, 1990).

#### **Face-to-face semi-structured interviews**

A face-to-face semi-structured interviews method, as the name suggests, is a person-to-person interview, which typically involves going to the interviewee's home or work place and conducting the personal interview (Christensen, 2004). Christensen (2004) suggests that the technique has the advantage of allowing the interviewer to clear up any ambiguities in the question asked or to probe for further information and clarification if the interviewee provides an inadequate answer. Also, it generally gives a high completion rate and more complete information.

Face to face semi-structured interviews were used to collect data from healthcare workers. Healthcare workers interviewed were antiretroviral therapy clinic counsellors, data clerks, nurses and a doctor. Pharmacy personnel were excluded because patients had little contact with pharmacy personnel except during patient treatment initiation.

Themes for discussion focused on levels of formal education, non-formal training, use of Standard Operating Procedure (SOP), perception about the job, information and communication, availability of medicines, facility capacity e.g. space and technical skills; also associated factors and solutions to patients' non-attendance at drug pick-ups and scheduled clinic visits.



### **Telephonic semi-structured interviews**

This method is about half as expensive as face-to-face interviews (Christensen, 2004), and the information collected from this method is comparable to that obtained in a face-to-face interview (Christensen, 2004).

Telephonic semi-structured interview schedules were developed and used to collect data from patients who missed their last drug pick-ups and scheduled clinic visits for a period of more than three days. Patients' treatment-supporters, care-givers, or family members were interviewed in cases where a patient could not be reached.

Although the interviewer in this method had some general established topics for investigation, this method allowed for the exploration of emerging themes and ideas rather than relying only on concepts and questions defined in advance of the interview. The interviewer used a standardized interview with a set of questions asked to all respondents. The questions were asked in a similar order and format to make a form of comparison possible between answers. However, the interviewer pursued and probed for novel, relevant information, through additional questions. The interviewer frequently had to formulate impromptu questions in order to follow up leads that emerged during the interview or to allow both himself and the person being interviewed the flexibility to probe for details or to discuss issues.

### **Observation checklist**

An observation checklist was used to collect data on operating systems, processes and structures. Three days were spent on observation at the antiretroviral clinic. The observation involved assessment of the quality of operating structures and systems and processes used in service provision, clinic and toilet cleanliness, space, overcrowding level, patients' waiting areas language barriers and relationships between patients and providers.

### **3.4 Problems experienced with data collection**

One of the major challenges with data collection was the staggering number of patients who could not be contacted because of lost files, incorrect contact details in the files or no contact

details, mobile phone numbers no longer working or poor mobile phone signal coverage. Many of the files available had missing information, especially information that was crucial to patient's follow-up such as last date of clinic attendance and next appointment date, age, gender or marital status. Some files had only patient's name and the area where a patient came from without residential address. By implication, unless the patient had a phone, there was no other way of being contacted. Mobile phone numbers no longer working or poor mobile phone signal coverage was an addition bottleneck.

At the time of study the clinic was largely reliant on paper files to keep patient details and records. Duplicate files were made, but often information such as contact details and addresses were not recorded. A total of 638 defaulters were identified, 205 were contactable, and only 95 patients were reached.

The data collection may also have been limited by the fact that all interviews with antiretroviral therapy users who missed their last drug pick-ups and scheduled clinic visits were done telephonically and the location of the patient during the interview may have precluded them from speaking freely.

### **3.5 Data analysis**

The interviews were transcribed from the recording. The transcriptions, together with the field notes and observation were analyzed for common themes. The common themes were placed into units of codes (Burnard, 1991). The latter were further analyzed for content, thereafter reported.

The outcomes of the document review and interviews were triangulated using data and methods triangulation. According to Lincoln & Guba (1985) triangulation is a "mode of improving the probability that the findings and interpretations will be found credible". The technique of data triangulation (Polit & Hungler, 1993) was used, whereby all the key participants were interviewed.

Method triangulation (Denzin, 1989) is the process whereby different methods are employed such as observation and interviews. Lincoln & Guba (1986) quote Diesing, saying, that, "the validity of one piece of evidence can be assessed by comparing it with other kinds of evidence

on the same point". This is supported by statement that "credibility can be enhanced if it can be corroborated by different and other sources" (Wellman & Kruger 2001).

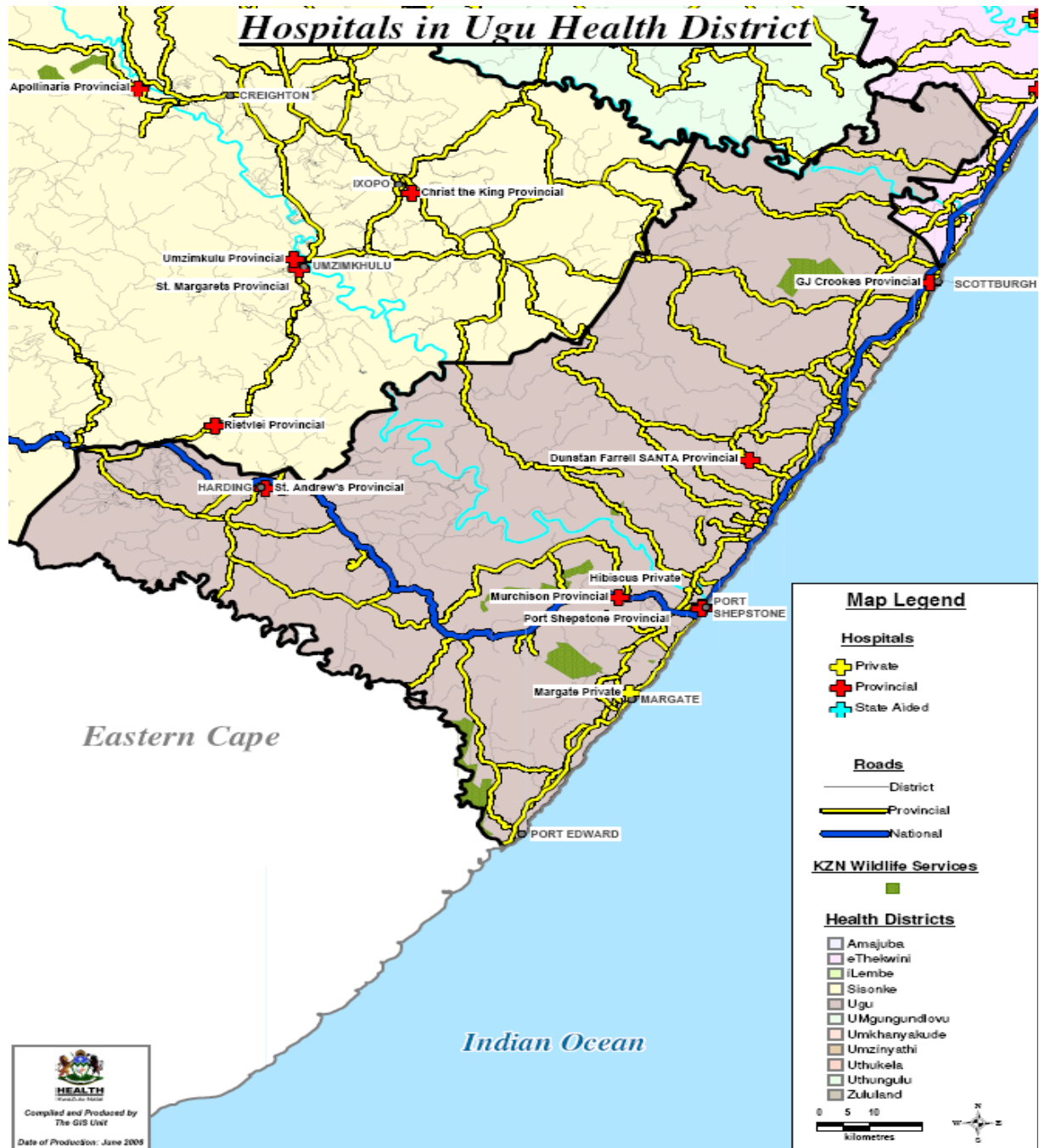
This was achieved by interviewing different groups namely, the healthcare workers, patients, care givers, family members, and treatment supporters. This was done in order to corroborate the information provided by the different sources.

### **3.6 Description of the study site**

The study was carried out at the Murchison Hospital situated in the small town of Murchison in Ugu District, Kwa Zulu Natal Province. The hospital provides free antiretroviral therapy services, and also serves as an initiation and maintenance site for patients who are on antiretroviral therapy. According to the Health System Trust report (2006), Ugu District Municipality (DC21) is one of 11 districts in Kwa-Zulu Natal Province; it is located in the South Eastern corner of the province with a population of slightly over 700,000. The proportion of pregnant women who were HIV-tested at the antenatal clinic has continued to decrease steadily over the past 4 years from 86.2% in 2003/2004 to 58% in 2006/2007, an indication that prevention efforts are not working and need to be intensified. TB data showed an estimated of 33.8% cure rate in 2005 and a 46% conversion rate in 2006.

Although KZN has adopted a comprehensive approach to managing HIV and AIDS, TB and STIs antenatal survey data indicated a significantly higher HIV prevalence rate. When compared to the rest of the country it was estimated at 39.1%, while the TB cure and conversion rates were estimated at 45.2% and 48.4% % respectively, well below the national average of 65% and 70% respectively. Also, the province has been reported as having the highest sexually transmitted infections (STI) incidence in the country consistently for the past 4 years.

Ugu map



## Chapter 4: Results and discussion

### 4.1: Results

#### 4.1.1: Results of interviews of patients, family members, care givers and treatment supporters

The table below represents a summary of gender distribution results of semi-structured interviews conducted with patients, care givers and family members in order to understand key factors associated with patients' failure to pick up drugs and keep scheduled clinic visits.

**Table 1: The following is the figure showing distribution of default reasons by gender**

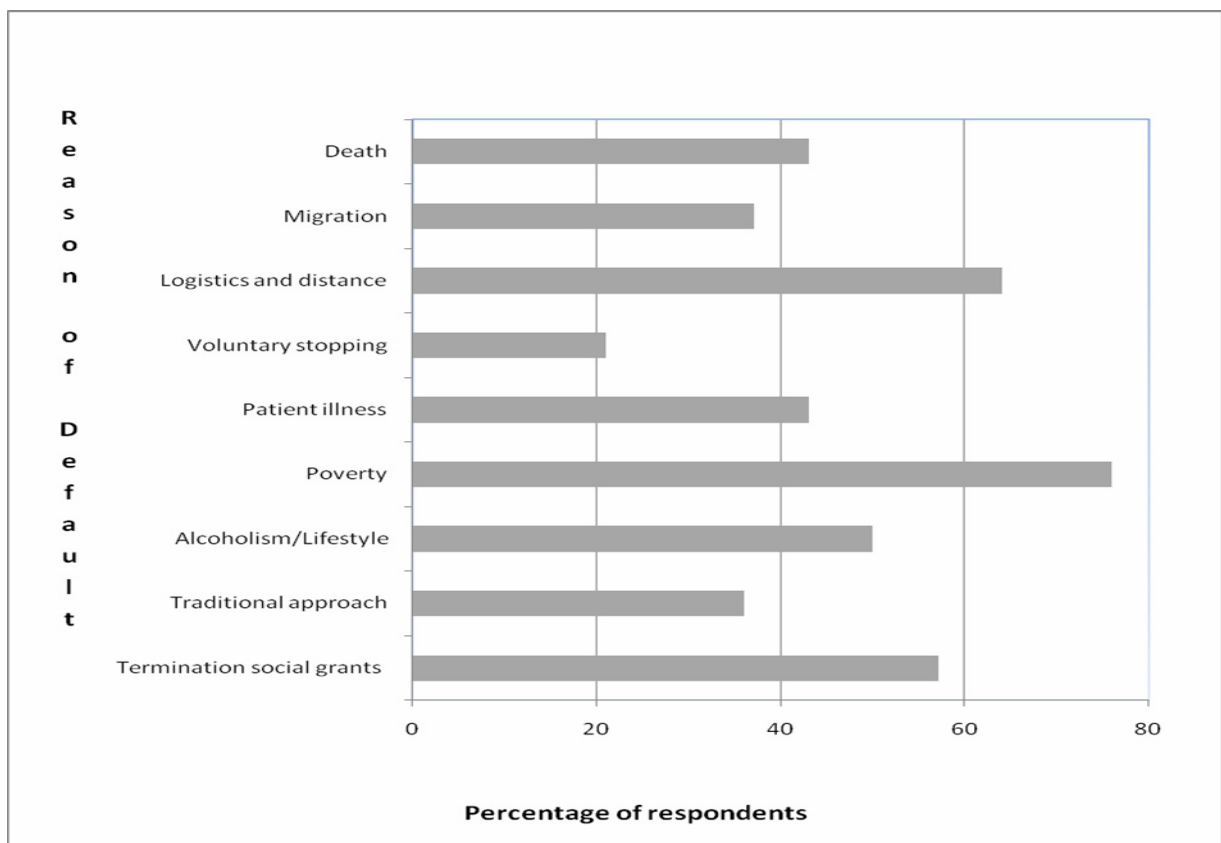
Factors	Numbers of respondents	Percentage	% of Female	% of Male
Death	47	49.5	60	40
Preference of Traditional medication	7	7.4	29	71
Side effects	3	3.2	67	33
Costs and logistics	14	15	64	36
Migration/travel	4	4.2	50	50
Private practice	2	2.1	0	100
Religious beliefs	1	1.1	100	0
Imprisonment	2	2.1	0	100
Hospitalization	3	3.2	67	33
Interpersonal relationships	1	1.1	100	0
Serious illness	4	4.2	80	20
Work schedules and commitments	7	7.4	83	17

In summary the main reasons that caused patients to fail to pick up drugs and keep appointments and that were frequently mentioned by patients, care givers, family members and patients' treatment supporters were patients' deaths (49.5%), costs and logistics (15%), patient bed ridden (4.2%), use of traditional medication (7.4%), travel and migration (4.2 %), side effects (3.2%), visiting private practice (2.11%), hospitalization (3.2%), work commitment and schedules (7.4%), interpersonal relationships (1.1%), and religious beliefs (1.1%).

#### 4.1.2: Results of interviews with health care workers

The figure below represents a summary of results of semi-structured interviews conducted with healthcare workers in order to understand key factors associated with patients' failure to pick up drugs and keep scheduled clinic appointments.

**Graph 2: Reasons for patients' defaulting frequently mentioned by healthcare workers.**

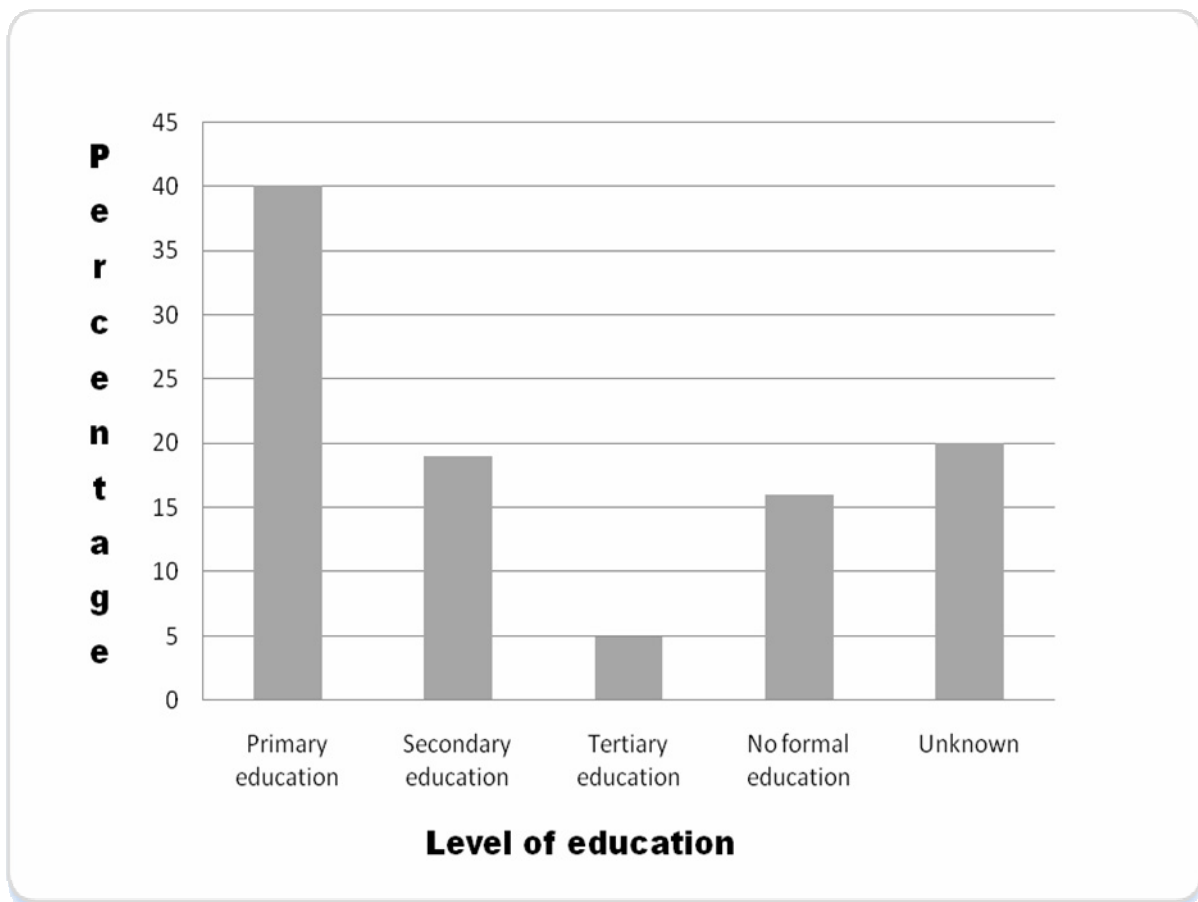


In summary the main reasons that caused patients to default as frequently mentioned by healthcare workers were termination of disability grants (57.7%), traditional medicine use (36%), alcoholism and life style (50%), patient illness (43%), poverty and logistics (76%), patients voluntary stopping (21%), distance (64.3%), migration (57.1%) and death (43%).

#### 4.1.3: Distribution of defaulters by education level

Of the patients who missed schedules drug pick-ups and clinic visit and who participated in this study, (almost 40%) had completed primary education and just over 19% secondary education, 5% tertiary education, 16% had no formal education and the educational level of 20% was unknown.

**Graph 1: The following figure represents distribution of the defaulters by level of education**



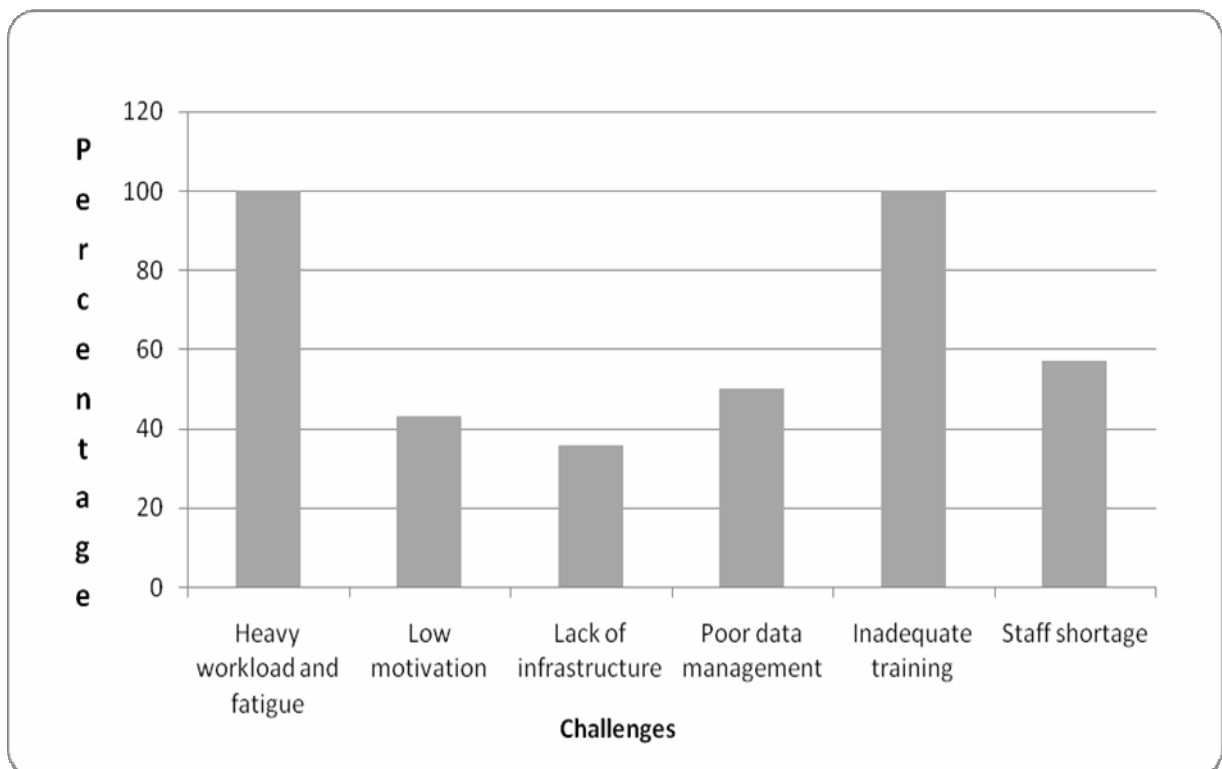
#### 4.1.4: Gender distribution of defaulters by Occupation

Of the 59 females who missed scheduled drug pick-ups and clinic visits and who were telephonically interviewed, the largest groups (35%) were not employed, followed by 31% who worked on farms, did domestic work, or ran informal businesses. Among the 35 males interviewed, most ran informal businesses, or they were labourers on sugarcane farms or forestry plantations.

#### 4.1.5: Challenges faced by healthcare workers

All the categories of staff complained of increased workloads, inadequate training to manage patients, staff shortages and fatigue. In addition counsellors complained of poor wages, delay in the paying of wages and lack of recognition, which resulted in low motivation.

**Graph 3: Challenges faced by healthcare workers.**





#### **4.1.6: Categories of healthcare workers at the antiretroviral clinic**

The figure below represents categories of healthcare workers who were involved in service provision at the antiretroviral clinic at the time of the study

**Table 2: Categories of healthcare workers at the antiretroviral clinic**

<b>Cadre of staff</b>	<b>Total</b>	<b>Qualification</b>
Counsellors	6	Matric education and HIV counselling education
ARV dedicated doctors	2	University graduate
Nurses	5	Diploma and university education
Data clerks	3	Matric and basic computer education

#### **4.2 Observation findings**

The information below was obtained mainly from observation and notes taken by the data collector who visited the facility.

##### **4.2.1. Structural issues**

The clinic consisted of three different structures (park homes) in 2008 and was largely separate from the rest of the hospital. The clinic was clean, equipped with running water and toilets, enough seats for patients and provided enough space to ensure the confidentiality of patients. In each facility all information, communication and education materials was well placed in the form of posters, mainly explaining the importance of adherence, healthy living and nutrition, both written in English and the local language, Isizulu.

#### **4.2.2. Service provision**

The facility operates from Monday to Friday. Patients' eligibility criteria to start antiretroviral therapy are the same as in the South African national guidelines. During initiation, all the patients are encouraged to come with treatment supporters. But the lack of a supporter does not disqualify anyone from anti-retroviral therapy initiation. Results from three days of observation showed that patients spent an average of less than three hours at the facility for drug pick-ups and clinic visit schedules. This varied depending on the time a patient showed up. This was evident from the patients' response where no patient interviewed highlighted long queues as a reason for default. Patients who came early in the morning spent less time. Most of the patients arrived between 9.00 am and 11.30am. From 13.30pm, most, if not all of the clinics were empty. Patient-provider relationship was warm. Language barrier was not a problem because most of the healthcare workers were from the same ethnic group as the patients, which is Zulu.

To reduce time spent by patients at the clinic, all patients were grouped into cohorts of 75-100 patients to be seen per day to make it easier to identify patients coming on a particular date. All patients and staff were trained on how the cohort system works; the cohort date was marked in the patient treatment calendar and file. Through the cohort system all patient files and drugs were pre-packed and delivered to the ARV clinic one day prior to patient appointment day, therefore patients received their pharmacy refill at the clinic and not hospital pharmacy, except for those patients who needed extra medication for other opportunist infections. All the healthcare workers were trained on Standard Operating Procedures (SOPs) and the level of job satisfaction looked good.

#### **4.3 Discussion**

This is a report summary describing the findings of a study that explored key factors associated with default to scheduled drug pick-ups and clinic visits. The purpose is to help design interventions.

#### **4.3.1. Death**

Death was identified as the main cause of non-attendance to scheduled drug pick-ups and clinic visits. Death was cited by 49.5% of respondents which included caregivers, treatment-buddies, patients' relatives as well as 49.5% of healthcare workers. This is in line with a study conducted by Variava (2007) on the pattern of default at Klerksdorp Tshepong Hospital Complex, in the North West Province of South Africa, where it was found that 42% of defaulters had died, the death occurred before they were due to return to the clinic and 87% of deaths occurred within six months of starting ART.

In this study it was difficult to establish whether the death occurred before they were due to return to the clinic or after. Efforts to clarify the patients' date of death from the vital death register available at the Department of Home Affairs were fruitless. The participation of the Department of Home Affairs was crucial because, quite often, if a person dies, family members do not inform healthcare facilities but always do notify the Department of Home Affairs to be issued a death certificate to enable them to bury the loved one.

#### **4.3.2. Logistics and costs**

Logistics and transport costs were identified as a second main cause of patients defaulting scheduled drug pick-ups and clinic visits. 15 % of patients, care-givers or family members interviewed cited the lack of money to pay for transport as a key challenge. Some complained that the antiretroviral clinic was too far away and not always easy to access. Erratic public transport schedules also caused them not to access the clinic. It was also evident in the study where only 36% of males cited cost as a reason for default compared to 64% of females.

#### **4.3.3. Serious illness**

This study identified serious illness in patients as one the causes for default and failure to attend the clinic. The fact that some patients were bed-ridden or too ill to come to the facility on the appointment dates led to default. Lack of ambulances or mobile clinics to reach patients in their neighborhoods and the fact that many households do not own cars are additional reasons. Requiring bed-ridden patients to travel long distances to fetch their antiretroviral drugs was

identified as a cause of non-attendance to follow-ups in the Eastern Cape, South Africa (Worley S, B. 2007). In the same Eastern Cape study it was found that myths, competition with traditional medicine, lack of disclosure and home-based support, as well as fear of losing social grants leads to default.

#### **4.3.4. Preference of traditional medicine**

Lack of involvement of all health actors has been cited in different studies as one of the challenges to a successful HIV treatment programmes (Eholie et al. 2006). This study identified that the preference of the traditional approach or traditional healer contributed to non-attendance by 7.4%. The most significant difference to other studies is the gender dimension of preference toward the traditional approach; out of the seven respondents who defaulted the appointment date because of visiting traditional health practitioners or using traditional remedies, five were males and two were females, showing that more males preferred the traditional approach than their female counterparts. The reason for the preference was that anti-retroviral therapy is a not a cure, and therefore they were still looking for somewhere where they can be cured. This is in line with the African concept of no disease without a cure (Ojikutu et al. 2007). Ashforth (2005) reports that in South Africa alone there are reportedly over 350,000 traditional health practitioners who serve 60-80% of the population in their communities, and are fully integrated into the societies that are hardest hit by the HIV/AIDS epidemic, making it difficult for western therapy to succeed.

#### **4.3.5. Religious beliefs**

This study identified that religious beliefs influenced patients to terminate the treatment. 1.1% of patients who defaulted cited religious belief as the reason and all were female patients. They argued that antiretroviral therapy is not a cure; and that it is only Jesus and God who can cure their conditions. Religious practices and spiritual beliefs may improve health and generally benefit patients through religious networks. Treatment programmes have achieved high treatment outcomes by using religious organizations to provide adherence education and HIV support programmes (Karpf, 2007). However, religious beliefs may also play a negative role in treatment programmes due to the stigma attached to HIV disease, particularly in geographical

areas and in population subgroups where religious practices are strong (Karpf, 2007, Sharon, 2006).

#### **4.3.6. Daily schedules and work commitments**

Combined with the extensive time required for each visit, ART requires a substantial amount of time spent away from other responsibilities such as employment. Daily work schedules or commitments were among the identified factors which constrained patients from keeping drug pick-up and clinic visit appointments. Truckers were the main group affected by daily work schedules and work commitments. Some highlighted that travelling long distances in different provinces in South Africa and across Southern African countries made them to miss appointment dates. Because of the gender dimension of the work category, only males were found to face such challenges.

The United Nations Development Program (2006) reported that, in the unforgiving economic environment of South Africa, the interruption of work is not taken lightly, also with 34% of the population living on less than \$2 a day, the most immediate concern for patients who must miss work is the loss of wages. Individuals with employment who are still struggling to afford the basic necessities may have to choose between attending a clinic and paying rent or feeding their children. Faced with such a choice, there is little doubt that securing the fundamentals will take precedence over drug pick-up and appointments at the clinic. Natrass (2006) highlighted that with unemployment rates estimated between 28-42%, most South Africans hesitate to do anything that may cost them their jobs. Consistently missing days of work to attend appointments or refill prescriptions will doubtlessly strain an employer-employee relationship.

Despite the good intent of national legislation, discrimination against HIV/AIDS victims is still a reality in South Africa, causing employees to conceal their HIV status. This causes failure to follow the treatment plan (Whiteside & Sunter, 2000). In Botswana, it was reported that 32% of patients feared that they could lose their jobs if they divulged their status at work (Weiser et al. 2003). If ART patients fear discrimination by their employer and do not disclose their status, it makes it difficult for them to get time off their work to go to the clinic, therefore negatively compromising drug pick-ups and clinic visit schedules.

#### **4.3.7. Drug side effects**

Side effects were cited by 3.2% of the respondents as the reason that led to failure to pick up drugs and attend scheduled clinic visits. This was cited by members of population groups who worked in heavy duty industry and truck drivers. The mentioned side effects were dizziness, nausea, exhaustion and headache, and the respondents showed ignorance of alternative measures. The most common adverse drug reactions include headaches, nausea, rash and peripheral neuropathy; and most seriously, lactic acidosis, hepatomegaly, central nervous effects, and intracranial hemorrhage (Max & Sherer, 2000). For those patients not well-informed or distrusting of their care provider, adverse drug reactions and the burden of continued adherence may outweigh the threat of a long-term disease and lead to the abandonment of ART (Weiser et al 2003). Also, even if patients remain faithful to their treatment, specific side effects may convince them to stray from their schedules.

A similar survey in Botswana reported that side effects were the fifth most mentioned reason for missing doses (Weiser et al. 2003). A more in-depth examination of side effects of ART on patients in developed nations established that patient-reported symptoms and medication side effects were significantly associated with poor adherence (Ammassari et al. 2001). Ammassari et al. (2001) also found that when experiencing such negative reactions, patients would self-prescribe 'drug holidays'. Even though the severity of many side effects diminishes over time, without proper education and support, patients may discontinue their life-prolonging treatment in favour of more immediate relief. Only three standardized regimens are currently widely available in South Africa, leaving fewer alternatives for any patients suffering from side effects of their medications (Stewart and Loveday 2005).

#### **4.3.8. Interpersonal relationships**

Provider-Patient's interpersonal relationships led to non-attendance at drug pick-ups and scheduled clinic visits by 1.1% of respondents. A study by Nachega et al. (2004) highlights that the nature of the relationship between patients and healthcare workers can impact negatively or positively on how patients stick to agreed treatment plans. A different study in Tanzania showed that patients would like to visit the facility if they believe that they will be treated humanely and

in a friendly manner. Treating patients negatively will affect patient trust in service-providers and ultimately cause patients to drop the treatment (Hardon et al., 2006).

#### **4.3.9. Migration and travel**

In this study migration and travel led to 4.2% of the patients failing to attend the clinic. This study identified that migrant patients often went back to their homes when they felt they needed care and support from family members or relatives, and this resulted in termination of treatment. Some patients moved because they preferred to die closer to their families and homes. Children were affected by the migration as well, especially if the parents happened to die. Most of them ended up in foster care far away from their original places of residence and treatment. In some cases foster parents were unaware of the child's HIV status, which affected children's continuation of antiretroviral therapy.

According to the International Organization for Migration 2004 report, the South African economy is unique in the degree to which it depends on migrant labor. Due to South Africa's wealth of mineral resources and multiple seaports that serve a large sector of sub-Saharan Africa, mining and trucking are especially prevalent examples of occupations. Migrant employees, primarily men, often move between homes in rural communities to the urban centres of industry for work. The many necessary appointments for treatment and the demanding drug schedules for ART impair a patient's ability to adhere to treatment schedules. Additionally, the high unemployment rates force people to travel in search of work.

Nachege et al. (2004) report that in a big township outside Johannesburg the main reason reported for missing antiretroviral doses was being away from home. Not surprising then that in a place like Soweto, with a high unemployment rate of 41% and where patients must be away from home to look for jobs drug pick-ups and clinical appointment default was high too. He concluded that this unstable life makes the strict schedules of ART difficult to maintain.

#### **4.3.10. Termination of Disability Grants**

According to the guidelines set by the South African Department of Health, only patients with a CD4 count <200cells/ $\mu$ L or a WHO Stage IV AIDS-defining illness are eligible for ART

(National Department of Health 2004). These are the same requirements for the disability grant provided by the South African Welfare Department meant to aid those “too ill or incapacitated to work” (Nattrass 2006). With these guidelines, an estimated 340,000 HIV-positive South Africans qualify for the grant (Nattrass 2006). At a maximum value of R740 (\$115) a month, comparable to a rural farm worker’s wage, this is a substantial source of income for people who qualify (Bureau of Democracy Human Rights and Labor 2005).

With these strict criteria for the disability grant, a serious dilemma arises with regard to the effectiveness of ART. This life-saving treatment has previously been assumed an unambiguous benefit to all those affected by HIV/AIDS because it qualifies them to receive the grant. However, once a patient begins responding to ART, their CD4 count rises and any opportunistic diseases subside, thereby disqualifying them from receiving the disability grant.

With unemployment rates estimated between 28-42%, the grant money is absolutely vital even to those capable of working, because they are usually unable to find a job (Nattrass 2006). Given the desperate socio-economic situation of the vast majority of HIV-positive people in developing countries, individuals in this position may be forced to trade their health for income. Nattrass (2006) pointed out that it is possible that a small but significant portion may opt to discontinue HAART so as to become AIDS-sick again in order to qualify once more for the disability grant and then once it is reinstated, go back onto treatment. He also reported that some people became angry when they are tested HIV negative, because they were hoping to get the grant. One woman is reported to have said, “I love this HIV because of the grant”. This is a glaring example of the appalling effect of flawed public policy and an indication that poverty can influence people’s health choices. This vividly demonstrates the complexity and severity of matters surrounding ART roll-out. This explains why 57.1 % of the healthcare worker respondents in this study cited the termination of the disability grant as a reason for patient default.

#### **4.3.11. Patients’ imprisonment**

Patients’ imprisonment was another factor which caused interruptions in the treatment plan. This affected more males than females, because most offenders or inmates in South African prisons are male. Even though the imprisonment of a patient contributed to only 1.1% of failure to pick up drugs and attend clinics, there is need for urgent attention.



#### **4.3.12. Healthcare workers' comments**

Even though healthcare workers cited fatigue, heavy work load, inadequate training, poor infrastructure and low motivation as factors affecting the quality of service provision; patients largely expressed appreciation of the quality of care provided. However, one respondent complained that she terminated her treatment because she was mistreated by one of the providers.

## **Chapter 5: Conclusion and recommendations**

### **5.1. Conclusion**

This study was undertaken with the purpose of affording policy makers and personnel working in the area of HIV and AIDS treatment, an insight into the nature of the key factors that lead patients on antiretroviral therapy to fail to pick up drugs and attend the scheduled clinic visits. The results derived from the study indicate clearly that death, logistics and associated costs were the main factors. Other factors were migration, interpersonal relations, preference for traditional health practice and the termination of disability grants.

Migration of children on ART to join foster care where the care-givers were unaware of the child's status also resulted in disruption of treatment. Another group affected was patients on ART prior to detention or being sentenced. The transition of patients from civilian life to prison settings needs attention. Most of the identified challenges and factors have a gender dimension. Therefore, for any solution to the challenges to be effective, the gender dimension needs to be taken into consideration.

Major challenges that face healthcare workers include inadequate training, low motivation, and burn-out, fatigue and poor data management. These directly impact on the quality of health service delivery. Although not all healthcare workers face the same challenges, the study was informative on the nature of specific and targeted intervention.

### **5.2. Recommendations**

The recommendations are made to improve drug picks-up and clinic visit schedules. These recommendations are based on the inputs provided by the respondents.

#### **5.2.1 Improvement of regularity of schedules drug pick-ups and clinic visit**

It is recommended that the following be done to improve adherence to treatment plan:

- Effective interventions to improve adherence to scheduled drug pick-ups and clinic visits need to be aligned with an overarching national multi-sectorial approach (NSP, 2007).

Government could play a crucial role by establishing and implementing effective and appropriate targeted policies and legislations to address these challenges.

- Targeted poverty reduction programmes especially for people living with HIV/AIDS and women in particular should be put in place.
- There is a need for new policies and legislation to ensure that inmates and prisoners can access quality care similar to the care in public health facilities.
- There is a need for policy and legislation which allows and encourages greater involvement and integration of all health actors including traditional healers to meet the diverse needs of patients.
- Mobile services should be made available to reach patients in their homes to support especially those who are ill and poor.
- Counselling and education with a gender-target dimension and culture-sensitive orientation is also needed and crucial.
- Capacity building oriented interventions targeting all players involved in comprehensive HIV prevention, care, treatment and support is urgently required.
- There is a need for the decentralization of HIV treatment programmes to make ARV therapy available at more convenient places and at all local clinics.

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