Exploring the knowledge, perceptions and attitudes of the side effects of antiretroviral drugs amongst staff and HIV patients at public healthcare institutions in the Frances Baard District of the Northern Cape South Africa, 2012

by

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Declaration

By submitting this research proposal electronically, I declare that the entirety of the work contained therein is my own original work, that I am the sole author thereof (save to the extent that it is otherwise explicitly stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously, in its entirety or in part, submitted it for obtaining any qualification.

J.Herbert March 2013

ABSTRACT

"What do HIV patients and staff members think about when they hear the word 'Side effect'? Skin rashes, dizziness, nightmares, painful feet are some of the common side effects that patients on antiretroviral drugs (ARVs) experience once treatment is initiated on ARVs but it is said that these side effects are temporary and transient. Are patients and staff able to understand the concept of a side effect if they can or cannot understand the manifestation of this condition called HIV? Does a patient perceive a side effect as a good or bad thing and will the side effects change as our patients continue on the ARVs and become older? As the HIV programs progress over time should we not be educating our patients on the longer term side effects such as cardio toxicity, bone disorders and nephrotoxicity or are we of the opinion that we should not tell our patients about the long-term side effects in case it scares them and disrupts treatment? " These are some of the questions that prompted this research study. The researcher explored the practices at two public healthcare facilities in order to understand the knowledge, perception and attitudes of the side effects of ARVs amongst staff and HIV patients. A total of sixty two (62) HIV patients and twenty five (25) staff members participated in this research study and the researcher used both the quantitative and qualitative research methods to execute the study. The objectives of the study were:

- To assess the knowledge, perception and attitude of the side effects of ARVs amongst staff and HIV patients at KHC and GDH
- To identify current practices at KHC and GDH that support the understanding and knowledge of the side effects of ARVs amongst staff and HIV patients
- To identify the gaps between the knowledge and existing practises amongst staff and HIV patients at KHC and GDH
- To provide recommendations to improve the perception, attitude and knowledge about the side effects of ARVs amongst staff and HIV patients

It was found that the patients and staff are knowledgeable about the common side effects of ARVs but patients have the need to be informed about as many side effects as possible in order for them to understand their condition. It is further recommended that support groups, counselling services and health talks be provided at facilities to encourage the understanding of the side effects of ARVs amongst all patients and staff members.

OPSOMMING

"Waaroor dink MIV-pasiënte en personeellede wanneer hulle die word “newe-effekte " hoor? Veluitslag, duiseligheid, nagmerries, pynlike voete is 'n paar van die algemene newe-effekte wat pasiënte op anti-retrovirale middels (ARMs) ervaar nadat hulle behandeling begin op ARMs en dit word gesê dat hierdie newe-effekte tydelik en verbygaande is. Is pasiënte en personeel in staat om die konsep van 'n newe-effekte verstaan as hulle dalk nie die manifestasie van MIV kan verstaan nie? Dink 'n pasiënt dat newe-effekte ‘n goeie of n slegte eienskap is en dink hulle die newe-effekte sal verander soos pasiënte op die ARMs verouer? Moet ons nie ons pasiënte en personeellede oplei oor die langtermyn newe-effekte soos kardio toksisiteit, been-afwykings en nefrotoksisiteit of is u van mening dat ons dit liewers moet vermy as om patiente af te skrik en hulle behandeling te ontwrig? Hierdie is 'n paar van die vrae wat deur die navorser gevra word in hierdie navorsingstudie.

Die navorser ondersoekdiepraktykeby twee openbaregesondheidsorgfasiliteite om ten eindediekennis,persepsies en houdingsvan dienewe-effekte vanARMsinpersoneel enMIV-pasiëntete verstaan. 'n Totaalvan sestig(62) MIV-pasiënte envyf en twintig(25)personeellede het in hierdienavorsingstudiedeelgeneemendie navorser het beide die kwantitatiewe enkwalitatiewe navorsingsmetodesgebruikomdiestudieuit te voer.

Diedoelwittevan die studiewas om:

• diekennis,persepsie enhoudingvan dienewe-effekte vanARMste assesseeronderpersonneel en pasiëntebyKHCenGDH

• huidigepraktykebyKHCenGDHwat ondersteuning bied virdiebegrip en kennisvan dienewe-effekte vanARMsonder personeel enMIV-pasiëntete identifiseer

• diegapingstussen diekennis enbestaande praktykeonder personeel enMIV-pasiëntete identifiseerbyKHCenGDH

• aanbevelingste voorsienomdie persepsie, houding enkennisoor dienewe-effekte vanARMsonder personeel enMIV-pasiëntete verbeter

Daar is bevind dat die pasiënte en personeel goed ingelig is oor die algemene newe-effekte van ARMS, maar pasiënte wil oor die meeste newe-effekte ingelig word om ten einde hul toestande te verstaan. Dit word verder aanbeveel dat ondersteuning groepe, beradingsdienste en gesondheid gesprekke voorsien moet word om die begrip van die newe-effekte van ARMS onder alle pasiënte en personeel aan te moedig.

DEDICATION

This study is dedicated to my parents who taught me the values of education, perseverance and commitment.

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May God abundantly bless you all.

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ABBREVIATIONS / ACRONYMS

AE	Adverse event
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARVs	Antiretroviral drugs
AZT	Zidovudine
CCMT	Comprehensive Care Management and Treatment
DoH	Department of Health
EFV	Efavirenz
FTC	Emtricitabine
GDH	Galeshewe Day Hospital
HCW	Health Care workers
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Immune Virus
KHC	Kimberley Hospital Complex
MCC	Medicine Control Council
MDGS	Millenium Development Goals
M&E	Monitoring and Evaluation
NADEMC	National Adverse Event Monitoring Centre
NC	Northern Cape
NCDoH	Northern Cape Department of Health
NDoH	National Department of Health
NIMART	Nurse initiated ART
NVP	Nevirapine
OIs	Opportunistic Infections
PMTCT	Prevention of Mother to Child Transmission
PSP	Provincial Strategic Plan
StatsSA	Statistics South Africa
TB	Tuberculosis
TB/HIV	Tuberculosis and HIV co-infection
TDF	Tenofovir
UNAIDS	Joint United Nations Programme on HIV/AIDS
VL	Viral load
WHO	World Health Organisation
3TC	Lamivudine
d4T	Stavudine

GLOSSARY OF KEY TERMS

CD4	CD4 cell or T4 'helper' lymphocyte
Incidence	The number of new HIV infections in a population over a specific time period.
Opportunistic infections	These are infections that are caused by HIV when the immune system is weak. Examples of opportunistic infections include TB, pneumocystic pneumonia, Cryptococcal meningitis and oesophageal candidiasis
Peer education	This refers to the education of persons by persons of the same age, rank, social status, occupation, class or category (peers).
Prevalence	The number of HIV infections as a proportion of a population at a specific time period.
Viral load	This is a measurement of the HI-virus in the blood

CHAPTER 1 INTRODUCTION

1.1 Introduction

"We don't tell our patients the side effects of ARVs otherwise they will not take their medicines" (GDH, 2012).This was the ephemeral comment that initiated this research study and it is one of the few studies that explores this topic. It provides us with the baseline knowledge and insight into the knowledge, perception and attitudes of staff and HIV patients towards the side effects of ARVs.

1.2 Background

HIV and AIDS have undoubtedly been recognized as one of the greatest challenges of the 21st century. Africa, a global continent of 53 countries (www.infoplease.com*)* has not escaped the doom and devastation of the HIV and AIDS epidemic, with a reported occurrence of 1.837 million new HIV infections in adults and children in 2011 and a loss of 1,223 million deaths between 2005 and 2011 (UNAIDS, 2011).At the southern tip of the continent of Africa lies South Africa, a country with a population of 50.59 million persons (Stats. SA, 2011 midyear population estimate) and a country with a rich diversity and plethora in science, history, politics, geography,cultures, languages, economies and its people. South Africa is known to have the highest burden of people living with HIV and AIDS in the world and it has been reported that 5.6 million persons are living with HIV ,with 5.1 million being adults above the age of 15 years of which 2.9 million of adults are women (UNAIDS,2011).The prevalence of HIV amongst the 15 – 49 year old age group in the general population in South Africa is 17.30% (UNAIDS,2011) .

South Africa is divided into nine provinces of which the Northern Cape is the largest province with a land surface area equating to 30.5% of the total area of South Africa (Southafrica.info, 2011) but with the smallest population in the country of 1, 906,731 million persons (StatsSA, midyear population estimates, 2011).The key economic sectors of the province are mining, agriculture, forestry and tourism but poverty and unemployment are some of the challenges that contribute to the proliferation of the HIV epidemic as many households live below the poverty line of R800 per month (DoHPSP,2011).The HIV prevalence in the general population (15-49 years of age) in the Northern Cape for 201l is 9.23% which is the second lowest in South Africa but the province continues to face

challenges such as the highest syphilis prevalence rate in the country of 3.8% in 2011 (NDoH,2012) and the third highest TB burden equating to a reported TB incidence of 358 per 10 000 persons in 2010 (DoH PSP,2011). The NDOH Antenatal survey 2012 reported an Antenatal HIV prevalence rate of 17% for the Northern Cape which is the lowest in the country but evidently it evokes questions as the highest HIV prevalence rate amongst pregnant women in the survey is the 30-34 year old population (NDoH ANC survey, 2012).

It is therefore of utmost importance that the population of the Northern Cape remains healthy because of its small population size and the future economic growth of the province.
The province is subdivided into five districts of which Kimberley, the capital city of the Northern Cape is situated in the Frances Baard District. Frances Baard has the largest population of 375 167 persons and the second highest HIV prevalence of 18.4% amongst pregnant women(NDoH Antenatal survey, 2012).The John Taole Gaetsewe District has the highest HIV prevalence of 27.5% amongst pregnant women (PSP, 2012).Females have a life expectancy of 57.4 years whereas males have a lower life expectancy of 54.1 years
(StatsSA,midyear population estimates, 2011).The Northern Cape has a projected estimate HIV incidence of 0.7% (or 3177 new HIV infections per annum) which accounts for 0.9% of South Africa's new infections (PSP,2012). HIV is the seventh highest cause of death in the Northern Cape amongst all age groups with TB , influenza and pneumonia reported as the main causes of death(StatsSA, 2008).

The Comprehensive, Care, Management and Treatment (CCMT) program is located in the National and Provincial departments of Health to strategically address the Millenium development goals (MDGS) of the HIV epidemic. The provincial CCMT program aligns its vision and objectives to that of the NDOH to support the activities in curtailing the HIV epidemic and it focuses on key priority areas such as HIV prevention, treatment, care and support; research monitoring and surveillance; access to justice and the protection of human rights. The CCMT program for adults in the Frances Baard district was piloted at the
Kimberley Hospital Complex (KHC) in 2004 and the Galeshewe Day Hospital (GDH) in 2008 and over the past nine years the program has expanded to the provision of ART (anti-retroviral therapy) at every health facility in the province.Over the years newer scientific discoveries and drug developments induced changes in the ART program and this necessitated the revision of policies which resulted in providing more access to health services and the provision of ART at an earlier stage to clients. With the rollout of ARVs

more staff were trained in the management of HIV and AIDS; nursing sisters were trained to perform HCT and to initiate new patients on NIMART. HCT, PMTCT and male circumcision was strategically prioritised in all facilities to reduce the provincial HIV prevalence and incidence. As at September 2012 there were 27588 persons (adults and children) on the provincial ART program (DoH, 2012). The Frances Baard district has a total number of 12780 persons (adults and children) on the ART program (DOH, 2012).

Antiretroviral therapy involves the provision of antiretroviral drugs (ARVs) to people living with HIV and AIDS to improve the quality of life and decrease patient mortality and morbidity. ARVs are provided to patients at public health facilities free of charge according to a specific process and criteria. The patient will undergo the necessary clinical consultation and readiness program before initiation on ARVs. All HIV positive patients who test positive with a CD4 count of <350 cell/mm^3, pregnant mothers, TB/HIV co-infected patients, CPR positive infants and any other category of eligible patients are initiated on antiretroviral treatment as per the revised national policy of August 2011(NDOH,2011).Once the patient has completed the readiness assessment and the clinician is satisfied, the patient will be initiated on a standardised regimen and be dispensed one month's supply of ARVs with a follow-up date to return to the clinic within 28 days. It is required of professional healthcare providers such as the Pharmacist, post basic Pharmacist Assistant or Nurse to dispense the ARVs and counsel the patient explaining the treatment, dosaging instructions, possible drug interactions and the side effects.

Patients are routinely initiated on treatment regimens known as regimen 1 or regimen 2.

Regimen 1 involves the initiation of the adult patient on Tenofovir (TDF), Lamivudine (3TC) and Efavirenz (EFV) or on Stavudine (D4t), 3TC and EFV. A pregnant mother who is HIV positive would routinely be initiated on Nevirapine (NVP), 3TC and TDF. In pregnancy the treatment regimen is changed because of the toxicities of the ARVs (namely EFV) and the potential side effects of the drug on the foetus during gestation as well as during lactation.

A patient is expected to continue using the prescribed ARVs for his/her lifetime unless he/she experiences any severe side effect or an adverse reaction to the ARV drugs. It is expected of the patient to adhere to the treatment dosaging schedule as it was provided by the health provider. An adherence level of 95 % is acceptable but an adherence level above 95% is considered "excellent" as it is indicative of "sound" adherence practices. The routine quantitative assessment of the viral load and CD4 count of the patient often serves to verify whether a patient is taking his/her ARVs, as a high CD4 count and a low or undetectable viral load is the overall objective in managing the patients' condition. Before treatment with ARVs

the CD4 count will be low and the viral load will be high but once a patient commences treatment with ARVs, the CD4 count is expected to increase and the viral load will decrease to 100,000 copies/ml or until it is 'undetectable'. A clinician would alter the treatment regimen in consultation with the patient to obtain an alternative positive clinical outcome if the above management objectives have not been met. Before patients are initiated on treatment the health care provider (staff member) at the clinic would counsel the patients and prepare them for the possible side effects of ARVs. This is done to prevent the patients defaulting or discontinuing the ARVs when they are on treatment. It is known that a patient could develop resistance to ARVs and this could lead to the transmission of the HI resistant virus. Counselling for patients on ART is provided by the clinician, nursing sister, adherence counsellor, social worker or psychologist, Pharmacist and the Post basic Pharmacist Assistant. The adherence counsellors perform a monthly pill count on the patients' ARVs and they will check for any possible reasons for nonadherence to treatment, misunderstanding or hindrances to compliance as patients may experience other social or personal issues such as the lack of food, lack of money for transport to the clinic, stigma, discrimination and it then requires the referral of the patient to the clinician, nurse, dietician or social worker for additional support. The interdisciplinary team at the facility has a responsibility to support treatment adherence and to mitigate any barriers that prevent patients from understanding their treatment regimen.

The side effects of ARVs are varied and extensive as one simply needs to read a package insert of ARV products to understand the complexity and overlap of the side effects in two or more ARVs. The side effects of ARVs are well documented but it still requires constant monitoring and reporting as the safety data of these drugs are limited to pre-registration clinical trials and the use of small and not large population sample sizes (Republic of South Africa,2009). The safety of ARVs in large populations is a therefore a challenge in the optimal management of patients.

1.3 Rationale for the research study

Side effects can be regarded as early side effects, medium side effects and late side effects with four major categories of side effects of patients on ARVs such as mitochondrial toxicity, metabolic abnormalities, hematologic abnormalities and allergic reactions (Republic of South Africa,2009).The patient could experience possible acute and long term side effects caused by the drug itself or by an interaction of the ARVs with food, herbal medicines, or traditional

medicines. Patients may not be aware that these side effects could be mild or fatal (death) with physical, mental or psychological changes occurring in their bodies. It is therefore important for the patient and staff to understand the side effects of ARVs to optimally manage and prolong the life of the patient.

As patients live longer on antiretroviral therapy, more complications occur and it is important that the patient is correctly informed to prevent complications of the side effects and non-adherence to treatment. The patient is generally informed of the "common" or basic side effects of ARVs such as nausea, vomiting, skin rashes, headache, nightmares or painful feet or legs. As soon as patients' experience any side effect they should inform the doctor or nurse about this, as the health provider needs to complete the adverse reaction form for further processing to the specific district and depot pharmacist in the province. The district pharmacist collates the data and submits the report to the KHC pharmacist and thereafter it is forwarded to the Medicine Control Council (MCC) and National Adverse Events Monitoring Centre (NADEMC) for further responses by the respective manufacturers. The MCC responds to any potential safety hazard on an ARV, as well as any other medicine to ensure that quality and safe medicine and ARVs are produced and availed to clients. The current status of adverse events monitoring and the reporting of ARVs in the province is not optimal due to various challenges and constraints.

It is equally important that patients are informed about the side effects of TB drugs and other common medicines such as hypertensive drugs, analgesics or diabetes medication to avoid the stoppage of *any* treatment or medication.

Patients have access to modern electronic technologies such as smart cellular phones, iPods, kindles, social media networks, television and the internet that allows them to access more information on ARVs. It is expected that the patients on the ART programme know about the basic side effects of ARVs but do the patients "look for" and spontaneously report any changes or medium or late side effects? As they get older and as their bodies change both physically and metabolically, should patients and staff not be more observant?

1.4 Research problem

The provincial "roll out" of the CCMT program since September 2011 still presents challenges to patients and staff at healthcare facilities. At public healthcare facilities long queues of chronic patients, inadequate staffing and the expansion of more health programs with more administrative functions retards the provision of quality services. There is the

continual pressure to meet the provincial and facility CCMT targets, to spend financial ARV budgets and the need to meet various expectations from different stakeholders (including the patient). Long waiting times at consultation rooms result in impatient clients at the pharmacy who are often not prepared to listen, question staff about their ARVs or seek further advice to optimally manage their treatment plan and the side effects they experience. The Consumer Protection Act (CPA) 68 of 2008 requires that consumers of products (such as medicines) be comprehensively counselled with the benefits, side effects, warnings and cost clearly communicated to the patient (PSSA,2011) Healthcare workers have the professional responsibility of providing advice, information and counselling to the patient. The information can be provided in the format of instructions and labelling of medications, patients information leaflets, posters, simple communication in an acceptable language, health education talks, health campaigns and counselling services.

It is not known at which stages of the treatment plan information is provided about the side effects of ARVs to patients, how this information is provided to patients and how the patients understand this knowledge to apply it to them. It is also not known if the staff (who are required to provide this information to the patients) are knowledgeable about the side effects of ARVs and whether they are aware about the provincial and national pharmacovigilance reporting systems. There appears to be a lack of standardisation in the practices to create awareness and educate staff and HIV patients about the side effects of ARVs. Further research is thus required to investigate the practices at these facilities in order to provide answers to the various questions.

1.5 Significance of the study

This research study was significant for the following reasons:

Firstly it provided an understanding between treatment literacy, patient education and knowledge amongst patients and staff. Secondly, the study informed us whether the current services address the need and knowledge about the side effects of ARVs amongst staff and HIV patients. Thirdly, the study provides information about the perception of the side effects of ARVs amongst staff and HIV patients so that it informs us how staff and patients perceive a side effect. It provides an understanding between the perception of side effects and knowledge in managing HIV using ARVs. The studyinforms us whether the patient or staff member sees the need to report an ’experienced ‘side effect to the respective persons or authorities. The process of the reporting of a side effect from patients and staff is a voluntary

process but it enables the patient and healthcare worker to contribute more positively to the management of the patient's condition and also to the management of the pharmacovigilance program in the province. Fourthly, the correct management of the side effects could lead to less defaulting or discontinuation of treatment by patients, less ARV resistance and a more cost effective CCMT program. An understanding of the side effects of ARVs encourages adherence to treatment which results in less defaulting or "lost to follow ups" on the CCMT program and in return this prevents the spread of the HI- resistant virus. Less ARV resistance implies that more patients will be initiated on the standardised treatment regimens (such as regimen one) rather than the more expensive ARVs(such as regimen two and the newer ARVs) and this enables staff to initiate more patients on ARVs as more financial resources would be available. Fifthly, the study provides information on the current practises at facility level in relation to the changing needs of the patients and staff.

The outcomes of this study provides recommendations to improve the knowledge, perception and attitude about the side effects of ARVs in staff and HIV patients.

1.6 Research Question

The research question for this study was to determine to what extent the current practices at KHC and GDH address the knowledge, perceptions and attitude of the side effects of ARVs amongst staff and HIV patients

1.7Aims and objectives

1.7.1 Aim of the study

The aim of the study was to establish to what extent the current provision of services at KHC and GDH in the Frances Baard district addresses the knowledge, perceptions and attitude of the side effects of ARVs amongst staff and HIV patients in order to improve the current practices.

1.7.2 Objectives

The objectives of the study were:

- To assess the knowledge, perception and attitude of the side effects of ARVs amongst staff and HIV patients at KHC and GDH
- To identify current practices at KHC and GDH that support the understanding and knowledge of the side effects of ARVs amongst staff and HIV patients

- To identify the gaps between the knowledge and existing practises amongst staff and HIV patients at KHC and GDH
- To provide recommendations to improve the perception, attitude and knowledge about the side effects of ARVs amongst staff and HIV patients.

Having stated the significance of this research study with the aims and objectives, the research problem defines the scope of this study. It is hoped that a positive perception, attitude and knowledge about the side effects of ARVs in patients and staff would facilitate the management of HIV in patients.

1.8 Research methodology

This was an exploratory study and the researcher used both the qualitative and quantitative methods in the research design to follow the best approach. The study was conducted over six weeks at two public healthcare facilities in the Northern Cape namely, Kimberley Hospital Complex (KHC) and Galeshewe day hospital (GDH).A convenience sampling method was used as this was the most practical approach and a total of 25 staff members and 62 HIV patients participated in the study.

1.9 Limitations of the study

The sampling sites were limited to facilities where the CCMT programme was in existence for a period longer than three years and the sampling site needed to have a doctor, pharmacist, a nurse and an adherence counsellor at the wellness clinic of the facility.

The target population had to be adults of 18 years or older. This excluded paediatric patients and adolescent patients younger than 18 years of age.

1.10 Outline of chapters

The format of the research report is divided into the following chapters:

Chapter 1

This chapter provides a background to the research study, the rationale for the study, the research problem and the significance of the research study. It also describes the research question with the aim and the objectives of the research.

Chapter 2

This chapter provides discussion around the existing knowledge and literature with relevance to the research problem. The reader is introduced to literature on key concepts such as knowledge, perception, attitudes, ARVs, side effects, legislation and adherence.

Chapter 3

In this chapter the methodology of the research study is discussed and it explains to the reader the research design, the research tools, the incurred costs and expenditure as well as the overall method of execution of the research study.

Chapter 4

This chapter presents the results and findings of the research study in the format of tables, graphs and brief comments.

Chapter 5

This chapter provides a detailed discussion of the results in relation to the preceding chapters (Chapters 1 to 4).

Chapter 6

This chapter of the report provides the reader with insight into the implications of the results and it provides recommendations to the study.

Chapter 7

This is the final chapter and the conclusion of the research report.

1.11 Conclusion

A review of the literature will be presented in the next chapter.

CHAPTER 2 LITERATURE REVIEW

2.1 Operational definitions of the literature review

2.1.1 Knowledge

Knowledge is defined as facts, information, and skills acquired through experience or education; the theoretical or practical understanding of a subject (Oxford dictionary, 2012)

2.1.2 Attitude

Attitude is defined as the way that you think and feel about somebody/something; the way that you behave towards somebody/something that shows how you think and feel (Oxford advanced dictionary, 2012)

2.1.3 Perception

Perception is defined as a belief or opinion, often held by many people and based on how things seem (Cambridge dictionary, 2012)

2.2 Antiretroviral drugs (ARVs)

2.2.1 What are Antiretroviral drugs (ARVs)?

ARVs are drugs that are used alone or in a combination form to manage HIV and AIDS but it does not cure you. ARVs retard the growth of the HI-virus enabling the immune system to function optimally and defend the body against any new opportunistic infections. The use of ARVs enables HIV patients to live longer and it provides them an improved quality of life. .Patients are provided with a combination of at least three ARVs in the form of a regimen as the different ARVs work at different stages of the lifecycle of the HI-virus. The ARVs work at different receptor sites in the body enabling the drugs to have both an effect and a side effect (or side effects) in the body.

The Hi-virus mutates in the body if the immune system is weak or suppressed allowing the Hi-virus to replicate in the body and certain ARVs will no longer be effective. It is often referred to as “resistance” to the drugs (ARVs) and an alternative treatment regimen (such as regimen 2 or 3) must then be prescribed for the patient.

2.2.2 Treatment regimens and ARVs

The science and the development of ARVs gave rise to the use of various treatment regimens and the public health sector regimens have been standardised to optimally manage most of the patients. At the clinics and hospitals reference is made to regimen 1, regimen 2, a regimen for pregnant patients and also salvage therapy for patients who are not clinically stable on any of the previously mentioned regimens.

The National Department of Health, RSA (2010) standardised the following regimens for adults and adolescents as described in Table 2.1below.

Table 2.1:National ART Regimens

First Line		
All new patients needing treatment	TDF + 3TC/FTC + EFV/NVP	For TB co-infection EFV is preferred. For pregnant women or women of child bearing age, not on reliable contraception, NVP is preferred.
Currently on d4T-based regimen with no side effects	d4T+3TC +EFV/NVP	Remain on d4T if well tolerated. Early switch with any toxicity. Substitute TDF if at high risk of toxicity(high BMI, older, female, TB treatment)
Contraindication to TDF: renal disease	AZT+3TC+EFV/NVP	
Second line		
Failing on a d4T or AZT based 1st line regimen	TDF+3TC/FTC+LPV/r	Virological failure must be followed by intensive adherence management, as resuppression is often possible. If repeat VL remains >1000 in 3 months, despite adherence intervention, switch.
Failing on a TDF-based 1st line regimen	AZT+3TC+LPV/r	Virological failure must be followed by intensive adherence management, as resuppression is often possible. If repeat VL

		remains >1000 in 3 months, despite adherence intervention, switch.
Salvage Therapy		
Failing any 2nd line regimen	Specialist referral	Virological failure on protease inhibitors is almost always due to non-adherence. Intensively exploring and addressing issues relating to causes of non-adherence will most often lead to resuppression. If VL remains high, refer where possible, but maintain on failing regimen.

Source:Clinical Guidelines for the Management of HIV & AIDS in Adults and Adolescents(NDoHRSA, 2010)

2.2.3 Side Effects

A side effect is defined as any unintended effect of a pharmacological product occurring at doses normally used in man, which is related to the pharmacological properties of the drug (Fomundam,2011).The early side effects of ARVs are gastrointestinal and flu-like symptoms, headache, dizziness, vivid dreams, rash and hepatitis.

The study by Nzienguiet al (2006) was conducted in Gabon and it was concluded that patients want to be provided the complete drug information including the side effects and any difficulties that could be experienced.

2.2.4 Adverse event management

An adverse event is defined as a response to a drug which is noxious and unintended and which occurs at doses normally used in man (MSH RPM plus, n.d).

Side effects are said to create barriers to adherence whereas adverse events result in patient morbidity and mortality (MSH, 2011).

The NDoH (2010) provided the following guidelines to manage adverse events:

1. Identify and assess the adverse event and its possible cause (e.g. medication, food, illness)

2. If the reaction is mild or moderate, the ART must be continued. The patient must be provided symptomatic treatment, counselled and monitored

3. If the cause is a single ARV, a single substitution can be made except if the patient is in virological failure

4. If the need is then to discontinue ARVs, all ARVs must be stopped together as discontinuing one ARV could lead to resistance

5. If a patient experiences any life threatening side effects such as lactic acidosis, hepatitis, kidney toxicity, pancreatitis, severe rash or Abacavir hypersensitivity reaction, all ARVs must be interrupted immediately

6. Adverse events must be recorded and reported regularly to the CCMT programme in the province. Serious adverse effects must be reported within 48-72 hours to the MCC or NADEMC.

Table 2.2 lists the important ART adverse reactions as stipulated in the guidelines of the National Department of Health, RSA (2010).These guidelines are used at the public healthcare institutions in the Northern Cape.

Table 2.2: Important ART Adverse Reactions and Safety monitoring

Antiretroviral	Adverse Reactions	Recommended safety Monitoring
Didanosine(DDI)	Peripheral neuropathy, GIT effects(bloating, flatulence, nausea, diarrhoea), hyperlactataemia , lactic acidosis, pancreatitis)	Clinical
Efavirenz(EFV)	CNS disturbances (dysphoria, vivid dreams, distractedness, dizziness, depression) Skin rash, hepatitis Possible link to congenital abnormalities-avoid during 1st trimester	Clinical
Lamivudine(3TC) and	Generally well tolerated	Clinical

Emtricitabine(FTC)		
Lopinavir/Ritonavir	GIT symptoms(mainly diarrhoea);lipid and glucose abnormalities, lipodystrophic changes	Fasting cholesterol and triglycerides and glucose at 3 months
Nevirapine(NVP)	Skin rash(from mild to life threatening) Hepatitis (can be fatal)	ALT(Alanine transaminases) at baseline and at week 2,3 and 8,and 12 and any time hepatitis symptoms occur
Stavudine(d4T)	Peripheral neuropathy, lipodystrophy/atrophy ,hepatic steatosis, hyperlactataemia, lactic acidosis, pancreatitis	Clinical
Tenofovir(TDF)	Nephrotoxicity	Check creatinine at baseline,monthlyx3,6 months and then annually
Zidovudine(AZT)	Bone marrow suppression (anaemia, neutropenia), GIT symptoms, lipoatrophy, myopathy, headaches, hyperlactataemia, and lactic acidosis	FBC (Full blood count) at baseline, then at months 1,2,3 and 6

Source: Clinical guidelines for the management of HIV and AIDS in adults and adolescents, NDoH RSA, 2010.

2.2.5 Costs

The provision of ARVs is said to reduce the HIV infection rate by at least two thirds (Van Niekerk and Kopelman, 2008).Nadross (2008) says that in South Africa this is affordable as the cost of a large scale rollout of ARVs is balanced by the savings in the health sector (Van Niekerk and Kopelman, 2008).There is little information about the cost of treating the side effects of ARVs (acute or fatal) against the affordability of the large scale rollout of ARVs.

2.2.6 ARV product information

There are 10 suppliers on the government tender HP13-2013 ARV (RSA, 2012) currently supplying ARVs to government pharmaceutical depots .Each ARV product is pre-packaged in a container with a package insert that provides details about the medication (use,, dosage, warnings, side effects and contra-indications) but often the package insert is not user friendly to the patient or health worker as it consists of technical, clinical terminology and language. At the facility level the package insert is often discarded in the waste bin as the ARV medicine bottle or packet of tablets/capsules is removed from the outer box or plastic package and the label is placed on the dispensed container. The outer box/package with the package insert is discarded in the refuse bin. Sometimes the ARVs would be repackaged and dispensed to the patient in a new container with the package insert also not provided to the patient. There is very little literature or pamphlets available from the supplier or manufacturer about the side effects of ARVs. "User friendly" patient information literature is needed to create more awareness and knowledge about the side effects of ARVs. Currently there is a lack of "patient friendly "literature from suppliers and manufacturers about the side effects of ARVs in any official language.

A study by Schumaker et al (2008) concluded that patients had a concern about the toxicity of ARVs as they felt concerned if the side effects differed from their expectations. It was recommended that healthcare professionals need to be more sensitive about their attitudes to pharmaceuticals and the concerns of patients must be considered to improve ART programmes.

2.3 Legislation

The Pharmacy Act No 43 of 1974 and the Medicines Control Act no 101 of 2004 regulate that all providers and dispensers of medicine have a professional obligation to inform clients (patients) about the medicine, the benefits, side effects and warnings of a medicine. "The pharmacist must counsel the patient on the common *severe* side effects or adverse effects or interactions and therapeutic contra-indications that may be encountered including the avoidance and the action required if they occur" (Pharmacy Act,53 of 1974,PRE-257).

The Consumer Protection Act (CPA) 68 of 2008 was enacted on 01 April 2011 and it outlines the responsibilities of all providers towards consumers, including the consumers of ARVs. This Act protects the interest of consumers and the rights of patients such as the right to good quality, fair value and safe medicines. The provision of safe, good quality ARVs is of

paramount importance for the CCMT programme. This implies that consumers or patients must be comprehensively counselled so that the patients understand the medicine, the side effects, the benefits, the costs and the warnings. Package inserts and patient information leaflets and other forms of written communication must be provided to the patient. The understanding, knowledge and the implications of the Consumer Protection Act by staff and patients at healthcare facilities is unknown.

2.3.1 Patient rights

Patients have the right to receive clear and adequate advice with regards to the safe and effective use of medicines (including ARVs).

2.3.2 Responsibilities of healthcare workers

The Consumer Protection Act (CPA) 68 of 2008 holds health professionals accountable so that we provide adequate counselling to the patients.

2.3.3 Dispensing and counselling

An Australian study by Puspitasari.et al (2010) showed that pharmacists will provide verbal counselling for new prescriptions but infrequently provide written information or information for regular medicines. They attribute the lack of consumers' interest to low counselling rates and they recommend that strategies regarding pharmacist counselling practices must be developed to involve consumers in the process.

The study by Basaket al (2009) recommends that the role of the pharmacist and the educational system must be adapted to meet the changing needs of patients. Part of this research study looks at the needs and expectations of patients and staff.

The study by Du Pasquieret al (2008) concludes that the consumers' needs for information as well as their expectations of the pharmacy profession are important for adherence purposes. The Pharmacist should be able to tailor consumer information to the consumers
needs and this study supports previous studies on adherence.

In our study and our situation will the healthcare providers be able to tailor and meet the needs of patients to meet their expectations?

Puspitasari et al (2009) supports the study that pharmacist counsel consumers less on the side effects, drug interactions, precautions, contraindications and storage but more on the directions for use, dose, medicine name and instructions of medicines.

2.3.4 Standard Operating Procedures (SOPS)

SOPS are designed to provide the guidance to the user on how to perform the required steps and action of the required function. The Northern Cape Provincial Standard Operating Procedures for Pharmaceutical Services developed SOPs to ensure that professionals comply

with legislation. The SOP on dispensing describes “dispensing” in four phases, namely phase 1 asthe evaluation and interpreting of a script, phase 2 as the preparation and labelling of medicines , Phase 3 as the final checks and phase4 as the provision of information to the patient. In phase 4 the dispenser provides information to the patient on the correct medicine use; possible side effects; storage; drug -food interactions and the correct storage of medicines. The SOPS of KHC and GDH indicate that counselling can be done by a Pharmacist or Pharmacist Assistant (under the supervision of a Pharmacist) and the patient must be counselled on the ‘common’ side effects and the appropriate action if the patient experiences the side effects.

2.4 Pharmacovigilance (PhV)

The outcome of the long term adverse effects of ARVs and the toxicity profile of ARVs is unknown but the monitoring of ARVs is important especially in large populations (WHO, 2007).

Patients who experience side effects and stop taking their ARVs lead to further problems, treatment failure and drug resistance .Pharmacovigilance is important for the safety of patients and to strengthen the ART programme and procedures in the health system.

2.4.1 Spontaneous reporting

A spontaneous report is an unsolicited communication by health care professionals or consumers that describes one or more adverse drug reactions(ADRs) in a patient who was given one or more medicinal products and that does not derive from a study or any data collection scheme(WHO, 2007)

Insufficient training on the prevention and management of adverse drug reactions to ARVs is being provided and this results in poor reporting of the adverse effects of ARVs (Fomundam, 2011).

2.5 Communication models

Lewis et al (1997) conducted a study on the pharmacist counseling of chronic patients and it was recommended that pharmacists use a different communication model to the traditional sender-receiver –message model. The pharmacist must take the patients need and level of understanding into account and counselling must be adapted to each patient to maximise therapeutic outcomes. The IHS Indian service model uses open ended questions with the pharmacist actively involved with the patient. The health communication model is said to enhance patient compliance and this model supports the IHS model. The need for effective

counselling is predicted to increase with the increase in chronic patients and studies have shown that pharmacists need to understand modern communication models to ensure that patients are maintained on drug therapy.

A new model by Helena (PSSA, 2012) called the green card training model was introduced and implemented at Ermelo Hospital pharmacy. The model describes how small green cards are fixed to the shelves in pharmacies under the relevant drugs. The cards contain information on the drug indications, common side effects, and dosages for adults and children and expected drug interactions. This helps staff to remember the information when counselling the patients. Alongside this presentations are also conducted by the Pharmacists and Pharmacist assistants as part of their training to increase their knowledge, confidence and communication skills (PSSA, 2012).However it has not been indicated if the model has been tested in HIV patients.

A study by Langlois-Klassenet al (2008) concluded that communication between patients and physicians is valuable as physicians could address issues such as potential herb- drug interactions and they could provide appropriate medical care. The study also showed that if physicians are willing to discuss herbal medicines with patients, patients will follow the advice from physicians and they will make more informed decisions about their health but an improvement in the physician- patients' communication is recommended.

In our study could this finding apply to the side effects of ARVs as well?

2.6 Interventions

Various studies have provided various interventions and strategies to encourage patients to be more knowledgeable about their ARVs.

2.6.1 Instructional strategies

Fomundam (2011) says that "the information should meet the patients' needs to achieve the best therapeutic outcome"(pg 4).

2.6.2 Behavioural strategies

Fomundam (2011) says that "patients must be encouraged to perform self monitoring of the side and adverse effects of medicines"(pg 4).

2.6.3 Motivational and empowerment strategies

Fomundam (2011) says that "patients must be encouraged to adopt new beliefs, attitudes, values and health care providers must target education to fill in the gaps in their knowledge base" (pg 4).

Pharmacists have an important role to play in positive patient outcomes. A study by March et al(2007) measured patient knowledge on drug toxicities(on a scale of 0 to 4) , the CD4 counts and viral loads and participants also had to gauge their own quality of life using a survey method. The study showed that with patient education, pharmacists were able to improve the patient outcomes significantly in their CD4 counts, viral load and drug related toxicities. The study by Cocohobaet al (2012) supports the study in that pharmacist counselling improves adherence and CD4 counts.

A study by Clark et al (2007) assessed the effect of a clinical pharmacist-directed patient education program on the therapy adherence of first time TB patients and multidrug-resistant (MDR)-TB patients. They compared the adherence of patients in a group of58 patients when educated by nurses or pharmacists. The study showed that the patients' adherence to TB treatment improved when a pharmacist provided patient education as it addressed the patients 'complete need of pharmaceutical care.

A study by Gupta et al (2010) was conducted in India amongst pharmacy and pharmacy co-workers to determine the availability, provision and knowledge of ARVs, attitudes towards HIV –infected persons and the self perceived need for training amongst community based pharmacies in an urban area of India. The study showed that there was a tremendous need for training on HIV theories and interventions were needed to reduce the stigma of those that stock ARVs towards HIV –infected persons. The study by Sheridan et al (1997) showed that time, the lack of training was more of a barrier than remuneration in counselling HIV patients and that support staff were less confident in providing advice on the prevention of HIV. Adherence and other roles of the pharmacist were not part of their study.

Van Tam et al (2011) conducted a study in Vietnam and concluded that 'stigma is a strong barrier to adherence and it also shapes the patients' attitude, in the ways that patients receive treatment as patients felt they wanted more support" .

2.7 Adherence

The adherence of patients to antiretroviral therapy is important as it enables the patient to remain on the treatment regimen longer and this delays resistance to antiretroviral treatment. A study by Uzochukwu et al (2009) showed that 75% of patients in southeast Nigeria were not adhering fully to the treatment regimen with an average number of 3.57 days off drugs per month. One of the reasons provided for the non-adherence was the physical discomfort (side effects) of ARVs amongst other reasons. The study by Garcia et al (2006) concluded that in patients who do not understand ART, 80% will fail therapy and become non-adherent.

They recommended that policymakers in Nigeria address the factors causing non adherence especially when scaling up on ARV treatment.

It is said that adherence to treatment cannot be identified on the physical appearance of a patient. Healthcare workers have to be trained to measure adherence to treatment using tools. A. study conducted by Steel et al (2007) provides healthcare workers with a tool that is able to measure adherence and support the activities of healthcare workers at facilities. This study supports other studies on adherence by emphasising the importance of "almost perfect adherence" for success on all treatment outcomes and less viral resistance. Steel et al (2007) argues that the "scale up" of patients of ARVs requires more interventions as non-adherence will result in more cost implications. This counter argues the study of Nattros as non-adherence and the use of alternative treatment regimens are more expensive. Steel et al (2007) further argues that the interpretations of adherence by healthcare workers will affect the clinical outcomes and management of the patient. Staff could misinterpret levels of non-adherence if a standardised tool is not used.

Support measures that enhance adherence and knowledge about ARVs include personalised printed medication, information and patient literacy materials. A study by Wong et al (2006) in South Africa concluded that the use of a culturally sensitive educational videotape could improve the patients' knowledge about medication and further studies must be encouraged using media technology. This study did not include the cultural practices in relation to the understanding of the side effects of ARVs amongst patients and staff.

Sanjobo et al (2008) conducted a study in Zambia with the aim to explore the patients and healthcare professionals' perceived barriers and facilitators to the patients' adherence to ART. It was found that the lack of communication and information about ART, lack of followup and counselling were part of the barriers to adherence.

The level of knowledge of ARVs and the side effects amongst patients and staff at our healthcare facilities in the Northern Cape is unknown. A study conducted in the Eastern Cape Province showed that there were challenges in the treatment and follow up of patients on ART. These challenges included the lack of training of healthcare providers, difficulty in communicating adverse drug reactions by patients, insufficient pharmacovigilance reporting as well as poverty in managing patients (Ruud et al ,2012).This study also showed that there was a need to improve pharmacovigilance practices especially with the "down referral" of patients to primary health care facilities. The study recommended that junior staff be continuously trained to improve the management of ARVS and the management of pharmacovigilance activities.

The study by Sharma et al (2007) showed that counselling in the last six month influences the adherence of the patient to ART.A client will experience a side effect but a client measures satisfaction by measuring the time spent with a doctor, the waiting time and the way the patient is treated. The experience of a side effect did not influence the perception of patient satisfaction at a facility. The study by Bartlet et al (2002) supports the fact that we need to educate and manage the side effects of patients in order to maintain adherence, educate and motivate patients. The study by Hoang et al (2011) supports the need for effective patient education programs because of the poor understanding of HIV and AIDS.

2.8 Patient literacy

A study performed by Hoang et al (2012) focussed on the importance of patient education around HIV and antiretroviral (ARV) medications. This study assessed knowledge and perceptions of HIV patients in on an ARV education program and it showed that patients had knowledge about HIV, but the results raised concerns over the patients' knowledge about their ARV medication and its side effects. Patients were concerned about the use of ARVs and their side effects. Zuniga (2006) reported that patients and physicians had different impressions of the type and incidence of side effects. The study by Hoang et al (2012) showed that the patient education program was not addressing the poorly understood issues and HIV and AIDS. Kaliyaberumal et al (2004) provided guidelines in a knowledge, attitudes and practice Study (KAP study) and they used the KAP study to conduct an educational diagnosis of the community.

A study by Nachega et al (2012) measured the adherence; drug resistance and patient-provider communication in 2035 HIV infected adults using a self reported questionnaire on adherence. This study showed that 57% patients reported a recall of 100% adherence, 18% reported drug resistance as a "good thing" and 71% of health care providers could offer practical recommendations about adherence. This study concluded that there is a critical need to improve patient-provider communication, to improve adherence and benefit the overall patients' health. A study by Negi et al (2006) assessed the knowledge, attitude and perception about HIV/AIDS among pregnant women in rural areas of Dehradun (India) and it was concluded that there was a need to increase the awareness of HIV/AIDS amongst illiterate and low socio economic people using all methods of information, education and communication.

A study by Manias et al (2007) studied the perspectives of consumers with osteoarthritis and healthcare professionals and found that consumers lacked understanding of the complexity of medicines and that dedicated time must facilitate an exchange of information.
In this study will our participants lack an understanding of their ARVs?

2.9 Attitude

It is important that the attitude of the healthcare provider enhances positive behaviour and positive health in an HIV patient.
A study by Matheson et al (1999) was conducted in communities measuring the attitude of pharmacists towards consumers and it was concluded that "if the negative attitude of the pharmacist is addressed, this would encourage more pharmacists to provide services and thereby improve service delivery". It is important to deliver programs and address the needs of HIV patients. The study showed that pharmacists need to change their attitude and stigma towards patients with HIV to improve services.
A study by Corice et al (2006) showed that "a concern for the views of consumers and the expanding role of nurses" may improve the health outcomes of consumers.
In this study it would be of interest to understand the role of the adherence counsellors and other health providers in improving the health outcomes of the patients.
A study by Sheridan et al (1997) showed the need for training and greater communication in community pharmacies to add value and support to HIV patients, as this resulted in more positive relationships and attitudes towards HIV patients.
The study by Williams et al (2008) concluded that consumers are unaware of the need, effectiveness and safety of all their medicines in chronic diseases but health professionals tend to focus on the directions of medicines and they believed that the risk of medication related adverse effects was overrated. It was concluded that the barriers and perceptions of consumers hamper the communication and partnerships with health professionals and this influences the effective communication, adherence and safety of medicines.
Peralta et al (2007) conducted a study in adolescents and demonstrated that adherence is improved when a patient –provide relationship incorporates trust, good communication, adequate education about medications, an overall perception of caring and the socio-cultural aspects is considered in the management of the patient.
The study by Agu et al (2012) evaluated the knowledge and attitudes of HIV infected patients in Nigeria in which 3650 patients participated from 36 hospitals and data from 63.8% of participants were analysed. Routine counselling and education was provided to the

participants. A total of 80.1% participants accepted to have been counselled on adverse drug reactions and 60.8% knew what to do when they suspected an adverse event. The study found that the knowledge of adverse reactions were associated with gender, educational and the employment status of the patients. It was generally found that the participants reported good knowledge and positive attitudes to the adverse effects of their medicines .The researcher argue that this was the converse of previous studies and that the patient counseling and education on drug therapy provided to these patients, may have contributed to these findings and it was recommended for future studies.

2.10 Perception

Coateset al (1983) conducted a study on the patient perception of the side effects of cancer chemotherapy drugs in different age groups, sex, marital status, domestic situations, diagnosis, treatment and response amongst 99patients. It was found that the nonphysical side effects contributed to 54% of the most severe symptoms so the patients' perception of the severity of the side effects is useful as a "cost benefit balance". The major physical side effects were vomiting, hair loss and nausea. The researchers concluded that depending on the patients' perception of the side effects of oncolytics, the clinicians could decide whether or not to use chemotherapy. However inHIV and AIDS the perception of the severity of the side effects cannot be used as a "cost benefit balance" to assess whether patients must be provided ARVs or not as the cost of ARVs is much more affordable and less costly than oncolytics drugs.

A study was conducted by Home et al (2008) to understand the perceptions of physician and patients on the use of an intravenous ARV drug called Fuzeon®. It was found that the perceptions amongst staff and patients were disconnected and it was recommended that the doctors and patients work together to meet the optimal situation. The study also suggested a nursing intervention to improve the perceptions of side effects amongst patients and doctors. A study on neurotiscm by Johnson and Neilands (2007) showed that the perceptions of health and side effects in HIV patients were linked to the individual differences in patients.

2.11 Conclusion

The above studies indicate that there are diverging goals, knowledge, perception and attitudes about HIV, ARVs and the side effects of medicine. There appears to be a need for more studies about the understanding and communication between health care providers and

patients about the side effects of ARVs. In determining whether the participants of this study have a similar or dissimilar understanding of the side effects of ARVs, we needed to ask questions and find practical solutions.

In the following chapter, the research plan for the study will be discussed.

CHAPTER 3 RESEARCH METHODOLOGY

3.1 Introduction

Christensen L.B. (2011) describes a research design as the outline, plan or strategy used to investigate the research problem.

3.2 Problem statement

It is not known at which stages of the treatment plan information is provided about the side effects of ARVs to patients, how this information is provided to patients and how the patients understand this knowledge to apply it to them. It is also not known if the staff (who are required to provide this information to the patients) are knowledgeable about the side effects of ARVs and whether they are aware about the provincial and national pharmacovigilance reporting systems. There appears to be a lack of standardisation in the practices that create awareness and educate staff and HIV patients about the side effects of ARVs. Further research is thus required to investigate the practices at these facilities in order to provide answers to the various questions.

3.3 The research question

The research question for this study was to determine to what extent the current practices at KHC and GDH address the knowledge, perceptions and attitude of the side effects of ARVs amongst staff and HIV patients?

3.4Aims and objectives

3.4.1 Aim of the study

The aim of the study was to establish to what extent the current provision of services at KHC and GDH in the Frances Baard District addresses the knowledge, perceptions and attitude of the side effects of ARVs amongst staff and HIV patients in order to improve the current practices.

3.4.2 Objectives

The objectives of the study were:

- To assess the knowledge, perception and attitude of the side effects of ARVs amongst staff and HIV patients at KHC and GDH

- To identify current practices at KHC and GDH that support the understanding and knowledge of the side effects of ARVs amongst staff and HIV patients
- To identify the gaps between the knowledge and existing practises amongst staff and HIV patients at KHC and GDH
- To provide recommendations to improve the perception, attitude and knowledge about the side effects of ARVs amongst staff and HIV patients.

3.5 The research approach

The research survey was conducted over six weeks from 08 November to 20 December 2012 at the wellness clinics of KHC and GDH in the Frances Baard district of the Northern Cape.

3.5.1 Design of the research study

A survey research method was used to investigate the research problem. Christensen (2011) describes survey research as a non- experimental research method which uses questionnaires or interviews as research tools in the study. The survey method is generally used to explore and measure the attitudes, perception and knowledge of participants in a research study. A sample of participants is selected and this enables the researcher to generalise the results to a larger population (Christensen, 2011).

A mixed method research design (that is both the quantitative and qualitative methods) was used to investigate the research problem. One of the advantages of this method is that it can combine the strengths of the quantitative and qualitative research methods and it can also minimise the weaknesses of the individual methods (Christensen, 2011).One of the disadvantages is that it is more costly and more difficult to conduct than the individual qualitative or quantitative studies (Christensen, 2011).

3.5.2 The sampling sites

The two public healthcare facilities that formed part of the study included the Kimberley Hospital Complex (wellness clinic) and the Galeshewe Day Hospital (wellness clinic). KHC is a tertiary hospital and GDH is a community health clinic and the wellness clinics are entities managed within these facilities.

Galeshewe Day Hospital is currently the largest wellness for adults in the FrancesBaard district in the Northern Cape Province. It is also the largest referral site in that it “down

refers" stable HIV patients to the local primary healthcare clinics or hospitals in the province for further continuation of the HIV patient on treatment. Kimberley Hospital Complex currently operates as the only tertiary hospital in the province and it also functions as a wellness clinic for all the Department of Health employees and private clients in the Province. Similarly HIV patients who attend the Kimberley Hospital Complex can also be "down referred" to secondary institutions (such as the District hospitals) and Primary healthcare clinics in the province if the client wishes to be referred.

The method which was used to select these two facilities was based on set inclusion criteria and the use of the convenience sampling method, as both facilities are located in Kimberley and are within 10 kilometres of each other. It was required that the wellness clinics had to be in existence for more than three years in order to be included in the study and it had to provide ART services to a general adult population of ages 18 years and above. The facility needed to have a pharmacy and the staffing structure needed to consist of at least one Pharmacist, a Pharmacist Assistant, a clinical doctor, a nurse and an Adherence counsellor in order to be part of this study. The pharmacies on site at the facilities are managed by Pharmacists with the support of either the basic Pharmacist Assistants (in GDH) or basic and Post-basic Pharmacist Assistants (in KHC).The staff at the wellness clinics needed to be involved in either the prescribing or dispensing or the counselling of HIV patients.

Of the 13 public healthcare facilities in Kimberley only two facilities met the inclusion criteria to be part of this study, namely Kimberley Hospital Complex (KHC) and Galeshewe Day Hospital community health centre (GDH).

3.5.3 The research team

The research "team" was composed of the researcher , a language practitioner who edited the documents and a statistician who assisted with the analysis of the data. Certified translators were utilised to translate the questionnaire and consent form for patients into the four predominant languages of the Frances Baard District viz. English, Afrikaans, Xhosa and Setswana. The consent form and questionnaire for staff were only available in English and Afrikaans as most staff are conversant in these two languages.

3.5.4 The target population

The participants (staff and HIV patients) were randomly selected with the proposed sample size of participants of 60 patients and15 staff members, but a response rate of 130% was achieved resulting in a sample size of 62 patients and25 staff members. The target population

of this study included adults above 18 years of age only. Minors were excluded from this study due to the practicality and personal nature of the questions. The staff participated voluntarily in the study and their occupational classifications included Adherence counsellors, Pharmacists, Doctors and Nurses.

At Galeshewe Day Hospital 59 patients and 12 staff members participated in the study and at Kimberley Hospital Complex six patients and 13 staff members participated in the study.

3.5.5 The sampling method

At KHC, the wellness clinic for HIV patients operates only on a Thursday. At GDH the wellness clinic for HIV patients operates from Mondays to Fridays from 07h30 till 16h00.

A pilot study of the questionnaires and consent forms for staff and HIV patients was conducted in Kimberley at a public healthcare facility called City clinic. The actual time to complete all forms (by the staff and patients) in the pilot study was approximately 45 minutes. Amendments were then made to the original questionnaires to improve the understanding of the questions and to avoid confusion or misinterpretations of the questions by the participants.

An average 'consultation' time that a patient is seen by a doctor, nurse, adherence counsellor or the pharmacist is approximately 35 minutes per individual consultation. Theoretically this meant that every third patient had a chance of being randomly selected or included in the study. Since patients had the choice of voluntary participation in the study, it resulted in the researcher using the convenience sampling method as the approach for practical reasons. The staff that participated in this study were randomly selected using the convenience sampling method, because the staffing numbers at both facilities are small. With the small staffing population at KHC and GDH ,the goal was to obtain a response from 24 out of 25 staff members to obtain a 95% confidence level (Christensen, 2011).

3.6 Ethical considerations

It was required to obtain institutional approval from KHC, GDH and the Research Ethics Committee (REC) of the University of Stellenbosch (U.S.) before this study was conducted. Approval to continue with the research was received from the REC Committee (U.S) on 05 November 2012.

The participants in this study included participants from all races, gender, education levels and occupations and the participants had to be above 18 years of age. Participation in this study was anonymous and voluntary and it was required for all participants to complete a

consent form before they participated in the study. Participants were not coerced into the study as participants were allowed to withdraw from the study if they chose to do so. One male patient at KHC chose not to participate in the study due to time constraints and work obligations, as the waiting time at the wellness clinic already delayed him for work.

The respect for persons and their autonomy is one of the ethical guidelines of research and the decision for non- participation was respected. Privacy and confidentiality before, during and after the research study was emphasised as a priority to all participants to ensure trust and participation from all the participants. Confidentiality was specified in the consent forms and this was explained to the participants by the researcher. The questionnaires indicated that the names or identifiers of participants were not required at any place on the answered questionnaires and this re-emphasised the importance of anonymity and privacy.

The participants were randomly selected from both facilities and the researcher or the participants were not paid to conduct or participate in this study.

As part of ethical research principles, it was necessary to inform the participants that any discomfort they experienced during the study would be referred to a doctor on site at the facility for counselling or treatment. The goal of this research study is for the benefit of the patients and society by improving the practises and knowledge at these facilities. This follows the principle of beneficence and nonmaleficence. (Christensen, 2011).

The privacy and storage of the data was emphasised to the participants to ensure their trust and to meet the ethical research standards. All collected data forms have been stored in a lockable cabinet in the data collectors' office and all electronic data has been stored on a computer with a restricted password access.

It was also required of the researcher to comply with the standards of non-plagiarism as is required by the University of Stellenbosch.

3.7Research instruments

The researcher designed the research instruments (questionnaires, consent forms and interview sheets) for the study.

Data was collected using the designed tools namely a questionnaire for patients and a questionnaire for staff. The self administered questionnaire was completed by the staff and the patients. Where patients were not able to complete the questionnaire by themselves, the data collector interviewed the patients as a semi structured interview with the participant responding according to the responses on the questionnaire. The participant was handed a

copy of the questionnaire to follow the questions and to choose from the listed responses. This was done to limit any bias from the researcher.

3.7.1. Questionnaire for patients

This tool was designed to measure the knowledge, perception and attitude of the side effects of ARVs amongst HIV patients. This questionnaire was available in English, Afrikaans, Setswana and Xhosa. It consisted of 40 questions subdivided into general demographic questions, questions on knowledge, perception and attitude. The entire questionnaire was composed of five open ended and 35 closed ended questions. When selecting an answer to the close ended questions, the participant had to *tick* a response in an answer box from the range of answers provided. The ordinal scale of measurement was used as part of this research study to measure the responses from the patients.

3.7.2 Questionnaire for staff

This tool was designed to measure the knowledge, perception and attitude about the side effects of ARVs as well as the attitude of staff when providing this information to the patient. This questionnaire was only available in English and Afrikaans as most staff are conversant in the basic languages. The questionnaire consisted of 41 questions consisting of six open ended and 35 closed ended questions. When selecting an answer to the close ended questions, the participant had to *circle* a response from the range of answers provided. The ordinal scale of measurement was used as part of this research study to measure the responses from the staff.

The questions were subdivided into four categories such as general demographic questions, questions about knowledge, perception and the attitudes about the side effects of ARVs.

Both the questionnaires for patients and staff were divided into the different constructs to provide information for this research study on the practices at the facilities.

It was decided to provide a tick box (for patients) and a circled response on the questionnaires (for staff) to avoid confusion with the data collection, data capturing and data verification processes.

3.7.3 Patient records

As part of the requirements of the REC, it was required of the researcher to include the "access to the patient's folder" in the consent form. This was included in the consent form of the patient only in the very last paragraph. The intention was to access the folder of the

patient in the presence of both the researcher and patient as it would only be accessed in illiterate patients upon their consent. Access would only be required to provide information about the patients current ARVs, if the patient did not have his/her supply of ARVs with him/her.

In this research study it was not required to access a patients' folder as patients either knew their ARVs and their treatment regimen or they carried empty pill packets/containers with them which served as proof to the data collector.

3.7.4 Observations

During the research study, the data collector observed certain practices at the wellness clinics whilst collecting the data at the facilities. Christensen (2011) refers to this as "open observation" as the participant might not be aware that the data collector is observing them as part of the study.

3.8 Data collection and analysis

The data was only collected by the data collector once a week using the research tools.

All staff who voluntarily participated in the study completed the consent form and the self-administered anonymous questionnaire. Both the forms for the staff participants were collected from the facility on the day that the research tools were provided or it was collected the following week (if the staff member was too occupied that day). The consent form and the questionnaire was handed back to me (the data collector) in separately sealed envelopes to maintain confidentiality and anonymity. The patients who volunteered had the choice of either completing the self administered anonymous questionnaire by themselves or they could participate in a semi structured interview with the data collector. At the end of each weekly "data collection day", all the completed questionnaires and consent form were placed in four separately sealed boxes for consent forms and questionnaires labelled 'staff' and 'patients'. It was the intention to conduct a formal interview with illiterate respondents but this was not required as the semi-structured interview met the objective. The questionnaires and the consent forms for patients were available in the four dominant languages namely English, Afrikaans, Setswana and Xhosa but the most practical medium in the study was English.

The data was analysed by Professor Kidd (Department of Statistics, University of Stellenbosch). The aim of the analysis was to report any trends and tendencies from the collected data and results of the study. Explanations regarding the statistical design are provided in this report in the format of text, tables and graphs. The results of the study should

validate the research question, aim and objectives of this research study and in conclusion, recommendations have been provided to support the findings of the research study.

3.8.1 Data handling and security of data.

The raw data was captured in a Microsoft Excel spreadsheet and a template designed by the statistician. The Statistica 11® software programme was used to format the charts and graphs. Each patient and each staff questionnaire had its own unique questionnaire number as a reference. The information was stored on a USB flash disk and other network drives on the computer. The backup of all data and documents was done to minimise any risks, losses or damage to the equipment. Only the statistician and the data collector had access to the electronic data, but access to this electronic data was restricted by a user password on the computer of the data collector and statistician. All hardcopies of the documents and data are being stored in a locked cupboard in the office of the data collector. The data will be destroyed after two years.

3.9 Conclusion

The results of the study will be discussed in the following chapter.

CHAPTER 4 RESULTS

4.1 Introduction

The results and analysis of the data will be discussed in two main sections, namely the results from the staff questionnaires and the results from the patient questionnaires. The results from both the questionnaires are presented under the following four subsections:

Section A: General demographic questions

Section B: Questions on knowledge

Section C: Questions on perception

Section D: Questions on attitude

The statistical analysis was performed by Professor M.Kidd(Department of Statistics, University of Stellenbosch) using the Statistica 11 ® software and the results are presented in the form of frequency tables, charts (2D – two dimensional histograms and column bar charts).The mean test was applied to format the results descriptively.

4.2 A. RESULTS FROM THE STAFF QUESTIONAIRES

The proposed sample population size was twenty staff members in total but twenty five persons participated in the study (N = 25).The response rate for participation of staff in the study is 130%.

Table 4.1 : Response rate of total participants in the study (N = 25)

Total proposed participants to be part of the study	Total number participants in study	Response rate (%)
20 persons	25 persons	(25/20) x 100% = 130% response rate

Table 4.2 : Staff participation per facility

	Staff participating(N = 25)	Percentage participation
KHC staff	13	(13/25) x 100% = 52.00 %
GDH staff	12	(12/25) x 100%= 48.00%
Total staff	25	(13+12) / 25 x 100% = 100%

The results of the staff questions are now discussed with a simplified analysis of the result included under each question and graph.

A. GENERAL QUESTIONS

Question 1: Age of the participants

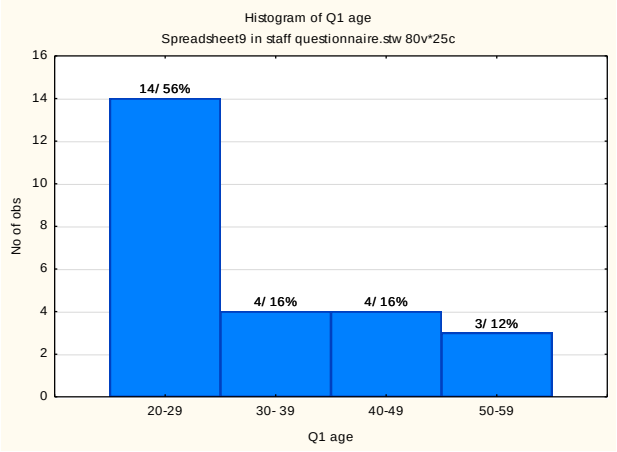

Figure 4.1: Number of participants vs. age

The graph shows that 59% of the participants were in the 20-29 year old age group, 16% was in the 30-39 year old age group, 16% was in the 40-49 year old age group and 12% was in the 50-59 year old age group. There was an equal distribution of participants between 30 and 49 years of age, with the highest category being the 20-29 year old participants. This indicates that the age of most staff at the wellness clinicsis between 20 and 29 years of age and this is notable as this young group of participants is expected to manage and deliver services to patients of various ages.

Question 2: Gender of participants

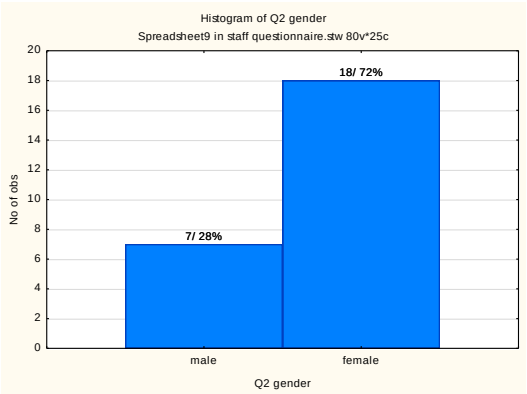

Fig 4.2: Number of participants vs. gender

The results show that 72% of the participants were female and 28% of the participants were male and this indicates that more female than male staff participated in the study. This corresponds in practise as there are more female staff than male staff at the wellness clinics.

Question 3: Highest Education level

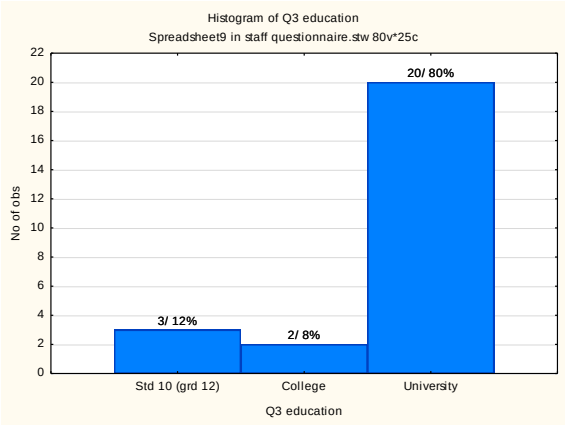

Figure 4.3 : Number of participants vs. the highest education level

From the graph it is observed that 80% of the participants have a university education whereas 12% of the participants completed grade 12(std 10) and 8% completed college. This indicates that the participants have a high education and literacy level and it would be expected that the participants are able to communicate in practise with the patients and other staff members.

B. QUESTIONS ON KNOWLEDGE

Question 4: Can HIV be cured?

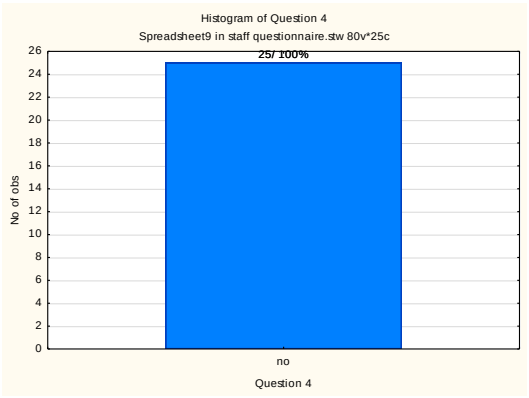

Figure 4.4 : Number of participants vs. the question "Can HIV be cured?"

The results show that 100% of all participants think that HIV cannot be cured This knowledge is important as the knowledge of the patients are influenced by the knowledge of staff. All staff were knowledgeable that 'HIV cannot be cured which is an important practice to follow.

Question 5: What treatment is provided at a clinic/hospital to a person with HIV?

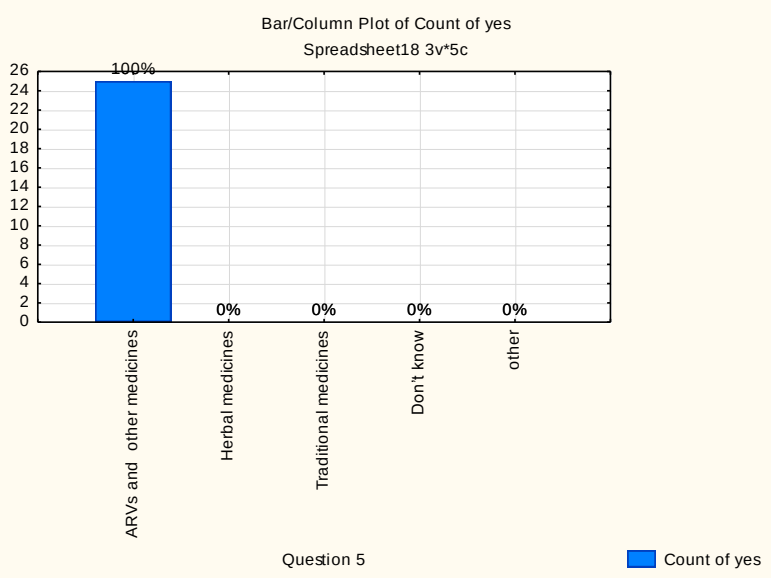

Figure 4.5 : Number of participants vs. the knowledge of treatment at clinics

The question was addressed to all staff as all staff were involved in the prescribing, counselling and dispensing of ARVs. All staff knew that only ARVs and other medicines are supplied at the facility, which indicates that all staff are familiar with the operational procedures at the clinic.

Question 6: Do you know the names of ARVs?

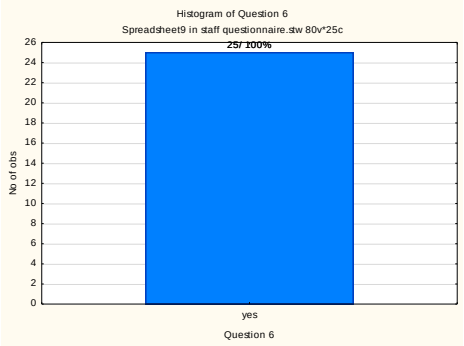

Figure 4.6 : Number of participants vs.knowledge of the names of ARVs

The graph indicates that all staff are knowledgeable about the names of ARVs. Examples of the generic names or the 'common' abbreviated names or the trade names of ARVs were provided. All staff were knowledgeable with regards to the names of ARVs as well as the dosage and frequency of the ART regimens. This is important especially if staff are involved in the counselling of patients.

Question 7: Do you know the dosaging and frequency of ARVs?

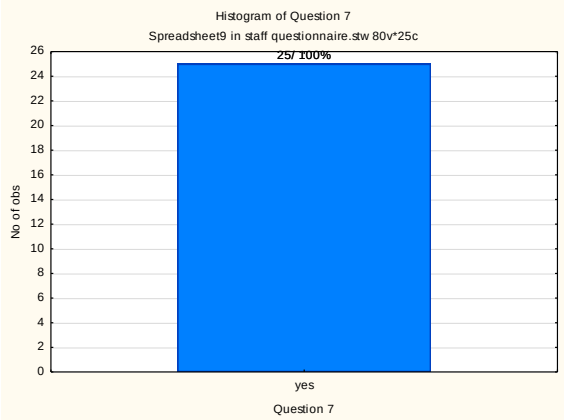

Figure 4.7: Number of participants vs. knowledge of dosaging and the frequency of ARVs

It is observed that all participants (100%) knew the dosaging and the frequency of ARVs. They could provide examples of the ARVs with its dose and frequency of the treatment regimen. This is essential as staff are required to know this as they are involved in the counselling and the management of HIV patients.

Question 8: What is a side effect?

This was an open ended question and various responses were obtained. The question was included to validate the participant's knowledge and understanding of the side effect of ARVs. The participant could either explain this by means of a theoretical description of the term "side effect" or a practical example .

The responses ranged from a pharmacological definition such as "an undesired or unintended effect of the ARV" to examples of symptoms such as diarrhoea, rash. dizziness, vomiting, bad dreams and headaches. Most of the respondents described examples of side effects rather than a technical definition of a side effect. The pharmacological definition of a 'side effect" was only provided by clinical staff whereas the examples of side effects were known by all categories of staff. The basic, common side effects were described by all participants with none of the participant referring to a medium or late side effect. This tells us that there is

more familiarity and an easier recall of the early than the medium or late side effects of ARVs. The common side effects are also the more experienced and common side effects that patients routinely complain about.

Question 9: Have you been told about the side effects of ARVs?

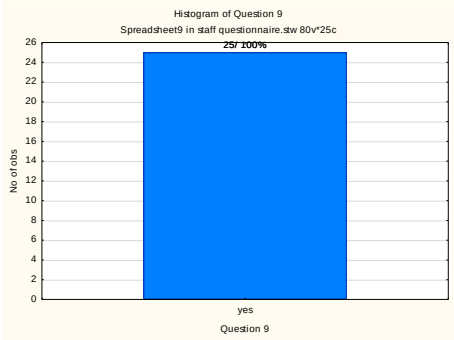

Figure 4. 8: Number of participants vs. the awareness of the side effects of ARVs

The graph shows that all participants (100%) were told about the side effects of ARVS and this implies that all staff have the knowledge to inform patients and other staff members about the side effects of ARVs.

Question 10: Who informed you about the side effects of ARVs? (More than 1 answer can be circled)

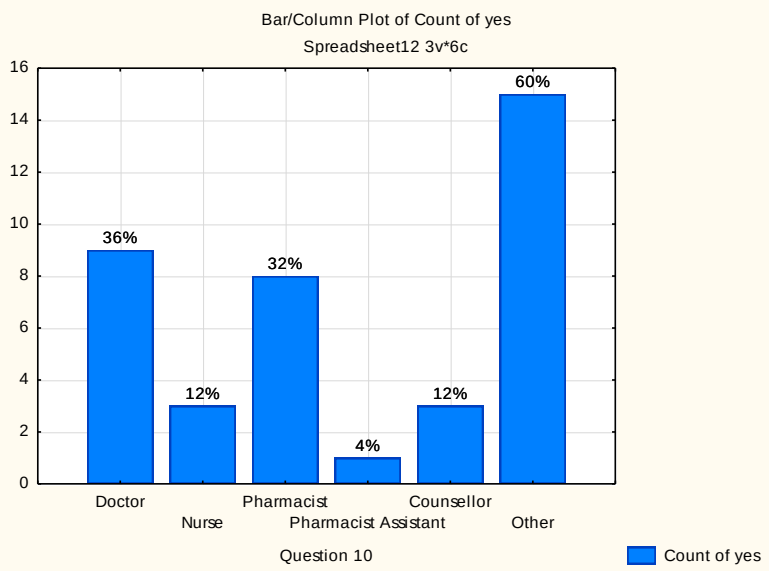

Figure 4.9 : Number of participants vs. the person/s who informed the participant about the side effects of ARVs

The graph indicates that 36% of the respondents were informed by a doctor, 12% were informed by a nurse, 32% were informed by a Pharmacist, 4% were informed by a

Pharmacist Assistant, 12% were informed by a counsellor and 60% were informed by the lecturers at a university or college. The results show that most of the participants were informed about the side effects through formal training and education whereas other participants gained knowledge through practical in- service training sessions as well as the experiences of working with a doctor, pharmacist or nurse. The Pharmacist Assistant was the least involved in providing knowledge and information about the side effects to other participants.

Question 11: Do you think that the side effects of ARVs are something serious?

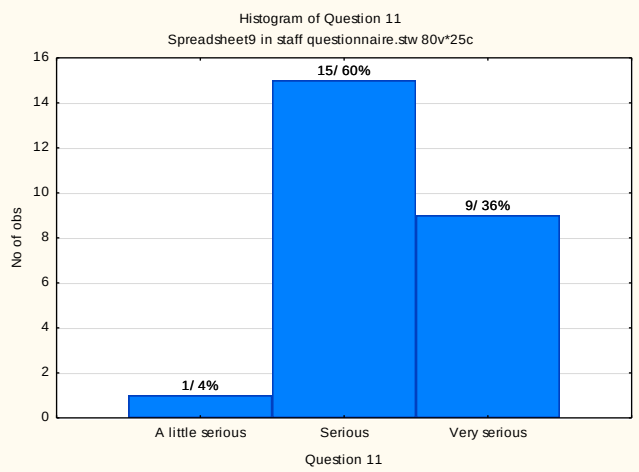

Figure 4. 10: Number of participants vs. the perception of the seriousness of ARVs

The results show that 60% of participants thought that side effects are a serious concern, 36% thought that side effects are very serious and 4% thought that the side effects are a little serious. None of the staff thought that side effects are not serious or nothing to worry about.
This question was asked to establish the perception of the seriousness of side effects by staff as the perception of staff could influence the perception ofthe patients.

Question 12: What do you think causes the side effects of ARVs?

This was an open ended question and it was asked to assess the individuals understanding of the mechanism of action of the ARVs. The question elicited various responses.
The responses ranged from “it’s something that’s in the medication”, “it’s the weak response of the immune system “or “it’s the toxicity of the ARVs”.

Generally most participants thought it was due to the new introduction of the ARVs to the body, which generated an undesired reaction and this was thought to be a side effect.

The responses from the participants indicate that the staff have knowledge about the action of the ARVs but there was difficulty amongst some participants in the understanding of the pharmacology and the mechanism of action of the ARVs. There was no mention of the influence of drug-drug; drug-food, drug-chemical interactions .This carries significanceas it can contribute to a side effect and it needs to be considered when patients are counselled or when ARV adherence levels are monitored.

Question 13: Do you think that the side effects of ARVs can be stopped or discontinued?

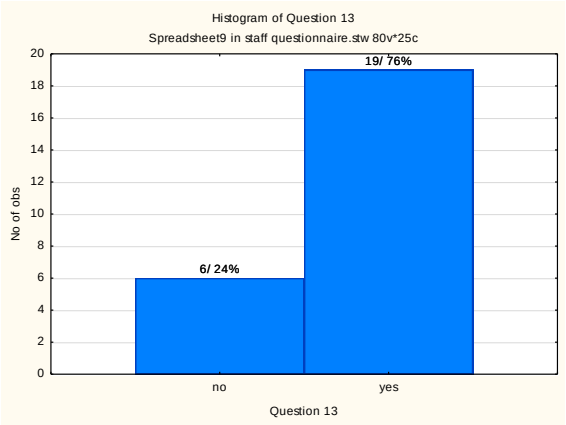

Figure 4. 11 : Number of participants vs. the perception of the discontinuation of ARVs

From the graph it is observed that 76% of the participants thought that side effects could be stopped or discontinued whereas 24% thought that the side effects of ARVs could not be stopped.

In practise if patients complain about the side effects they are referred to a clinician who provides symptomatic treatment for the relief of the side effect or in severe cases the patient is switched to an alternative treatment regimen.

Question 14: How many side effects of ARVs can be stopped?

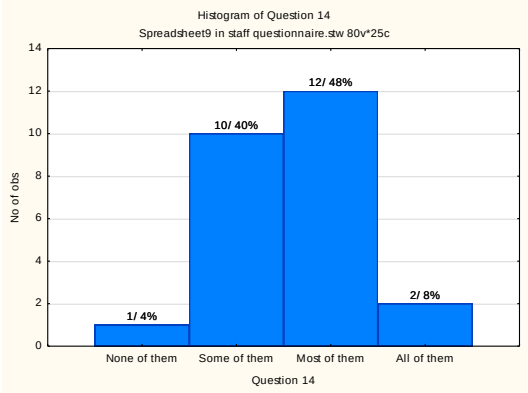

Figure 4.12 : Number of participants vs. the knowledge of stopping the side effects of ARVS

This question was asked to understand the participants' knowledge of the length and duration of the side effects of ARVS. From the graph it is observed that 48% of the participants said that most of the side effects can be stopped, 40% said some of them can be stopped, 8% said all of them can be stopped and 4 % said none of them can be stopped. Most of the participants thought that most of the side effects could be stopped, as transient side effects stop after 3-4 weeks of initiating treatment with ARVs. The medium and late side effects of ARVs are more challenging and complicated to stop and the clinician will weigh up the benefits of the drug in comparison to the side effect in order to derive the best clinical outcome for the patient.

Question 15: Do you think that side effects can change over time with the treatment of ARVs?

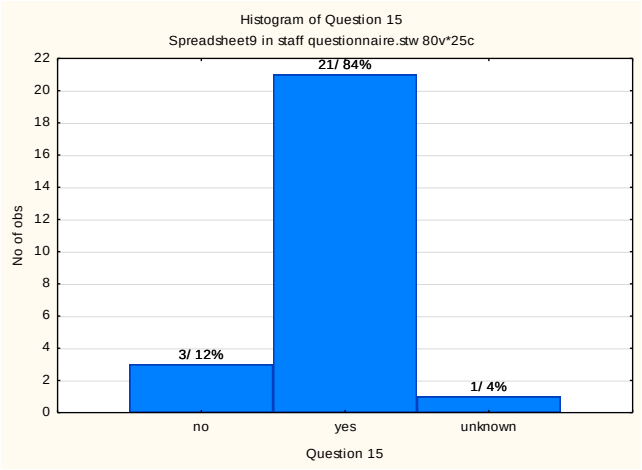

Figure 4.13. : Number of participants vs. knowledge of the change of side effects of ARVs over time

The graph indicates that 84% of the participants thought that side effects could change over time, 12% said that side effects could not change over time and 4% did not know whether the side effects could change over time.The results indicate that the participants are awarethat the side effects could change. This knowledge was based on their practical experiences of the side effects in patients and the knowledge of the medium and late side effects of ARVs in HIV patients.

Question 16: Did you receive training on the side effects of ARVs?

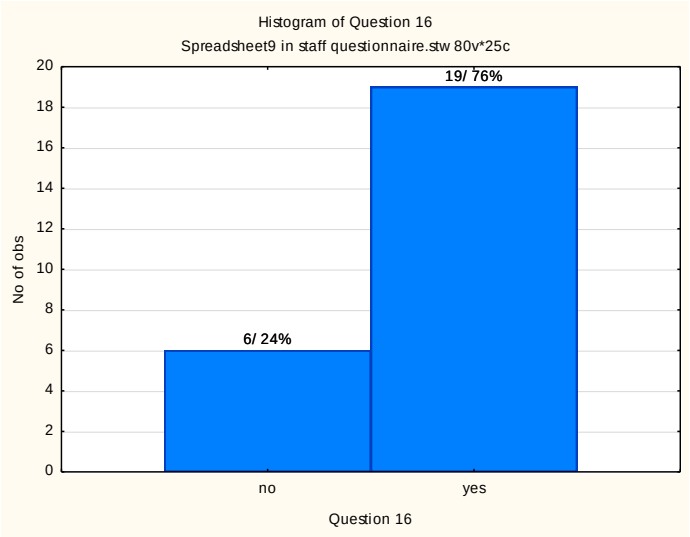

Figure 4. 14 : Number of participants vs. completion of training

It is observed that76% of the participants were trained on the side effects of ARVs whereas 24% of participants said that they were not trained on the side effects of ARVs.

The staff were provided with formal or informal service training on the side effects of ARVs. It is critical that 100% of staff are trained on the side effects of ARVs.

Question 17: When and where did you receive training about the side effects of ARVs? Please explain.

This was an open ended question and it elicited various responses.

The question was included to validate the answer to question 16 above.

Participants were trained at university, at formal workshopsprovided by external consultants or at “in- service” training sessions” at the clinic. Only one participant provided a date when he received training.

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C. QUESTIONS ON PERCEPTION

Question 18: Do you think the side effects of ARVs are something good or bad?

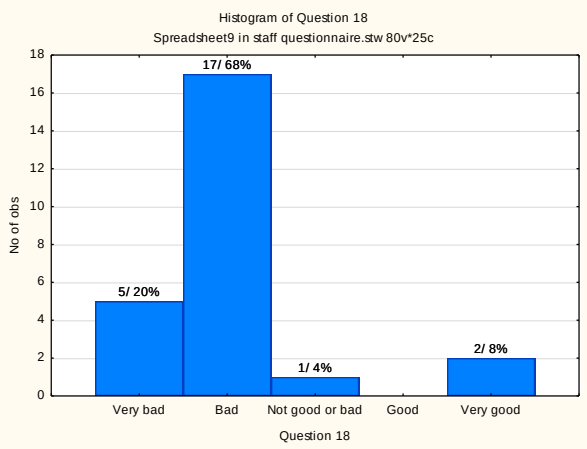


Figure 4.15 : Number of participants vs. the perception of the bad or good side effects of ARVs

The graph shows that 68% of the participants thought that side effects are bad, 20% thought side effects are very bad, 8% thought the side effects are something very good and 4 % of the participants said that side effects are not good or bad. None of the participants thought that side effects are something good that happens to you. Most staff thought that a side effect is something bad that happens and this is the 'normal' theoretical perception, but the above results also show that two participants thought a side effect is something very good. The participants explained this perception that a side effect is something good or very good as the clinician is then able to prescribe alternative drugs to customise the regimen or "suit "the patient.

Question 19: Is it difficult to understand the side effects of ARVs?

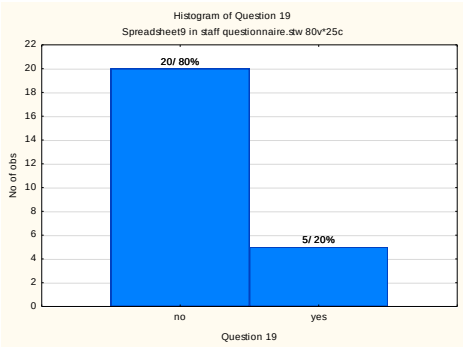


Figure 4. 16: Number of participants vs. the difficulty in understanding the side effects of ARVs

It is observed that 80% of the participants said it was not difficult to understand the side effects and20% of the participants said that it was difficult for them to understand the side effects of ARVs.Most staff said that it not difficult to understand the side effects of ARVs and this was because the side effect is interpreted in 'layman's terms and not using scientific or clinical terminology.

This also implies that staff need to understand the actions of the ARVS in the body in order to understand the side effects especially if a side effect cannot be translated into non-scientific terms.

Question 20: If yes (in number 19 above) please explain:

From the results 80% of the participants said it was not difficult to understand the side effects of ARVs but five participants said it was difficult because of the pharmacology and mechanisms of action of the ARVS. One participant said it was difficult because of the different treatment regimens of ARVs which is confusing. This indicates that we need to look at different ways in training staff about the side effects so that all staff can understand the terminology and applications of the side effects of ARVs.

Question 21: Do you think patients know about the side effects of ARVs?

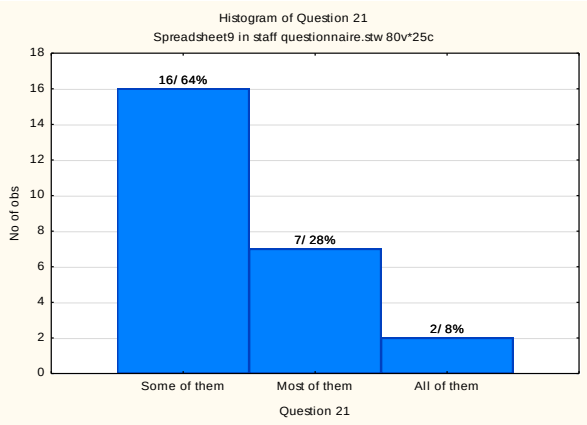


Figure 4.17 : Number of participants vs. the perception of other patients' knowledge on the side effects of ARVs

The results show that 8 % of participants thought that all patients know about the side effects of ARVs, 28% said that most of them know and 64% said that only some of the patients know about the side effects. The highest percentage of respondents thought that only some patients know about the side effects which indicates that staff needto improve the knowledge and communication of the side effects to all patients In practise one would expect all of the patients to know about the side effects of ARVs as all patients are counselled about the side

effects before starting ARVs. These low results indicate that staff need to use different interventions and approaches to communicate more effectively to patients and to improve this perception.

Question 22: Do you think that patients must be told about the side effects of ARVs?

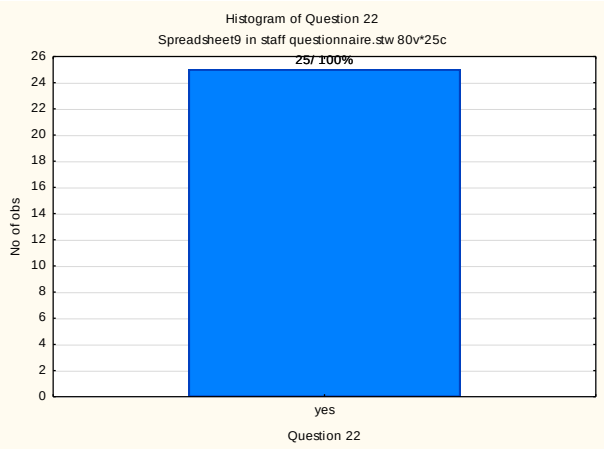


Figure 4. 18 : Number of participants vs. the perception of patient knowledge on the side effects of ARVs

The results show that 100% of the participants (i.e. all staff) think that patients must be informed about the side effects of ARVs. This result is an important finding and contrary to the introductory statements in chapter 1 of this research study.

Question 23: Do you think that patients look for the side effects of ARVs or any changes in their body?

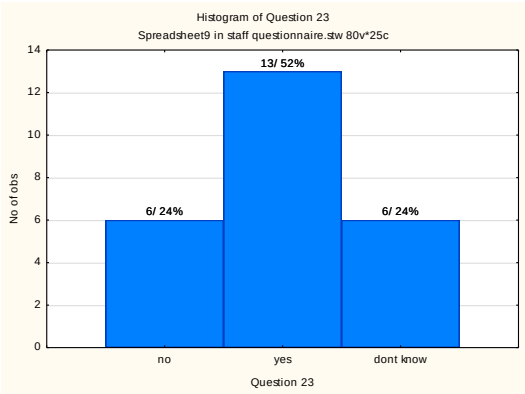


Figure 4.19Number of participants vs. the perception of the application of patients' knowledge about the side effects of ARVs

The graph shows that 52% of the participants thought that patients look for the side effects or any changes in their bodies whereas 24% said that they do not know if patients look for the side effects or any changes in their bodies and 24% did not think that patients look for any side effects or changes in their bodies**.**There is an equal distribution of negative responses to this question but most participants thought that patients could apply the knowledge of the effects to themselves. Staff should encourage all patients to look for the side effects or changes in their bodies so that their condition could be managed more optimally.

Question 24: Do you think that the patient's knowledge about side effects is linked to adherence?

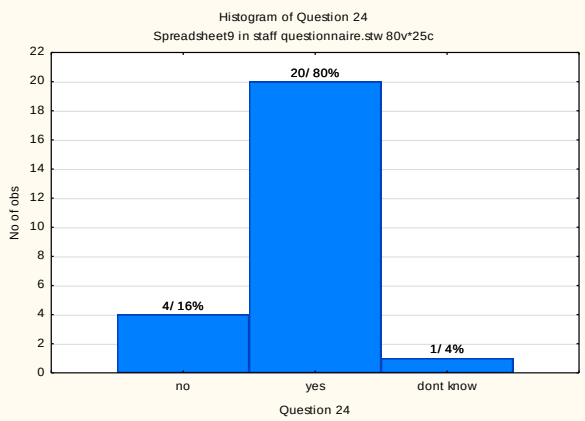


Figure 4. 20 : Number of participants vs. the link to the adherence of ARVs

From the responses it is observed that 80% of the participants think that the patients' knowledge of the side effects is linked to adherence, 16% thought that it is not linked to adherence and 4% did not know if there was any linkage of the patients knowledge of the side effects and adherence. This implies that if patients are not knowledgeable about the side effects it could lead to defaulting and non adherence to treatment. Adherence is an important element in the management of patients and this emphasizes the need for patients to understand their ARVs and treatment regimens.

Question 25: When do you think patients must be told about the side effects of ARVs? (More than 1 answer can be circled)

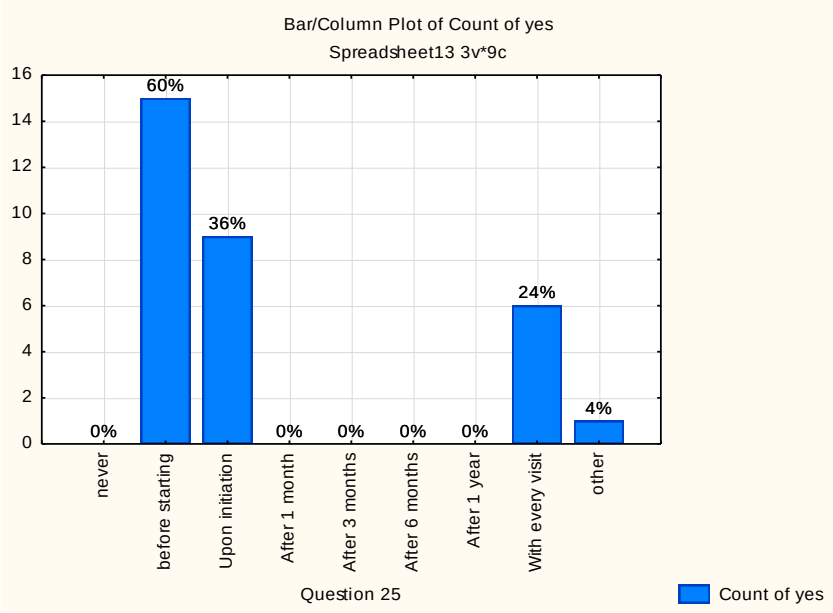


Figure 4. 21 : Number of participants vs. the frequency of telling patients about the side effects of ARVs

The results show that 60% of responses indicate that patients must be told about the side effects before starting ARVs, 36% said that patients must be told when ARVs are initiated, 24% said that patients must be told with every visit and 4 % said that patients must be told when there is a regimen or a dosage change. None of the participants indicated that patients should be told after 1, 3, 6 or 12 months (1 year) of initiation. T his perception is important as it influences the knowledge of patients and it also provides an explanation of the current practices that staff follow at the clinic.

Question 26. Do you think staff members at this facility know about the side effects of ARVs?

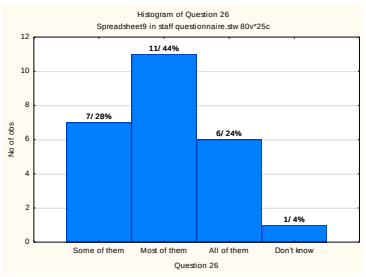


Figure 4.22 : Number of participants vs. the perception of the side effects of ARVS amongst other staff members

This question was asked to gauge the communication and practices followed at the facility as staff interact with patients and other staff members

From the graph it is observed that 24% of participants said that all of them know,44% said most of them know, 28% said some of them know and 4 % did not know if staff knew about the side effects of ARVs. A low percentage of staff think that all of their colleagues know about the side effects of ARVs and to correct this perception, more training needs to be provided staff at the clinics.44% of staff think that most of the colleagues at facilities know about the side effects of ARVs. This implies that for 100% of staff to know about the side effects ,more training needs to be provided to the staff.

Question 27: Who do you think must inform patients about the side effectsof ARVs? (More than 1 response can be circled)

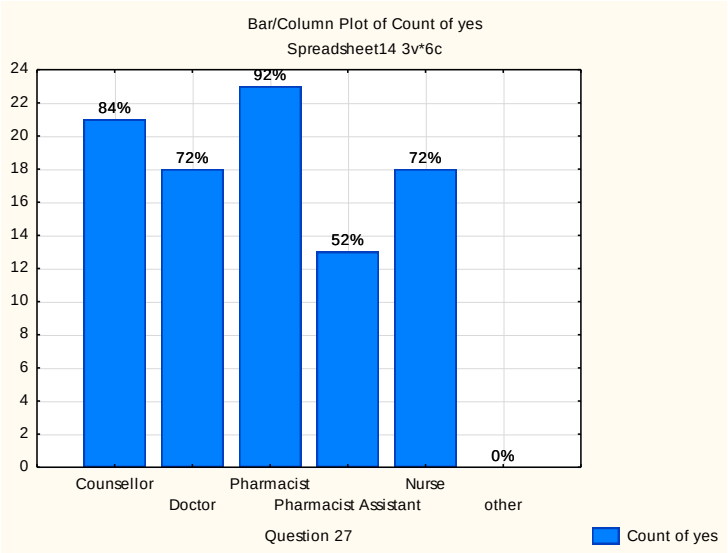


Figure 4.23 : Number of participants vs. the person/s responsible for informing patients about the side effects of ARVs

The results show that 92% of respondents thought that the pharmacist must inform patients about the side effects of ARVs. ,84 % thought it was the counsellors' resposnsibility,72% said it was the doctor and nurses' responsibility to inform patients and 52% thought it was the pharmacist assistants' responsibility.

The respondents thought that the Pharmacist had the highest percentage and responsibility to inform patients about the side effects of ARVS although all participants play a role in informing patients about the side effects of ARVs. In practice it was observed that the pharmacists were not counselling patients about the side effects of ARVs due to time

constraints and the huge patient numbers that are seen on a daily basis. Interventions are needed to correct the practices and perceptions of the role of the pharmacist, as well as the role of other staff members in finding the best practical and sustainable solution .

Question 28. Do you think there is enough time spent educating patients about the side effects of ARVs?

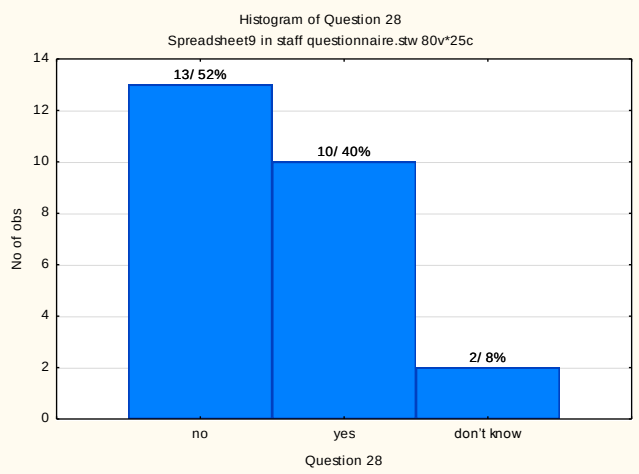


Figure 4.24 : Number of participants vs. the perception of time spent educating patients about the side effects of ARVs

The graph shows that 52% of participants thought that not enough time is spent educating patients about the side effects of ARVS,40% of participants thought enough time was spent in educating patients about the side effects, and 8% did not know if enough time is spent educating patients about the side effects of ARVs.Thus result supports the response to question 26 because if not enough time is being spent in educating patients about the side effects then not all of the patients will know about the side effects of ARVs. Time is an important element in the communication and education of patients about their condition. An intervention is thus needed to spend more time educating patients about the side effects of ARVs.

D. QUESTIONS ON ATTITUDE

Question 29: Do *you* inform patients about the side effects of ARVs?

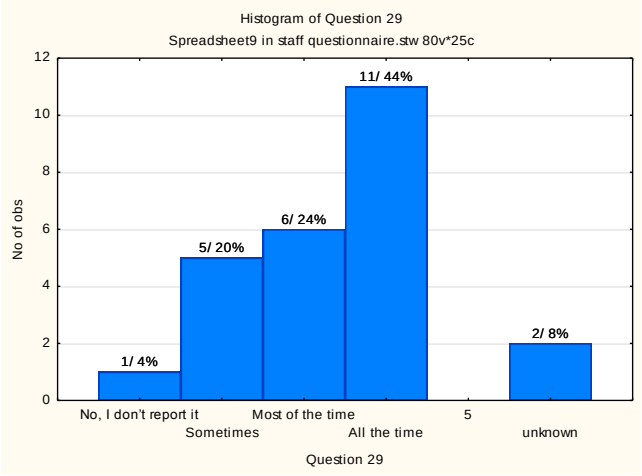


Figure 4.25 : Number of participants vs. the attitude of participants to inform patients about the side effects of ARVs

It is observed that 44% of the participants said they inform patients about the side effects of ARVs all of the time,24% said they inform patients most of the time,20% said they inform patients sometimes, 4 % do not inform patients and 8% of the results were invalid(unknown). The results indicate fewer than half of the participants inform the patients all the time about the side effects of ARVs. It is expected that all patients must be informed about the side effects of ARVS and this means that staff need to find a practical solution to inform all patients about the side effects of ARVS all the time.

Question 30: Do you tell them the same side effects each time they visit the Clinic /hospital?

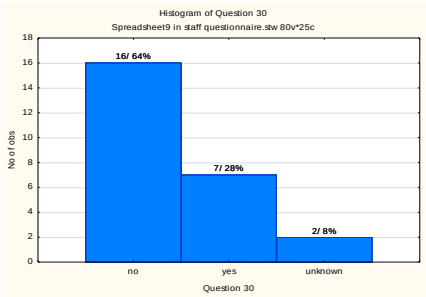


Figure 4. 26: Number of participants vs. the provision of the same or different side effects by staff to patients

The results show that 64% of participants do not tell the patients about the same side effects every time they visit the facility,28 % tell patients about the same side effects every time they visit the clinic and 8% of the results were unknown (invalid) .In practice this means that the participants need to have a structured approach of recording the side effects in the patients folder ,in order for the patient and staff member to know what side effects were previously discussed with the patient. This was not standard practise at the clinics amongst all staff members.

Question 31: How many side effects do you tell them of each ARV?

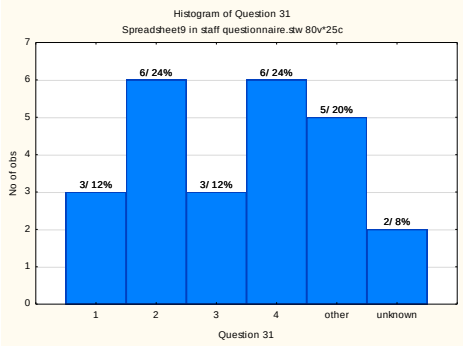


Figure 4. 27 : Number of participants vs. the number of side effects provided to patients

The results show that 24 % of the participants provide 2 side effects per ARV to the patients, 24% of participants provide 4 side effects per ARV, 12% provide 3 side effects per ARV, 12% provide 1 side effect per ARV, 20% provided an independent number based on the patients level of education and 8% of the participants responses were unknown (invalid).

The graph shows an equal distribution between 2 and 4 side effects, as well as between 1 and 3 side effects per ARV but most of the participants shared 2 or 4 side effects per ARV with patients.

Question 32: How do you decide how many side effects you must tell the patient?

This was an open ended question toprovide information how staff decides how many side effects to tell a patient. Most participants said that they explain the most common ones and the most experienced side effects that patients complain about. Some of the responses are described below:

“If the patient has a reasonable understanding and asks questions, I explain as much as possible.”

"It's important to tell everything you know."

"I explain if the patients ask."

"I must have an understanding what regimen the patient is introduced to then I would decide to tell the patient. "

This question was asked to see whether a patient's individual need could be addressed. The results show that staff inform patients about the side effects of ARVs but they think that it depends on the individual's treatment regimen and the patients understanding of their condition.

Question 33: Do you tell them the general or specific side effects of ARVs?

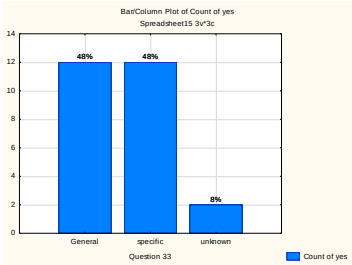


Figure 4.28 : Number of participants vs. informing patients about the general or specific side effects of ARVs

The graph indicates that 48% of participants inform patients about the general side effects of ARVs, 48% inform patients about the specific side effects of ARVs and 8% of the responses were unknown (invalid).An equal distribution is observed between the provisions of general or specific side effects to patients. This means that in practice both the general and specific side effects are told to patients as in theory many of the side effects of the ARVs overlap. The specific side effects such as lipodystrophy are uniquely related to an ARV drug such as Stavudine tablets.

Question 34: When patients tell you their side effects what do you do?

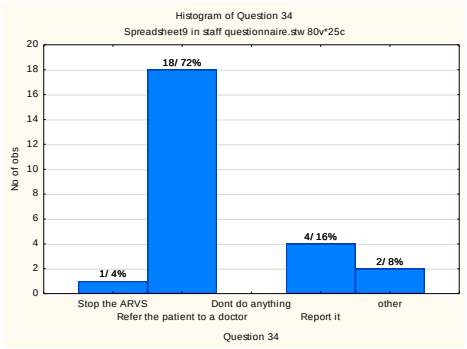


Figure 4.29: Number of participants vs. the response of staff in managing side effects

It is observed that 72% of the participants refer the patient to a doctor, 16% report the side effect, 4% of participants stop the ARVs and 8% of the responses were unknown (invalid).A low number of side effects are reported and this practice needs to be improved to an optimal and practical level of reporting as all side effects need to be reported.

In practise when patients experience a side effect they are referred by the staff to a doctor. This implies that the doctor is one of the key role-players at wellness clinics and at ART sites. The results indicate that we expect the doctors to initiate and report the side effects of patients to MCC and the respective authorities.

Question 35: Do you report the side effects of ARVs?

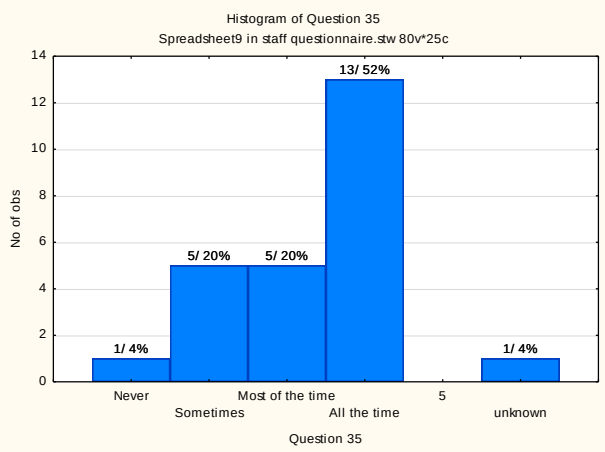


Fig 4. 30:Number of participants vs. the frequency of reporting side effects of ARVs

The graph shows that 52% of the participants report the side effects all the time, 20% report it most of the time, 20% report it sometimes, 4% of participants never report it and 4 % of the responses were unknown (invalid).The results imply that only half of the participants report the side effects of the ARVS all of the time which is below the expectation that all side effects must be reported to the respective authorities.This shows that there is a need for an improvement on the reporting of the side effects or the process of reporting needs to be investigated to improve the current status of reporting in the province.

Question 36: To whom do you report the side effects of ARVs? (More than 1reponse can be circled)

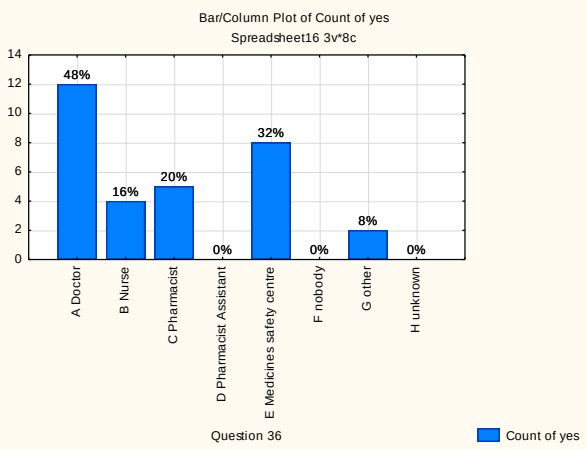


Figure 4. 31: Number of participants vs. the reporting of the side effects to a person/s

From the graph the responses indicate that 48% of the respondents report the side effects to a doctor, 32% report it to the Medicines Control Council, 20% report it to a Pharmacist, 16% report it to a nurse, and 8% to a counsellor and 0% report it to a Pharmacist Assistant. This shows that the doctor has the greatest responsibility to report the side effects of ARVs. The low percentage of reporting from nurses and Pharmacists requires further investigation.

Question 37: Do you want to know more aboutthe side effects of ARVs?

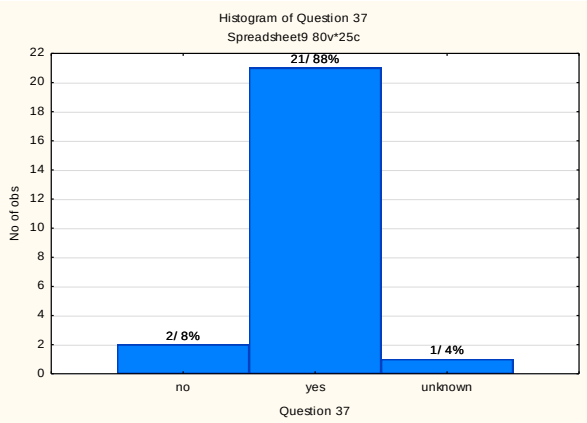


Figure 4. 32 : Number of participants vs. the need for more knowledge on the side effects of ARVs

From the graph it is observed that 88% of participants want to know more about the side effects of ARVS,8% do not want to know more about the side effects of ARVs and 4% did

not know if they wanted to know more about the side effects of ARVs. This indicates that there is a need for more awareness and training on the side effects of ARVs.

Question 38: Do you ask questions about the side effects of ARVs?

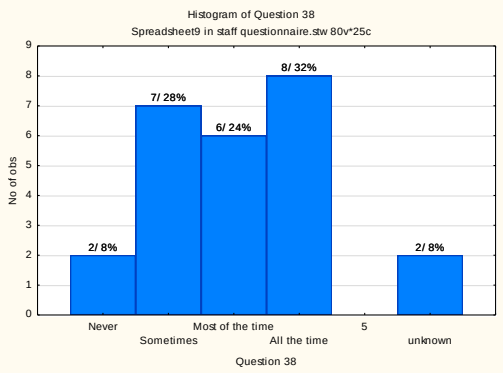


Figure 4.33: Number of participants vs. the frequency of asking questions about the side effects of ARVs

The results show that 32% of the participants ask questions about the side effects of ARVs all the time,28% of the participants ask questions sometimes,24% ask questions about the side effects most of the time, 8% of participants never ask questions and 8 % of the responses were unknown(invalid).

Learning is gained through asking questions to patients and staff and the low results could be due to the complexity in understanding the pharmacology of the ARVs and the side effects. This indicates that training must be provided to staff to improve their knowledge on the side effects of ARVs.

Question 39: Do you read more about the side effects of ARVs?

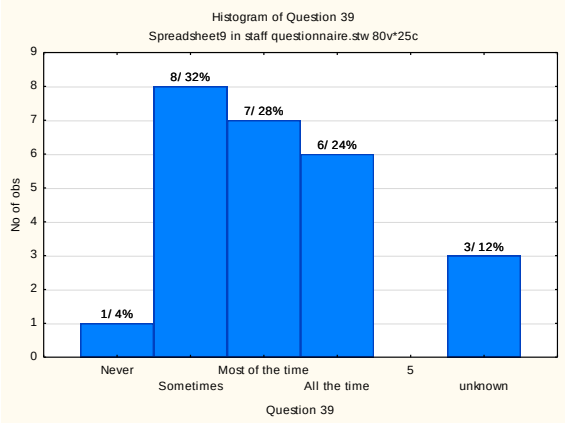


Figure 4.34: Number of participant vs. the frequency of reading about the side effects of ARVs

The graph shows that 24% of the participants read about the side effects of ARVs all the time,32% read about the side effects of ARVs sometimes,,28% read about the side effects most of the time, 4% 'never 'read about the side effect of ARVs and 12% of the responses were unknown(invalid). Staff should be encouraged to read more about the side effects of ARVs so that they are 'up to date 'and knowledgeable about the side effects of ARVs. In practise the provision of pamphlets, brochures and posters at clinics would create an enviroment to enable staff to read more about the side effects of ARVs.

Question 40: What do you think will assist patients to know more about the side? effects of ARVs? (More than 1 can be circled)

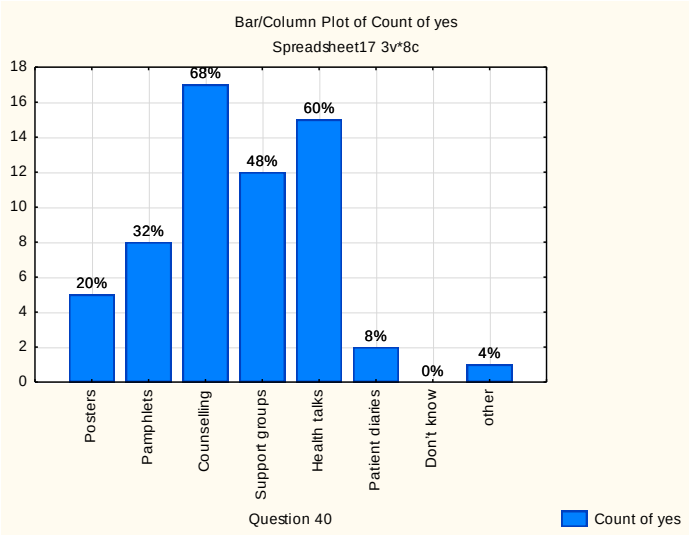


Figure 4.35: Number of participants vs. aids to support patient knowledge in understanding the side effects of ARVS

It is observed that 68% of respondents thought that counselling was necesssary, 60% suggested health talks,48% suggested support groups, 32 % suggested the use of pamphlets, 20% suggested the use of posters, 8% suggested the use of patient diaries and 4% suggested a combination of *all* these measures toimprove the patients' knowledge and understanding of the side effects of ARVs. This indicates that counselling, support groups and health talks should be prioritised to assist and provide patients with more knowledge about the side effects of ARVs. The staff thought that pamphlets and posters are useful but it ranked the used of reading materials lower than the use of counselling, health talks and support groups as the staff routinely have to interact with patients with low education levels. These suggestions are critical interventions that are needed at the wellness clinics.

Question 41: Do you have any suggestions how the clinic/hospital can improve its services so that staff know and understand about the side effects of ARVs?

This was an open ended question and it was asked additionally to question 40 to obtain a wider source of responses. Most participants suggested that more training should be offered. The participants also suggested the following:

"Ongoing in-service trainings and workshops"

"More workshops after new research studies"

"Everyone should start being more involved in HIV and AIDS"

"By using every tool available and making full time provision"

"Increase time for health talks and make pamphlets in addition to counselling"

"Improve staff shortages"

"Make a delegated person responsible to deal exclusively with the side effects in counselling patients"

"Have patient diaries, pamphlets, posters and proper tracking systems"

"Develop a DVD and play this to patients during counselling and support group sessions"

The results of this question supports the results of question 40 (above).It was also suggested that the number of staff at the wellness clinics need to be increased and staff need to be more supported in their respective roles.

4.2BRESULTS FROM THE PATIENT QUESTIONNAIRES

The proposed sample population size was 60 HIV patients (in total) but 62 patients participated in the study.

The response rate for participation in the study is 103% with N = 62.

Table 4.3 : Participation of total HIV patients in the research study(N=62)

Total participants intended to be part of the study	Total number participants in study	Response rate (%)
60 patients	62 patients	(62/60) x 100% = 103% response rate

Table 4.4 : Participation of HIV patients per facility and per gender		
	Patients participating(N = 62)	Percentage participation
KHC patients	7	(7/62) = 11.29 %
GDH patients	55	(55/62) = 88.71%
Total patients	62	100%

The results of the patient questionnaires are now discussed with a simplified analysis of the result included under each question and graph.

A. GENERAL QUESTIONS

Question 1: Age of participants .

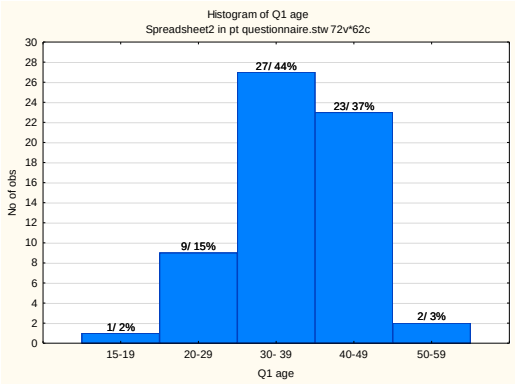


Figure 4.36 : Number of participants vs. age

The graph shows that 44% of the participants were in the 30-39 year old age group, 37 % were in the 40-49 year old age group, 15% were in the 20-29 year old age group, 3% were in the 50-59 year old age group and 2%(1 participant) was in the 15-19 year old age group. This participant was above 18 years of age in order to be included in the study.The graph presented the highest distribution of patients between the 30-39 and 40-49 year old age groups. This appears to be in line with the results of the national antenatal survey (NDOH, 2011) that shows the highest HIV prevalence amongst femalesin the 30-34 year old age group. Age is an important element of any analysis as it carries significance in the approach, culture and manner of communication between person to person/s and health worker to patient/s.

Question 2: Gender of participants

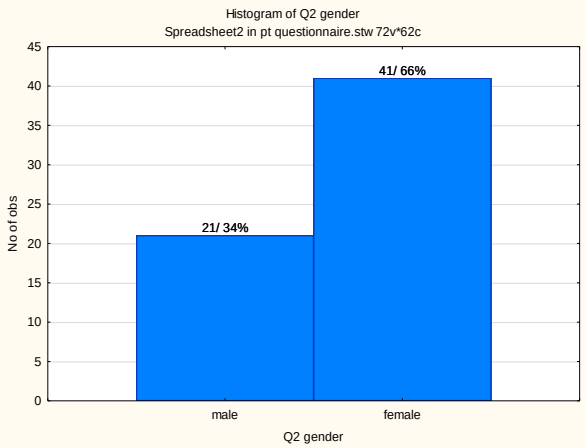


Figure 4.37: Number of participants vs. gender .

From the graph it is observed that66% of the participants in the study were female and 34% were male participants which could signify that there are more females than males attending the wellness clinics. This result is in line with the trend that more females than males are initiated on ART within the CCMT program in the province. (CCMT data, 2012)

Question 3: Highest Education level

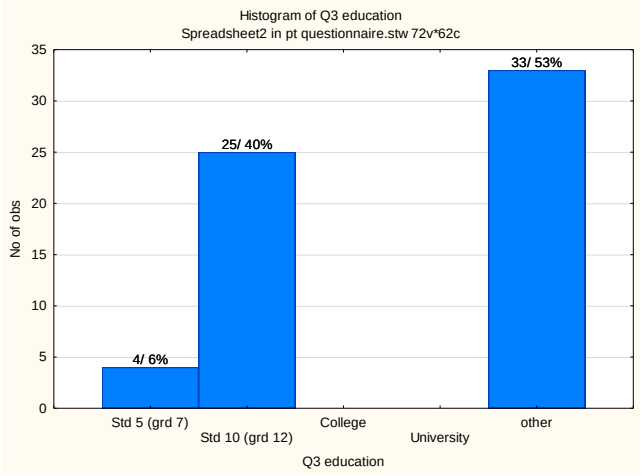


Figure 4.38 : Number of participants vs. the highest level of education

From the graph it is observed that only 40% of the participants had a grade 12 (standard 10)education level, with 6% of the participants having an education level of grade 7(standard 5)and 53% of the participants had another education level. The other education levels included grades 2,3,6,8,810 and 11.The lowest level of education was grade 2.The education level of the participants is important as it enables the researcher to understand and relate the results to other questions in the study. Education is an important concept in the management of HIV patientsand their adherence to treatment.

B. QUESTIONS ON KNOWLEDGE

Question 4: Can HIV be cured?

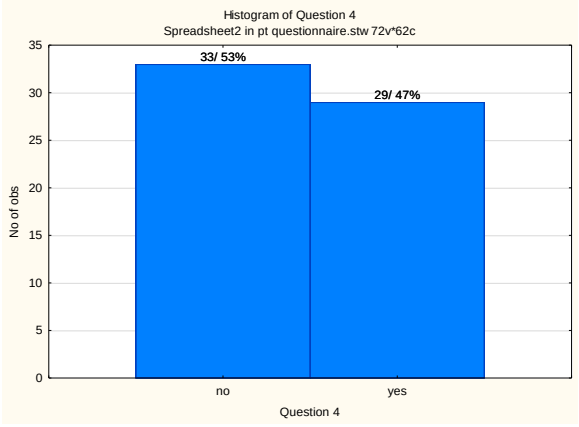


Figure 4.39 : Number of participants vs. responses to the question"Can HIV be cured?"

The graph shows that 47% of the participants said that HIV can be cured and 53% said that HIV cannot be cured. There was a higher percentage of patients that think that HIV cannot be cured. This perception is important with regards to the management and approach of the patients as it shows us their understanding of their condition in the management of HIV. The results do not show if the perceptions are related to the age group, gender or educational status of patients or whether the perceptions are related to the communication or practices at the facilities.

Question 5: What treatment is provided at a clinic/hospital to a person with HIV?

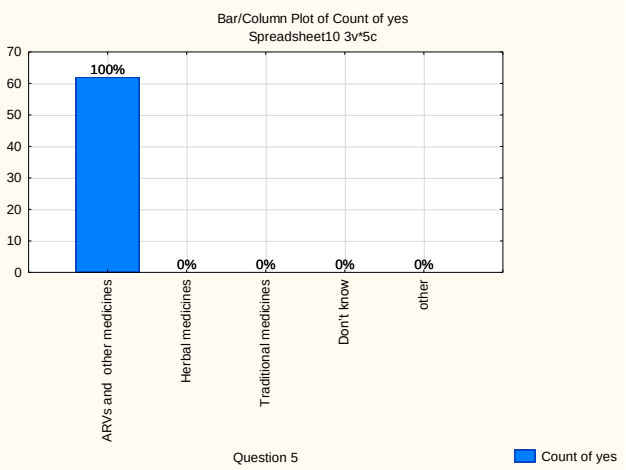


Figure 4. 40: Number of participants vs. knowledge of treatment at a clinic or hospital

The results indicate that 100% of the participants said that ARVS (and other medicines) are provided at the clinic or hospital to a person living with HIV. This shows that all the participants knew that ARVS (and other medicines) are provided at the clinic/hospital. and herbal or traditional medicines are not provided at the clinic or hospital. The participants were able to provide examples of other medicines which are routinely used by HIV patients such as Co-trimoxazole tablets®, TB medicines, hypertensive medicines and vitamin tablets.

Question 6: Are you taking ARVs?

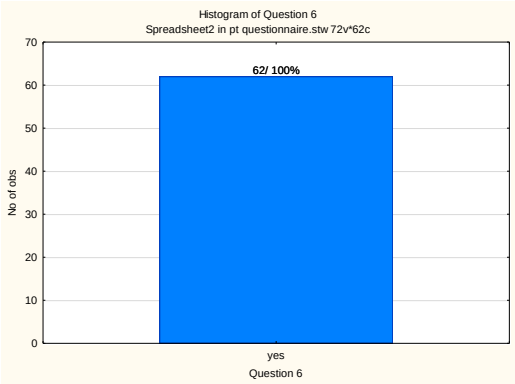


Figure 4.41 : Number of participants' vs. the usage of ARVs

The results show that 100% of the participants are taking ARVs as part of their treatment. This implies that all patients have some awareness or familiarity of their medication by means of the 'common' names, generic or trade names, dosage or the dosaging schedule or the side effects they have experienced.

Question 7: How long have you been taking ARVs?

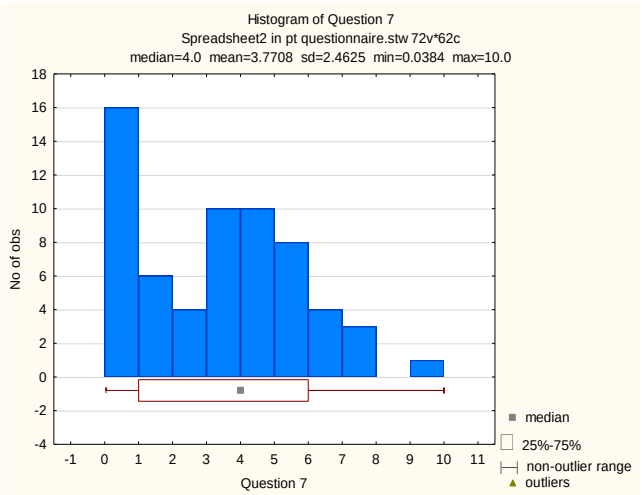


Figure 4.42: Number of participants' vs. duration of the participant on ARVs

This graph indicates that 16 patients are 0 - 1 year on ARVs, 6 patients are between 1- 2 years on ARVs, 4 patients are between 2- 3 years on ARVs, 10 patients are between 3-4 years on ARVs, 10 patients are between 4- 5 years on ARVs, 8 patients are between 5-6 years on ARVs, 4 patient are between 6-7 years on ARVs, 3 patients are between 7-8 years on ARVs and 1 patient is between 9-10 years on ARVs. There are no patients between 8-9 years on ARVs.

The graph also shows the mean (average) number of years for all the participants on ARVs as 3.7708 years (approximately 3.8 years or rounded to an average of 4 years).The median of the graph is 4.0 which means that 4.0 years is the midpoint of the graph in which half of the participants are below this point and the other half are above this point. This implies that half of the participants are graphically shown to the left or the right of this point of 4 years.25-75% of all the participants fall within 1 to 6 years on treatment and all participants are represented in the 0 to 10 year period with no outliers depicted on the graph. The graph informs us that in this study the highest number of patients were under 1 year on ARVs.

The length that a patient is on ARVs is important as it informs us of the patients' knowledge, understanding and their adherence to ARVs. It also is able to provide us with knowledge of the counselling practices at the facilities. It is expected that the patients with the least number of years on ARVs should be able to recall more side effects, as they would have more recent experiences of the side effects or they would remember the side effects from recent counselling sessions in comparison to the recall of the side effects in a patient that has been 4 years on ARVs. The knowledge of the length of patients on ARVs is important as it could be used to guide staff in counselling patients more effectively on the side effects of ARVs.

Question 8: Do you know the names of your ARVs?

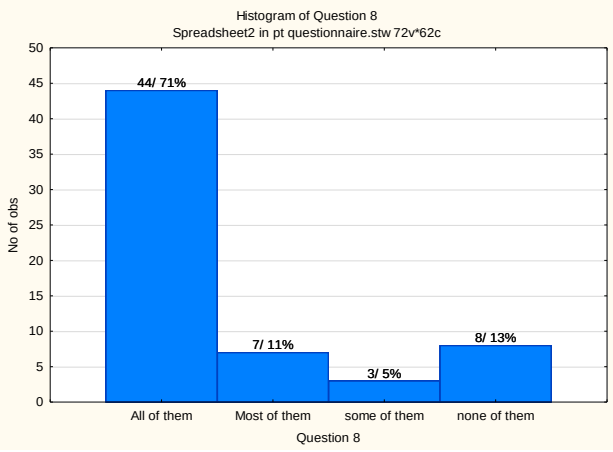


Figure 4.43 : Number of participants' vs. knowledge of the names of ARVs

The results indicate that 71% of the participants knew all of the names of their ARVs, 11% knew most of the names of their ARVs, 5% knew some of the names of their ARVs and 13% knew none of the names of their ARVs. The graph has not been further analysed in terms of the length of treatment on ARVs vs. knowledge of the names of the ARVs or the education levels vs. knowledge of the names of their ARVs but the data that was collected show that the participants with no knowledge of the names of their ARVs either have a low education level (grades 1, 2, 8) or they are elderly patients in the 40-49, 50-59 year old groups or they are patients that are under 1 year on ARVs. The knowledge of the names of ARVs is important as it is a step that is used to measure the adherence of the patient to the treatment schedule and it enables the staff and the patient to identify the ARVs that could cause side effects in the patient. The results indicate that staff should encourage all patients to know the 'names of their ARVs.

Question 9: How do you take your ARVs? Please explain.

This was an open ended question and it generated various responses.

All participants knew how to take their ARVs and they could describe to the data collector how many tablets they take in the morning and at night. Some participants were not familiar with the trade or common name of the ARVs but they could identify the ARVs from the pill packets or containers .This proves that the patients are counselled on the identification, dosage and names of their ARVs.

Question 10: Are you taking other medicines or herbs or traditional mixtures with your ARVs? Please explain.

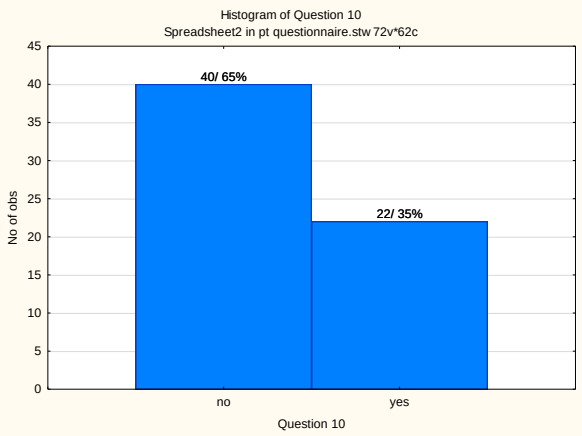


Figure 4. 44 : Number of participants vs. use of other medicines, herbs or traditional mixtures with ARVs

The graph shows that 65% of participants are not using other medicines, herbs or traditional medicines with their ARVs. The results show that 35% of the participants were using additional medicines such as hypertensive drugs, TB medicines and prophylactic drugs (such as Co-trimoxazole® tablets).One participant said that he uses an herbal product to "cleanse" his blood. This question is important as patients need to be aware of the effects of other medicines with the use of ARVs, as it could induce a drug-drug or a drug –herb interaction which could result in a side effect.

Question 11:Do you think it is important to take your ARVs as you are told at the clinic?

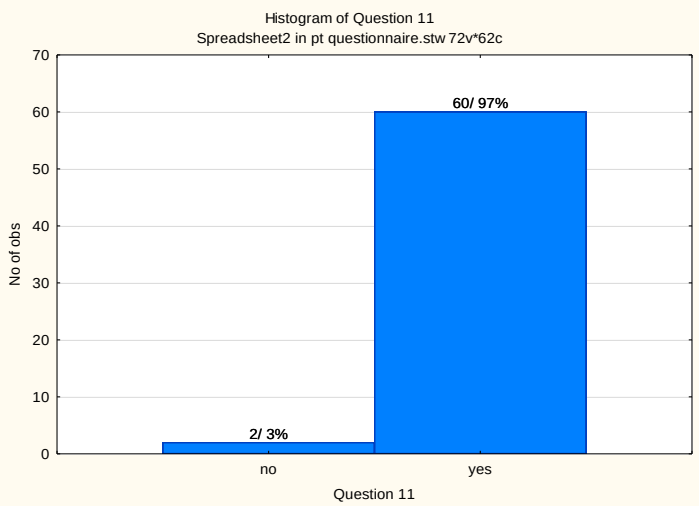


Figure 4.45 : Number of participants vs. the importance of taking ARVs as instructed by clinic staff

From the responses 97% of the participants said it was important for them to take their ARVsasthey were instructed at the clinic and 3% said it was not important for them to take their ARVs as they were instructed at the clinic. The participants said that it was important for them to take their ARVs as they were instructed because it improved their condition and their quality of life. The two participants said that it was not always possible for them to take their ARVs at the recommended time and they would deviate from the instructions if it was not possible for them to take their ARVs at the time.They considered it more important not to miss a dose. than the exactness of the time when taking ARVs.

Question 12: When you take your ARVs do you follow the instructions exactly as you are told at the clinic?

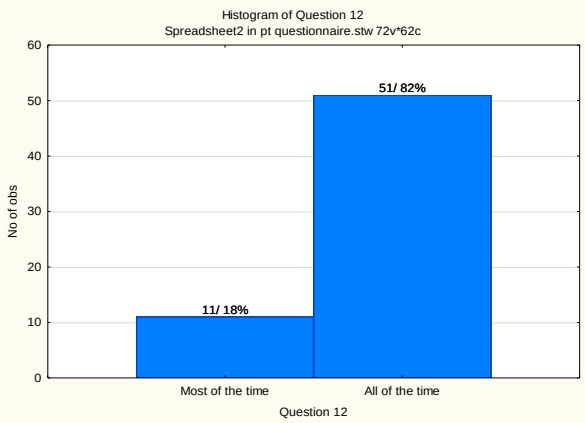


Figure 4. 46 : Number of participants vs. the exactness of following instructions when taking ARVs

The graph shows that 82% of the participants take their ARVs exactly as they are told at the clinic all of the time and 18 % of participants follow the instructions exactly as they are told at the clinic most of the time. This is important as patients need to understand the importance of adherence to ARVs for a longer quality of life.

13: Do you know what will happen if you stop taking your ARVs? (More than 1 answer can be ticked)

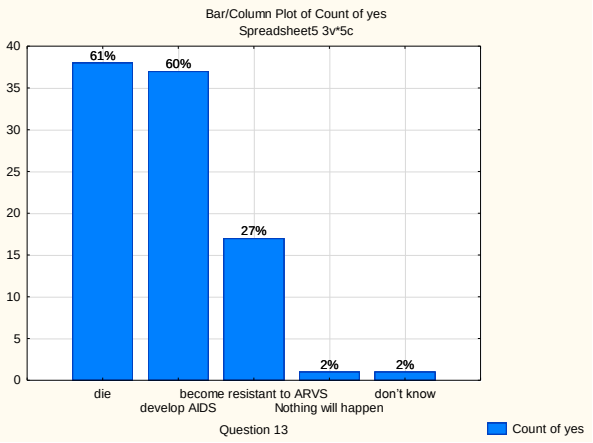


Figure 4. 47 : Number of participants vs. the responses to the discontinuation of ARVs

The results indicate that 61% of the respondents think that they could die, 60% of the respondents think that they could develop AIDS, 27% think that they could become resistant

to ARVS, 2% of participants think that nothing could happen and 2% did not know what will happen if they stop taking their ARVs. This shows that the participants knew that the discontinuation of their ARVs could lead to death or AIDS but only 27% of the participants acknowledged the possibility of the resistance of ARVs. This is important as the defaulting of participants (possibly due to the side effects of ARVs)could result in a patient being resistant to ARVs . Staff should make patients more aware about theresistance of ARVs in order for them tounderstand their treatment and to manage their side effects.

Question 14. Have you been told about the side effects (unwanted effects) of ARVs?

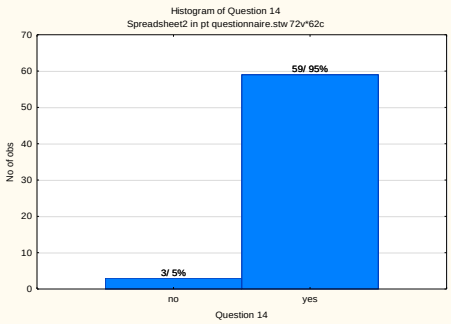


Figure 4. 48 : Number of participants vs. the awareness of the side effects of ARVs

The results show that 95% of participants were told about the side effects of ARVs with 5% of participants not aware of the side effects of ARVs. This indicates that it is the practice at the clinics to inform patients about the side effects of ARVs.

Question 15. What is a side effect (unwanted effect) of an ARV? (Please explain)

This was an open ended question and a variety of responses were obtained from the participants. This question was included validate the participantsunderstanding of a side effect. The patients could either describe the experience of a side effect or they could provide an example of a side effect.

The participants provided examples such as “rash, dizziness, runny stomach, loss of memory, black nails, headaches, dreams, weight gain,skin,flu,pimples,big shoulders and stomach, painful legs, feet, cramps, dark skin and big buttocks.” Most of the participants provided examples of side effects rather than a definition of a side effect and this was based on their own experiences or examples of side effects they were counselled on. The participants knew the common or basic side effects and not one participant provided an example of a medium or late side effect. This was observed in the participants that were on ARVs for 5 to 9 years as well. Weight gain and lipodystrophy was not perceived as a side effect by any participant.

Question 16: Who informed you about the side effects (unwanted effects) ARVs? (More than 1 answer can be ticked)

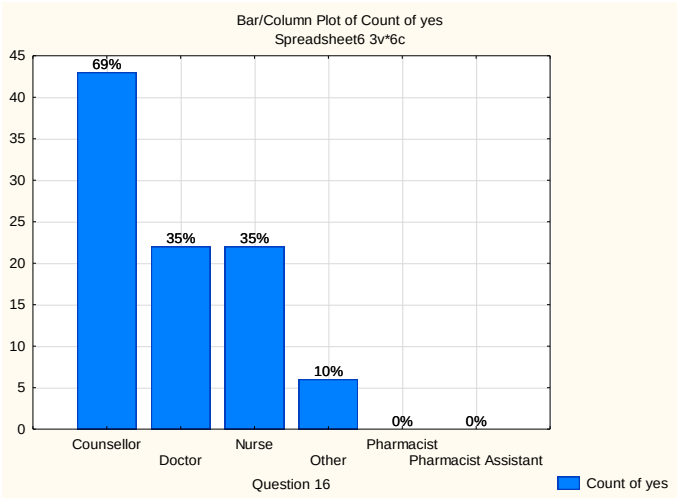


Figure 4. 49 : Number of participants vs. persons who informed the participants of the side effects of ARVs

The graph shows that 69% of the respondents were informed by a counsellor, 35% of the respondents were informed by a doctor, 35% were informed by a nurse, 0% were informed by a Pharmacist, 0% were informed by a Pharmacist assistant and 10% were informed by a combination of health providers such as a counsellor and /or a doctor and/or a nurse. This graph shows an equal distribution of responses between a doctor and a nurse which confirms the practice that patients are seen by an available doctor or nurse. The graph also indicates the important role of the counsellor and the perception of the low role of the Pharmacist in informing patients about the side effects of ARVs.

Question 17:When do they tell you about the side effects (unwanted effects) of ARVs? (More than one answer can be ticked here)

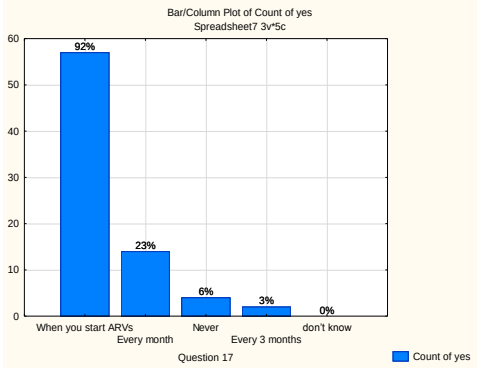


Figure 4. 50 : Number of participants vs. the time the participants are told about the side effects of ARVs

The results show that 92% of the respondents were told about the side effects when they started treatment on ARVs,23% of the respondents indicated they are told every month,6% of the respondents said they were never told about the side effects and 3% said they are told every 3 months. This indicates that most patients are informed about the side effects of ARVs when they are initiated on ARVs .A low percentage of respondents indicated that they are informed monthly about the side effects of ARVs.

Question 18: Do you think the side effects (unwanted effects) of ARVs are something good or something bad?

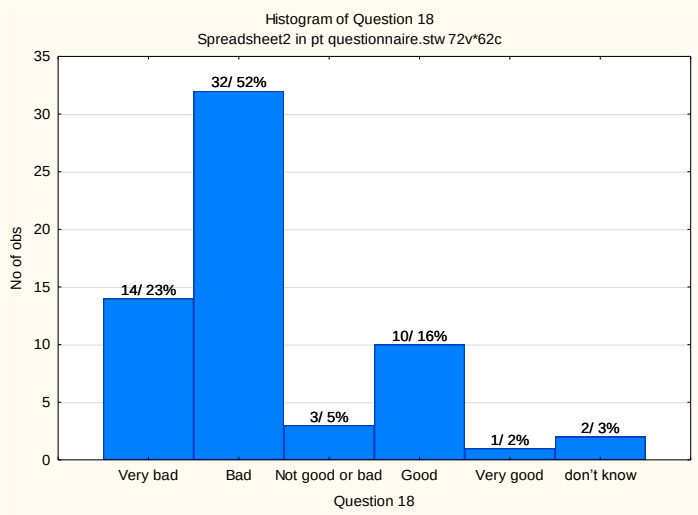


Figure 4.51 : Number of participants vs. the perception of the good or bad side effects of ARVs

From the graph 23% of participants thought side effects are very bad,52% thought side effects are bad,5% did not think side effects are good or bad,16% thought that side effects are something good, 2 % thought it was very good and 3% did not know if side effects are good or bad. The graph shows that most of the participants think that side effects are something bad. A small percentage of patients thought that side effects are something good or very good because the doctor is then able to understand and treat your condition as a 'unique 'case.

Question 19: Do you think that the side effects (unwanted effects) of ARVs are something serious or something not to worry about?

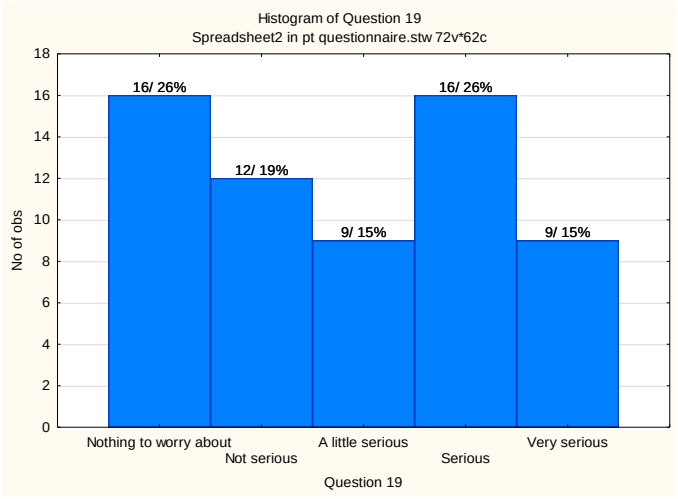


Figure 4.52 : Number of participants vs. the seriousness of the side effects of ARVs

The graph shows an equal distribution of responses indicating that 26% of participants thought that side effects are something serious or 26% thought it was nothing to worry about, 19% of the participants' perceived side effects as something not serious and 15 % of participants perceived a side effect as either something a little serious or something very serious. The perception of the degree of seriousness of a side effect of an ARV by patients is important as it can inform staff how to manage the patients with their side effects.

Question 4.20: What do you think causes the side effects (unwanted effects) of ARVs?

This was an open ended question. Most of the participants thought a side effect was caused because "it was the first time they used ARVs". Other participants thought it was because of the ARV drug or chemical itself and "the ARV was fighting with the soldiers (immune system)" hence the response of a side effect. Examples of the responses of the causes include:

"They don't take their tablets correctly"

"They don't sleep enough and follow a healthy lifestyle

"Worries"

"Others don't accept their condition"

"Body is getting healed"

Most participants knew that the ARVs can cause side effects in the body and they were aware that the 'common' side effects are transient and temporary.

Question 21: Do you think that the side effects (unwanted effects) of ARVs can be stopped or discontinued?

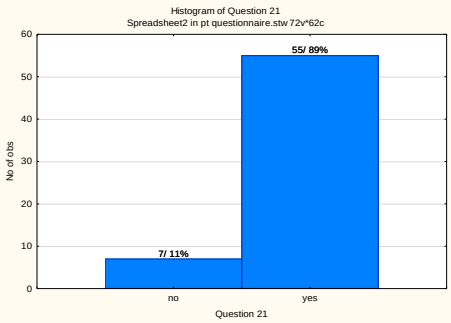


Figure 4. 53 : Number of participants vs. the perception of discontinuation of ARVs

The results show that 89% of participants thought that the side effects could be stopped and 11% thought that side effects could not be stopped. Patients who experience side effects are routinely provided symptomatic treatment to stop the side effects or the clinician will prescribe an alternative drug(ARV) if the side effect is problematic to the patient. This question gauges the perception and knowledge of the patient on the early, medium and late side effects of ARVs .

Question 22: How many side effects (unwanted effects) of ARVs can be stopped?

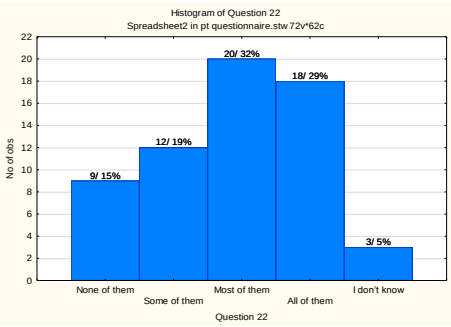


Figure 4. 54 : Number of participants vs. the number of side effects that can be stopped

From the graph it shows that 32% of the participants think that most of the side effects can be stopped, 29% think that all of them can be stopped, 19% think that some of them can be stopped,15% think that none of the side effects could be stopped and 5% did not know if the side effects can be stopped. There is no known theoretical answer to this question and the perception (that most of the side effects could be stopped) was based on the patients' experience and treatment of their side effects or it was based on the knowledge the patients acquired during the counselling sessions.

Question 23: Do you think that side effects (unwanted effects) can change over time the longer you are on treatment with ARVs?

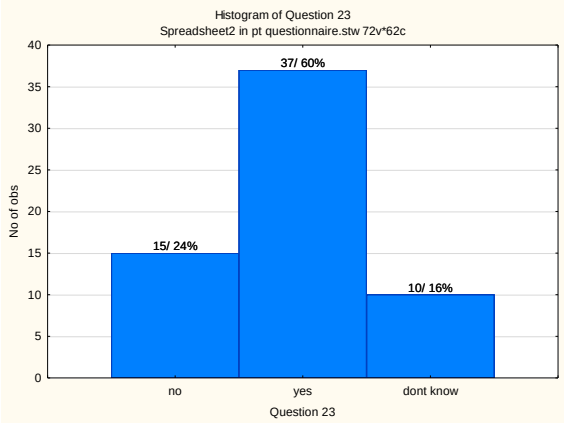


Figure 4. 55 : Number of participants vs. the perception of the change of side effects of ARVs over time

From the graph it is observed that 60% of participants thought that side effects could change overtime, 24% did not think that ARVs could change over time and 16% did not know if side effects could change over time. There is no known answer to this question as it tests the perception of the participant against the prediction of side effects in elderly HIV patients.

Question 24:Is it difficult for you to understand the side effects (unwanted effects) of ARVs?

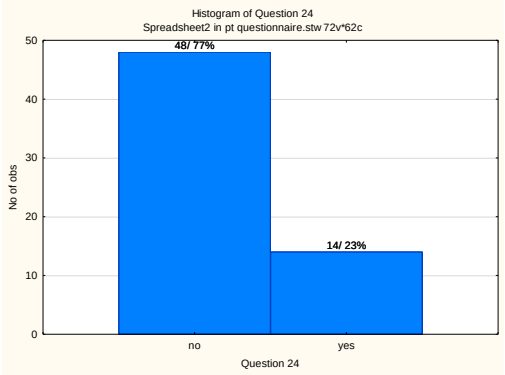


Figure 4.56 : Number of participants vs. the difficulty in understanding the side effects of ARVs

The graph shows that 77 % of participants said that it was not difficult for them to understand the side effects whereas 23% of participants said that it was difficult for them to understand the side effects of ARVs. It is essential for the staff to use different approaches when counselling patients on the side effects so that all patients understand the side effects of ARVs. This could prevent the defaulting of patients on ARVs.

Question 25: If yes (in number 24 above) please explain:

The participants provided various reasons why they found it difficult to understand the side effects of ARVs. Some of the reasons were as follows: "Because of their understanding of HIV," because "side effects are the same for everybody", "because you don't understand why and how it works" and "because of the long names".

It is essential that patients understand the side effects in order for them to be able to manage their condition.

Question 26: Do you look for the side effects (unwanted effects) of ARVs or any changes in your body when you take your ARVs?

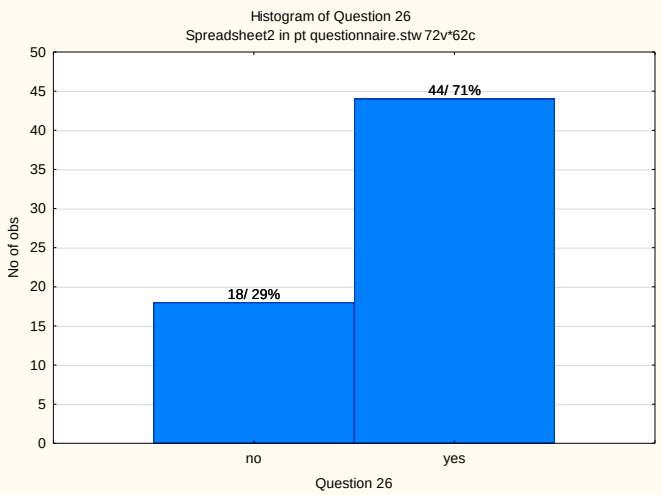


Figure 4. 57 : Number of participants vs. the physical observation of side effects in the participants

The graph indicates that 71% of the participants look for the side effects or physical changes in their bodies whereas 29% do not look for the side effects or physical changes in their bodies. The reason why participants do not look for the side effects or physical changes is unknown as it was not further explored. Possible reasons could include fear or the lack of knowledge in the understanding of the medium and late side effects of ARVs in the body.

This implies that there could be an underreporting of the side effects of ARVs by the patients.

Question 27: Are you told about the side (unwanted effects) of ARVs at every clinic visit?

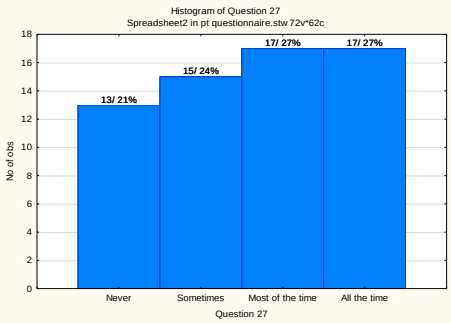


Figure 4.58 : Number of participants vs. the provision of information regarding the side effects of ARVs

From the responses it is noted that 27% of participants are told all the time and most of the time when they visit the clinic, 24% of participants said they are told sometimes and 21% said they are never told about the side effects when they visit the clinic every month. There is an equal distribution of responses between most of the time and all the time. This indicates that staff are informing the patients about the side effects of ARVs when they visit the clinic but it would be more effective if 100% of the patients could be told monthly about the side effects of ARVs.

Question 28: Do they tell you about the same or different side effects (unwanted effects) every time you visit the clinic?

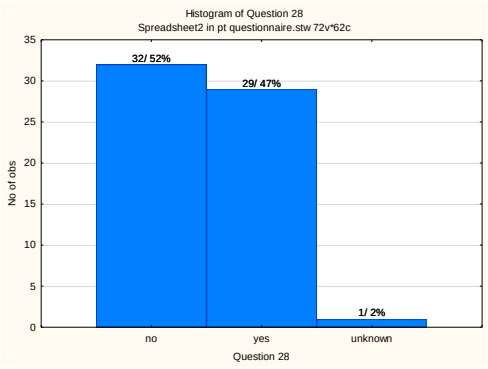


Figure 4.59: Number of participants' vs. responses to the question on the same or different side effects

The results show that 52% of participants said that they are told about different side effects every time they visit the clinic whereas 47% of the participants said that they are told about the same side effects every time they visit the clinic and 2% did not know whether they are told about the same or different side effects every time they visit the clinic. It is important

that the staff inform the patients about different side effects when they visit the clinic in order for the patient to understand, expect and manage the possible side effects of the ARVs.

Question 29: Do you think the staff at the clinic know about the side effects (unwanted effects) of ARVs?

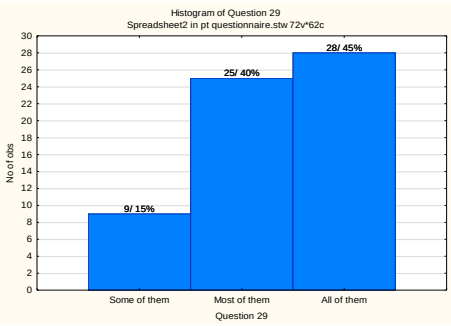


Figure 4.60 : Number of participants vs. the knowledge of staff on the side effects of ARVs

The graph shows the perception of patients about the knowledge of staff on the side effects of ARVs .Participants were asked this question because in practise any available counsellor, nurse, pharmacist or doctor would consult with the individual patient. This implies that the patient has the experience of engaging with different staff members at the clinic.

The results show that only 45% of the participants thought that all staff know about the side effects of ARVs, 40% said that most of them know and 15% said that some of the staff know about the side effects of ARVs. The results indicate that not 100% of staff know about the side effects of ARVs and an intervention is needed to address this perception.

Question 30: Do you think that other HIV patients know about the side effects (unwanted effects) of ARVs?

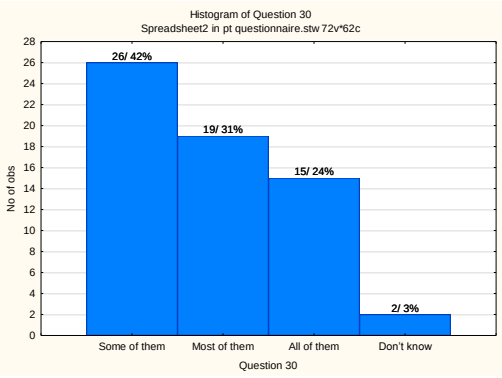


Figure 4. 61 : Number of participants vs. the perception of the knowledge of other patients on the side effects of ARVs

The results show that 24% of the participants said that all of them know,31% said most of them know,42% said some of them know and 3% did not know about the knowledge of other patients. The highest percentage of the participants indicated that only some of them know, which indicates that an intervention is needed to address the practices and the knowledge of the patients so that 100% of patients know about the side effects of ARVs.

C.QUESTIONS ON ATTITUDE

Question 31: What do you do when you experience any side effect (unwanted effect) of the ARVs?

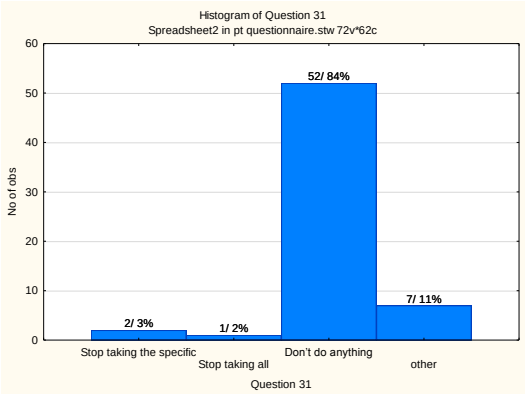


Figure 4.62 : Number of participants vs. the responses to managing a side effect

The results indicate that 84% of participants would not do anything (but continue with their ARVs), 3% of the participants would stop taking the specific ARV causing the problem, 2% would stop taking all the ARVs and 11% would continue with their ARVs and return to the clinic. This indicates that the participants are knowledgeable about the management of a side effect as well as the practises that are followed at the clinic.

Question 32: Do you report the side effects (unwanted effects) of the ARVs?

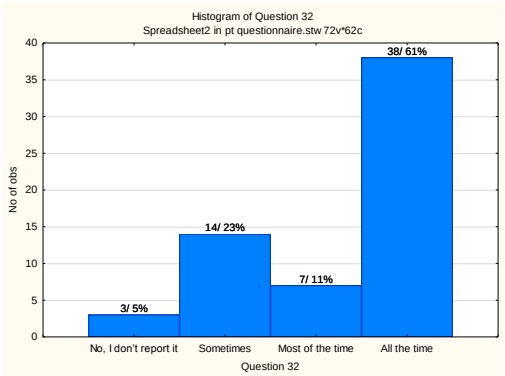


Figure 4.63 : Number of participants vs. the reporting of side effects of ARVs

The graph indicates that 61% of participants would report a side effect all the time to the staff at the clinic,23% would report a side effect sometimes,11 % would report a side effect most of the time and 5% would not report a side effect to the clinic staff. It is expected of a1l participants to report any side effect to the staff at the clinic. The reasons for the low reporting of the side effects should be further investigated. Staff should encourage all patients to report any side effect and the staff should educate the patients about the significance of reporting the side effects of ARVs.

Question 33: To whom do you report the side effects (unwanted effects) of the ARVs?(more than 1 answer can be ticked)

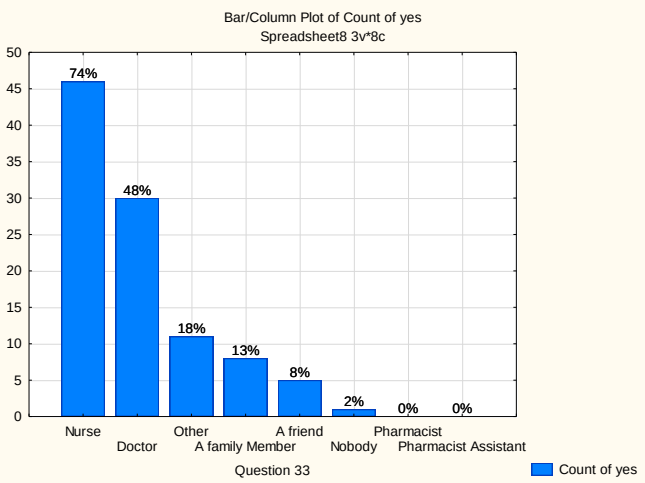


Figure 4.64Number of participants vs. the reporting of the side effect to a person

From the graph it is observed that 74% of side effects are reported to a nurse, 48% of side effects are reported to a doctor, 13% of side effects are reported to a 'family member', 8 % of side effects are reported to a friend, 2% are not reported to anybody and 18% of side effects are reported to the combination of a nurse, doctor and the counsellor. It is interesting to observe that 0% of the participants report a side effect to a Pharmacist or the Pharmacist Assistant .This suggests that an intervention is needed to involve the Pharmacist in the management of the side effects of the patient as the Pharmacist dispenses the ARVs to the patients at both the clinics.

Question 34: Do you want to know more about the side effects (unwanted effects) of ARVs?

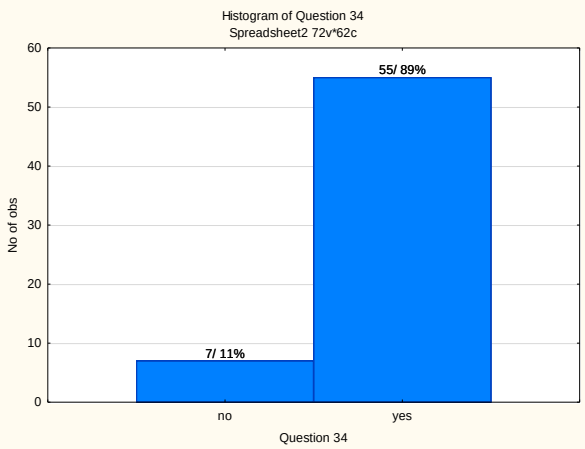


Figure 4. 65 : Number of participants vs. the need for more knowledge on the side effects of ARVs

The results show that 89% of participants want to know more about the side effects of ARVs whereas 11% of participants do not want to know more about the side effects of ARVs. The participants who do not want more information on the side effects indicated that they already know about the side effects of ARVs. This suggests that the same side effects were repeated to these participants. The participants who wanted to know more about the side effects showed more interest because they thought it was important for them to know and manage their condition.

Question 35: Do you ask questions about the side effects (unwanted effects) of ARVs at your clinic?

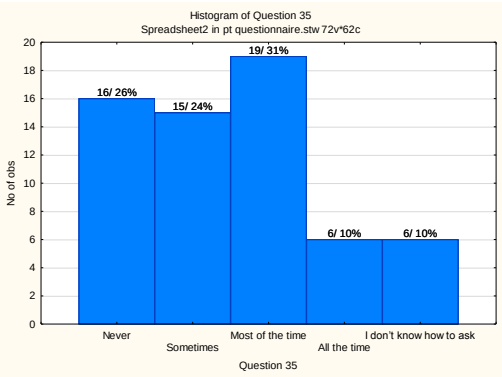


Figure 4.66 : Number of participants vs. the frequency of asking questions about the side effects of ARVs

The results show that 31% of participants ask questions on the side effects of ARVs most of the time ,10 % ask questions all the time,24% of participants ask questions sometimes,26% never ask questions on the side effects of ARVs and 10% do not know how to ask questions on the side effects of ARVs. The result that shows 26% of participants never ask questions could imply that patients are either not interested in the side effects or it could be that the side effect was something they expected(hence their weak response)or it could imply that patients do not understand the side effects. It is also noted that 10% of the respondents did not know how to ask questions about the side effects of ARVs.This is important as 100 % of the patients must know how and where to ask about the side effects of ARVs at the clinic. This suggests that the practices and communication at the clinics need to be improved.

Question 36: Do you read more about the side effects (unwanted effects) of ARVs?

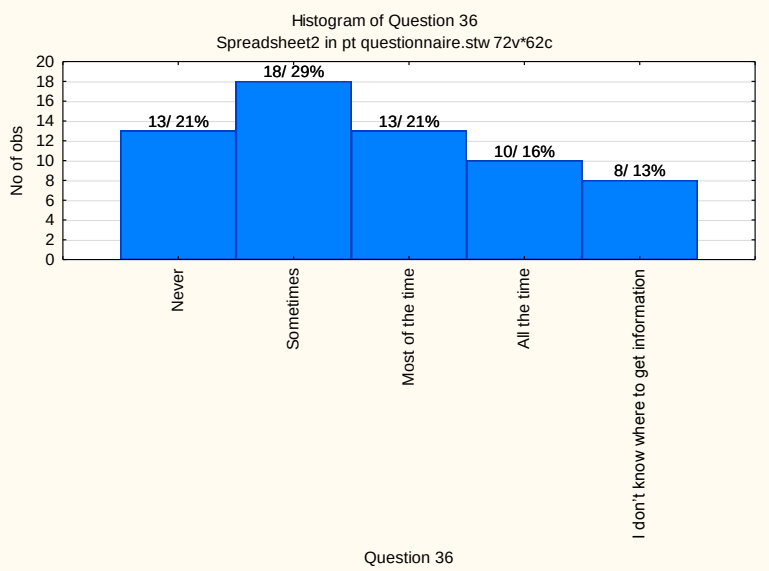


Figure 4.67 : Number of participants vs. the frequency of reading about the side effects of ARVs

The graph shows that 29% of the participants read more about the side effects of ARVs sometimes,21% read more about the side effects of ARVs most of the time.21% never read more about the side effects of ARVs,16% read about the side effects of ARVsall the time and 13% of participants do not know where to get the information.The low results indicate that access to the information about the side effects of ARVs is a challenge and the clinic should explore different approaches to avail information to the patients.

Question 37: What do you think will assist HIV patients to know more about the side effects (unwanted effects) of ARVs? (More than 1 can be ticked)

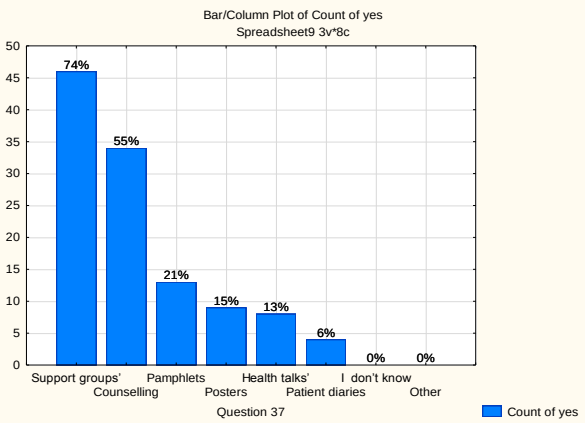


Figure 4. 68 : Number of participants vs. the use of different approaches to inform patients about the side effects of ARVs

The results indicate that 74% of the respondents suggested the need for support groups, 55% of the respondents suggested the use of counselling, 21% of the respondents suggested the use of pamphlets, 15% of the respondents indicated the need for posters, 13% suggested the use of health talks and 6% of the respondents indicated the use of patient diaries. The support groups, counselling and pamphlets are the three priority suggestions that will assist other HIV patients to understand the side effects of ARVs. The face to face approach in support groups and counselling sessions appear to be more practical because of the low education levels of the patients.

Question 38: How many side effects (unwanted effects) of each ARV do you think they must tell you about when you visit the clinic?

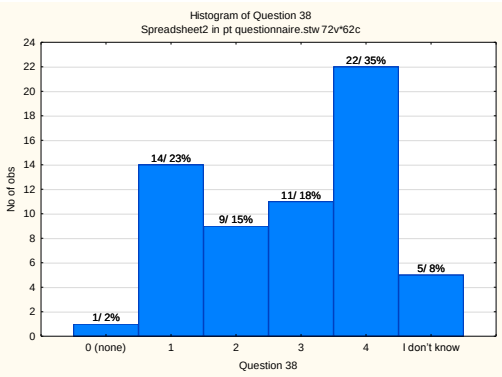


Figure 4.69 : Number of participants vs. the requested number of side effects for patients

This question was asked to the participant to gauge the need of the participant for more knowledge about the side effects of ARVs. The results show that 35% want to know 4 side effects per ARV,23% want to know 1 side effect per Arv,18% want to know 3 side effects per ARV ,15% want to know 2 side effects per ARV,8% do not know how many side effects they would like to be told about and 2% do not want to know more about any side effects of ARVs.

These results are important because it indicates that 35% of patients want to be told about as many side effects as possible and 23% of participants want to be told about 1 side effect of every ARV.

Question 39: When must they tell you about the side effects (unwanted effects) of your ARVs?

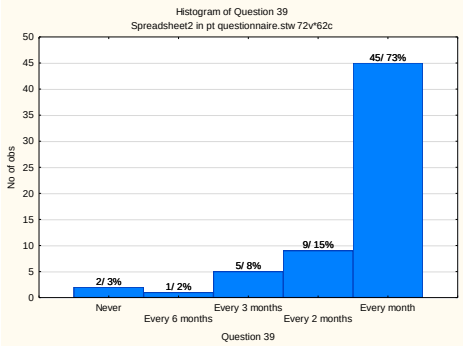


Figure 4.70 : Number of participants vs. the provision of information about the side effects of ARVs

It is observed that 73% of participants want to be told every month about the side effects of ARVs,15% of participants want to be told every 2nd month,8% want to be told every 3rd month,2% want to be told every 6 months and 3% never want to be told about the side effects of ARVs. These results imply that the staff should inform the patients about the side effects of ARVs monthly , every 2 months or every 3 months depending on the need of the patient but the majority of patients would like to be told monthly about the side effects of ARVs.

Question 40: Do you have any suggestions how the clinic can improve its services so that all HIV patients know and understand the side effects (unwanted effects) of ARVs?

This was an open ended question and the purpose of the question was to generate responses additional to the responses provided in question 37 .

Most participants felt the suggestions in question 37 were sufficient. Other responses included the following:

“Give classes or talks on a Saturday to patients”

“Tell them every month”

“Clinic must help patients to accept their condition”

“Health talks for patients or support groups”

‘They must recruit more people with HIV”

“Get more staff at the clinic”

“Give counselling, health talks”

“Start a support group”

The participants strongly suggested the need for support groups and health talks as they felt this would assist other patients in understanding the side effects of ARVs.

4.3 Conclusion

The main findings of the results of this study are discussed in the following chapter.

CHAPTER 5 FINDINGS OF THE STUDY

5.1 Introduction

This chapter provides discussion around the results of the staff and patient questionnaires. Firstly the results and findings of the staff responses will be discussed, secondly the results and findings of the patient responses will be discussed and thereafter the results will be analysed within the theoretical context of this study.

5.2 Limitations of the study

The sampling sites were limited to facilities where the CCMT programme was in existence for a period longer than 3 years and the sampling site needed to have a doctor, pharmacist, a nurse and an adherence counsellor at the wellness clinic of the facility.

The target population had to be adults of 18 years or older. This excluded paediatric patients and adolescent patients younger than 18 years of age.

5.3 Challenges of the study

The period in which the data was collected (November to December) was a challenge as the clinics operated with minimal operational staff due to the staff either being involved in exams or on vacation. Stable patients at the wellness clinics were provided with two months' supply of ARVs from November due to the "scaling down" of activities for the vacation period in December/January. At KHC very few patients were booked for the clinic in December which explains the minimal participation by patients from KHC in the study. The data was collected by the data collector once a week at the clinics over a four to eight hour period due to work obligations.

5.4 The main findings from the responses of staff and patients

5.4.1 Demographic analysis

The demographic analysis shows that the largest age group of staff((59% of staff) were between 20 and 29 years of age whereas the largest age group of patients(44% of patients) were between 30 and 39 years of age. This implies that at the clinics young staff have the responsibility of educating patients much older than themselves. More female participants (72% in staff and.66% in patients) than male participants (28% in staff and 34% in patients) participated in the study. The highest education level of the staff was at university level

whereas the highest education level of patients was grade 12(std.10) .The lowest education level amongst staff was grade 12(std 10) and grade 2 in respect of the patients.

5.4.2 Knowledge

All of the staff (100% of staff) said that HIV cannot be cured whereas only 53% of patients said that HIV cannot be cured. The reasons for this discrepancy amongst the patients requires further investigation. All of the staff (100%) knew the names, dosaging and frequency of ARVs whereas only 71% of patients knew the names of ARVs and 100% of patients knew the dosage and frequency of their ARVs. The generic names and trade names of ARVs confuse the patients ,as different suppliers have their unique product trade name and as a result patients familiarise themselves with the shape and colour of the tablet rather than the name of the ARVs. All the patients who participated in the study were taking ARVs. The largest percentage of patients (25%) were less than 1 year on ARVs and the average number of years for all the patients of the study was 3.77 years. The staff were able to provide a clinical definition and examples of side effects whereas the patients were only able to describe examples of the side effects of ARVs such as diarrhoea, headaches, nightmares, painful legs or feet, big buttocks. It was also found that the examples that the patients provided coincided with the examples which the staff described. All staff (100%) were informed about the side effects of ARVs whereas only 95 % of patients said they were informed about the side effects of ARVs.

The study showed that the key persons who informed staff about the side effects were the lecturers at university(60%),the doctor(36%),the nurse(12%),the pharmacist(32%) and the counsellor(12%) whereas in the group of patients the key persons who informed them about the side effects were the counsellor(69%),the doctor(35%),the nurse(35%) or a combination of the counsellor and/or doctor and/or nurse(10%). When the participants were asked about the “seriousness” of the side effects of ARVs, 60% of staff thought that side effects are serious, 36% thought it is very serious and 4 % thought it is a little serious. None of the staff thought that side effects are nothing to worry about or that it is not serious. In the group of patients, 26% thought that side effects are serious, 15% thought that it is very serious, 15% thought it is a little serious, 19% thought it is not serious and 26% thought it is nothing to worry about.

The patients were asked if they were using herbs, traditional mixtures or other medicines with their ARVs and 35% of patients were using other medicines such as TB drugs, hypertensive

drugs, prophylactic treatment such as Co-trimoxazole® or Isoniazid tablets® and 1 patient was using Stomata ® mixture to "cleanse" his blood.

When taking their ARVs, 97% of the patients thought that it was important to follow the instructions of the healthcare workers but only 82% of the patients followed the exact instructions (in terms of dosage and timing) of the healthcare workers all the time and 18% followed the exact instructions most of the time. In the group of participants of staff, 80% thought that the knowledge of side effects in patients is linked to adherence, 16% did not think that there was a linkage and 4 % did not know if the knowledge of side effects in patients is linked to adherence. When patients were asked what could happen if they stopped their ARVs, 61% said that they could die if they stopped their ARVs,60% said they could develop AIDS, 27% said they could become resistant to ARVs,2 % thought that nothing will happen and 2% did not know what could happen to them. The staff thought that the main reasons for the cause of a side effect was the introduction of the ARV to the body, the toxicity of the drug and the weak response of the immune system to the ARV. The patients thought that the side effect was caused by the 'soldiers' fighting with the ARV in the body, it was because the patient was not adhering to the treatment regimen or they were not following a healthy lifestyle.

The question was asked whether the side effects of ARVs could be stopped or discontinued and 76% of staff said it could be stopped with 24% saying that it cannot be stopped. In the group of patients 89% said it could be stopped and 11% said it could not be stopped. In the group of staff participants , 48% of staff said that most of the side effects could be stopped, 40% said that some of them could be stopped, 4% said none of them could be stopped and 8% said that all the side effects could be stopped. In the group of patients ,32% thought that most of the side effects could be stopped,19% said some of them could be stopped,15% thought that none of them could be stopped,29% said all of them could be stopped and 5% did not know if the side effects could be stopped. The question was asked whether side effects could change over time and the results show that 84% of staff said it could change, 12% said that it could not change and 4 % did not know if it could change ,whereas in the group of patients 60% said that it could change, 24% said that it could not change and 16% did not know if the side effects could change over time.

It was also observed that only 76% of the staff were trained on the side effects of ARVs. From the responses amongst staff, 24% of the respondents indicated that all staff know about the side effects of ARVs, 44% of the respondents said most of them know, 28% said some of

them know and 4% did not know if staff were knowledgeable about the side effects of ARVs. In the responses from patients, 45 % of the respondents thought that all of the staff know about the side effects, 40% thought that most of them know and 15% said that some of them know about the side effects of ARVs.

5.4.3 Perception

Amongst the group of participants of staff ,68% of staff thought that side effects are something bad,28% thought that it is very bad,8 % thought it was very good and 4% did not know if it was good or bad. Amongst the group of patients , 52% thought that that side effects are bad,23% said it was very bad,2% thought it was very good,16% thought it was good and 3% did not know if it was good or bad. It was observed that the participants (80% of staff vs. 77% of patients) did not think it was difficult to understand the side effects of ARVs. The difficulty that staff experienced was in understanding the mechanism of action and the pharmacology of the ARVs in the body whereas in the case of the patients, the side effects are explained in a simple 'layman's' language. All staff (100%) thought it is necessary to inform patients about the side effects of ARVs but the results show that only 8 % of staff thought that all the patients know about the side effects of ARVs, 28% thought that most of them know and 64% thought that some of the patients know about the side effects of ARVs. The responses from the patients indicated that 24 % thought that all patients know about the side effects, 31% thought that most of them know, 42% said some of them know and 3% did not know if other patients know about the side effects of ARVs. In gauging the application of knowledge about the side effects of ARVs, 71% of patients said that they look for any physical changes in their bodies or any side effects and 29% said they do not look for any signs or symptoms of side effects of ARVs. The responses from staff indicate that 52% of staff think that patients look for side effects or changes in their bodies, 24% of staff think that patients do not look for any signs or symptoms and 24% did not know if patients looked for the side effects or physical changes in their bodies.

It was necessary to know the practices of informing patients about the side effects of ARVs. Amongst the staff, 60% of staff thought that patients must be informed about the side effects of ARVs before starting treatment, 36% thought that patients must be informed when they start ARVs, 24% said patients must be informed with every clinic visit and 0% thought that patients must be informed at 1 or 3 or 6 or 12 months after initiation of ARVs. With regards to the patients 73% want to be informed monthly, 15% want to be informed every 2nd month,

8% every 3 months, 2% every 6 months and 3% never want to be informedabout the side effects of ARVs. This gap in results between the staff and patients is an important finding to address the knowledge of the side effects in patients. From the responses of the participants, the staff thought that the responsibility of informing patients about the side effects of ARVs is a responsibility of the pharmacist(92%), counsellor(84%), doctor(72%), nurse(72%) and the Pharmacist Assistant(52%). In practise, the patients said that they were informed by the counsellor(69%),doctor(35%),nurse(35%),0%(Pharmacist) and 0%(Pharmacist Assistant).The results from the respondents indicated that 57% of staff thought that not enough time is spent educating patients about the side effects,40% said enough time is spent educating patients and 8% of the responses were invalid.

5.4.4 Attitude

The attitudes of staff and patients towards the side effects of ARVs were also assessed as part of this study. The results show that 44% of the staff inform the patients about the side effects of ARVs all the time, 24% inform patients most of the time, 20% inform patients sometimes, 4% do not inform patients and 8% did not respond to the question. In practice, 27% of the patients said they were informed about the side effects all the time, 27% were informed most of the time they visit the clinic, 24% were informed sometimes and 2% were never informed about the side effects of ARVs. It was also found that 24% of staff tell patients 2 or 4 side effects per ARV, 12% tell patients 1 or 3 side effects per ARV, 20% tell patients an independent number of side effects depending on the patients' understanding, adherence and education and 8% provided no responses to the question. In the group of patients it was shown that 35% of patients wanted to know 4 side effects of each ARV, 23% wanted to know 1 side effect, 15% wanted to know 2 side effects per ARV, 18% wanted to know 3 side effects per ARV, 2 % did not want to know any side effects and 8% did not know how many side effects per ARV they must be told. The results to the question shows a gap in the results between the staff and the patients.

Another finding shows that 48% of staff inform patients about the general side effects of the ARVS ,28% tell them the specific side effects of ARVs and 8% of the responses were invalid , whereas 47% of the patients said that they were informed about the same side effects ,52% said they are informed of different side effects and 2% did not know whether they are informed of the same or different side effects every time they visit the clinic.

When patients experience a side effect 72% of the staff will refer the patient to a doctor, 16% will report the side effect to an authority, 4 % will stop the ARVs and 8 % of the responses were invalid. In the group of patients, 84% of patients said if they experienced a side effect they would continue with their ARVs and not do anything, 2% will stop their ARVs, and 11% will return to the clinic the next day and continue to take their ARVs. The staff responses indicate that 52% of staff will report a side effect all the time, 20% will report it most of the time, 4% would never report it and 4% of the responses were unknown. In the group of patients it was observed that 61% of patients report the side effects all the time,23% report it sometimes,11% report it most of the time and 5% do not report any side effect. Amongst the staff it was found that 48% of staff will report the side effect to a doctor, 32% will report it to the MCC, 20% will report it to a pharmacist, and 16% will report it to a nurse, 8% to a counsellor and 0% to a Pharmacist Assistant. The group of patients indicated that 0% of patients will report a side effect to the Pharmacist,74% will report it to a nurse,48% will report it to a doctor,12% will report it to a family member,8% will report it to a friend,2% wil not report it to anyone and 18% will report it to the combination of doctor and/or nurse and /or a counsellor. The participants (88% in staff vs. 89% in patients) wanted to know more about the side effects of ARVs, .It was also shown that the participants read up most of the time (28% in staff vs. 21% in patients) or sometimes (32% in staff v.29% in patients).Additional results show that the participants asked questions all the time (32% in staff vs. 10% in patients) or sometimes (28% in staff vs. 24% in patients).about the side effects of ARVs. In the last question the staff and patients provided suggestions to improve the knowledge about the side effects of ARVs in other patients.. Amongst the group of staff, 68% of staff suggested counselling, 60% suggested the use of health talks and 48% suggested the use of support groups to improve patient knowledge. In the group of patients, 74% of patients suggested support groups, 55% of staff suggested counselling, 21% suggested pamphlets.15% suggested the use of posters, 13% suggested health talks and 6% suggested the use of patient diaries to improve patient knowledge about the side effects of ARVs. Other suggestions from the staff and patients includes the use of Saturday classes for patients, training for staff, increasing the staff complement at the clinics, having a delegated person to deal with the side effects of ARVs and also the use of educational materials such as DVDs on the counselling of the side effects of ARVs. It was also suggested that additional people with HIV be recruited at clinics ,as the clinics need to assist patients to accept their HIV status as a key priority.

5.5 An overview of the results

The results were graphically presented as total groups of participants for staff and for patients because of the small number of participants per facility. This made it difficult to compare the different variables and results between the two facilities (KHC and GDH) and this resulted in the analysis of the total populations of staff and patients .

The small sample size also makes it difficult to generalise the results of this study to a larger population size in the general population.

The findings of this study support the view of previous studies that recommend the pivotal role of the Pharmacist in counselling patients about the side effects of ARVs. The staff of the wellness clinics prepare and encourage patients to manage their side effects and this supports the study of Bartlett (2002).

This study also supports the study by Agu et al (2012) as patients at the wellness clinics are knowledgeable about the side effects of ARVs and they have a positive attitude with the reporting of ARVs.

This refutes previous studies that argue that patients do not want to know about the side effects. The attitude of staff with regards to the reporting of side effects can be improved as this will encourage more pharmacists' and other role-players to become more involved in the reporting of the side effects. The need for more involvement of the pharmacists in the management of the side effects correspond with the views of Matheson et al (1999).

The low result of the involvement of pharmacists at the clinics correspond with the findings of Fritsch et al (1997).The suggestion of the use of a videotape to counsel and inform patients is supported by the study of Wong et al (2006).In the study by Hoang et al (2011), 38% of patients were concerned about the side effects of ARVs. The results of this study similarly support the study of Hoang et al (2011).

The study that was conducted by Ruud et al (2012) in the Eastern Cape produced similar findings to the results of this study .The health providers also experienced challenges with training, communication and pharmacovigilance. Our study did not include poverty as a challenge as this was not measured in the study. This study could not support the findings of Nachega et al (2012) as the adherence levels of the patients were not measured quantitatively.

5.6 Conclusion

The findings and analysis of the results of this study provides us with a baselinereport on the practises at the wellness clinics. In the next chapter, recommendations are discussed to improve the practices at the wellness clinics..

CHAPTER 6 RECOMMENDATIONS

6.1 Introduction

One of the objectives of this study was to improve the current practices at KHC and GDH. These interventions have been recommended to produce a more positive change to the current operations. Combinations of interventions are recommended rather than following one single approach .In doing so, it aims to reinforce, sustain and extend the impact of the interventions.

6.2 Recommendations

It is recommended that the wellness clinics introduce and implement a combination of these interventions as a project and in a phased approach to improve the quality of service s and care of the patients.

The strategic interventions that are proposed are mainly educational interventions, administrative interventions and regulatory interventions.

The educational interventions can be introduced to the staff members using various approaches such as scheduled training programmes, workshops and staff meetings. Printed materials such as posters, pamphlets, package inserts, patient information leaflets and brochures should be made available for staff and patients. The wellness clinics should consider retrieving journals form the Kimberley Hospital Medicines Resource Centre on a monthly basis to motivate staff to read more about HIV and medicines .The display of quarterly indicators at the facility on the monitoring of the side effects and the discussion of clinical case studies at weekly meetings should also be encouraged amongst the staff as it would also educate staff on the management of the patients as well as the side effects of ARVs. The wellness clinic should also access audiovisual materials (DVDs) on ARV products from suppliers,various nongovernmental organisations (ngo's) and training service providers as part of the project plan. DVDs on topics such as counselling, communication, the monitoring of side effects, adverse reactions, quality care, staff motivation and support groups should be accessed or recorded (if it is not available) to train staff and the key role-players as part of the project.

Staff at the wellness clinic should initiate support groups for HIV patients based on their duration of treatment on ARVs. (e.g. support group 1 is for patients under 1 year on ARVs). The support groups should be coordinated by the clinic manager but it could be a delegated

responsibility to empower staff and patients in leading and managing a support group session. The support group sessions and health talks could be conducted once a month and as staff or patients become more confident with the sessions, it could be expanded to one group session per week. It is also recommended that the Pharmacists and Pharmacist Assistants become more involved in these support group sessions as they are able to focus on the overall pharmaceutical care of the patient.

It is also proposed that the following administrative interventions be introduced at the clinics. Standard operating procedures (SOPS)should be amended to include clear instructions on the counselling of patients and the reporting of the side effects of ARVs. The SOPS should specify the best approach that could be implemented for staff and patients. It could suggest that the counsellors could become part of the pharmacy human resource requirements of the in future. The SOP must include a reporting tool that can be used to monitor the counselling sessions and the reporting of the side effects. This report must be inserted in the file of the patient so that the healthcare provider is able to follow-up on the previous counselling sessions and knowledge of the patient.

Systems at the workplace must be able to facilitate the recording and reporting of the side effects manually or electronically. The pharmacies should consider the use of the green card model as part of the workplace procedures and systems. The self reporting of the side effects of ARVs by patients must be encouraged by all staff and feedback must be provided to patients in the form of the support groups, health talks and visual aids such as graphs and videos. The reporting of the side effects and adverse events of ARVs must be cascaded to the provincial Pharmacy Therapeutic Committee (PTC) to motivate and encourage staff to report regularly on the side effects of ARVs.The cost of the side effects should be calculated and monitored to inform staff about the possible financial implications to the ART programme.

The following regulatory interventions should be considered at the provincial and national levels. The regulatory authorities (such as MCC, NADEMC) should enforce suppliers to produce patient information literature and the ARV product package inserts in all official languages. The suppliers should produce posters and pamphlets about ARVS in adequate quantities (or they should outsource this function) for usage in the public healthcare institutions. The safety of ARV products must be communicated from the MCC to all health departments, provincial depots and health professionals to implement the monitoring of side effects and adverse reactions at various levels.

6.3 Implementation of the interventions

These recommendations should be implemented as a "quality care project" at these wellness clinics, with the possible expansion of these practices to other public healthcare facilities in the province.

6.4 Monitoring and evaluation of the interventions

It is important to monitor and evaluate these interventions by compiling a standardised monitoring and evaluation plan with set indicators to evaluate the outcomes of this project. The quarterly and annual monitoring of the project is proposed for practical purposes.

6.5 Conclusion

It is important that these recommendations are not seen in isolation (as a vertical entity) but it needs to be incorporated as part of the daily operational practices in managing healthcare providers and patients at public healthcare facilities. It is hoped that these interventions could develop into a positive project plan that can become a best practice model in the quality care and management of HIV patients.

It is further recommended that more studies (with larger sample sizes) be conducted to explore the perception and communication of the side effects amongst the healthcare provider and the patient.

CHAPTER 7 CONCLUSION

This study concludes that staff and HIV patients (at the two public healthcare institutions in the Frances Baard district) are knowledgeable about the side effects of antiretroviral drugs (ARVs).The staff and patients at these facilities perceive the side effects of ARVS as a 'bad' experience but they demonstrate a positive attitude to the side effects by reporting the side effects of ARVs to the respective authorities. The current practices *do* support the existing knowledge, perception and attitudes of the side effects of ARVS amongst staff and patients, although there is room for improving the current practises through the recommended interventions. It was found that patients want to know more about the side effects of ARVs which is in contrast to the perception of staff that patients should only be told the 'common' side effects of ARVs to prevent patients defaulting or discontinuing their treatment.

With the continuous training of staff and the education of the patients(by means of health talks, support groups, counselling and patient- friendly literature) this approach would serve a dual purpose in improving the communication between the healthcare provider to patient and it would also strengthen the approach and management of the HIV patient.

In encouraging our patients to speak about their side effects, it could reduce the stigma associated with HIV and this would assist patients in accepting and speaking more openly about their condition.

"In understanding the side effects of ARVs, we start to understand the management of HIV and that is our ultimate purpose."

REFERENCES

Agu K.A., Oparah A.C., Ochei U.M. (2012). Knowledge and attitudes of HIV-infected patients on antiretroviral therapy regarding adverse drug reactions (ADRs) in selected hospitals in Nigeria;3,95-101,dol.10.4103/2229-3485.100657

Bartlett J.A.(2002).Addressing the challenges of adherence.J Acquir Immune Defic Syndr,2002 Feb 1;29 suppl 1:S2-10.Retrieed from http://www.ncbi.nlm.nih.go/pubmed

Christensen L.B., Johnson R.B., Turner L.A. (2011).*Research Methods, Design, andAnalysis*.11th Ed, pp 311,360, 463. Pearson.USA.

Clark P.M., Karagoz, Apikoglu-Rabus S. (2007).Effect of pharmacist-led patient education on adherence to tuberculosis treatment. pp 497-505 .dol 10.2146/ajhp050543.

Coates A.,Abraham S.,Kaye S.B.,Sowerbutts T.,Frewin C.,Fox R.M.,Tattersall M.H.(1983).On the receiving end-patient perception of the side effects of cancer chemotherapy.*Eur J Cancer Clin Oncol*.1983 Feb;19(2)203-6.Retrieved from http://www.ncbi.nlm.nih.go/pubmed

Cocohoba J.M.,Althoff K.N.,Cohen M.,Hu H.,Cunningham C.O.,Anjali S.(2012).Pharmacist counseling in a cohort of women with HIV and women at .risk for HIV. *Patient Prefer Adherence*.2012;6:457-463.doi:10.2147/PPA.S30797.

Countries in Africa (n.d) infowww.infoplease.com/askeds/**countries-africa**.html. Retrieved 03 October 2012.

Department of Health, (2011). *The National Antenatal Sentinel HIV and Syphilis prevalence survey, South Africa* 2011, National Department of health.www.gov.za. Retrieved 12 December 2012.

Department of Health (2012).CCMT data on the ART programme.www.ncpg.gov.za. Retrieved 12 December 2012.

Dictionary(2012)www.oxforddictionaries.com,Retrieved 08 October 2012

Dictionary(2012).www.cambridge.org.Retrieved 08 October 2012

Dictionary.www.oxfordlearnersdictionaries.com. Retrieved 08 October 2012

Dlamimi Bongani Dlamini, C. H. (2008). *Being positive.* Lightship Communications.

Du Pasquier S.,Aslani P.(2008).Concordance –based adherence support service delivery:consumer perspectives.*Pharm World Sci*.2008 Dec;30(6):846-53.Epub 2008

Fomundam H. (2011). Therapeutic management of HIV and AIDS. Focus on Adherence and medication safety. Unpublished class notes. (Africa Centre, P.D.M), University of Stellenbosch.

Formundam H. (2011). Therapeutic management of HIV and AIDS: Challenges of Drug Therapy-Pharmacovigilance. Unpublished class notes. (Africa Centre, P.D.M.) University of Stellenbosch.

Fritsch M.A.,Lamp K.C.(1997).Low pharmacist counseling rates in the Kansas City,Missouri,metropolitan area.*Ann Pharmacother*.1997 Sep;31(9):984-91.

Galeshewe Day Hospital (n.d).Standard operating procedure for dispensing of medicines. Unpublished notes.

Garcia R.,Badaro R.,Netto E.M.,Sila M.,Amorin F.S.,Ramos A.,Vaida F.,Brites C.,Schooley R.T.(2006).Cross-sectional study to evaluate factors associated with adherence to antiretroviral therapy by Brazilian HI-infected patients. *AIDS Res Hum Retroiviruses*.2006 Dec: 22(12):1248-52.

Gupta A.,Sane S.S.,Gurbani A.,Bollinger R.C.,Mehendale S.M.,Godbole S.V.(2010).Stigmatizing attitudes and low levels of knowledge but high willingness to participate in HI management: a community-based survey of pharmacies in Pune,India.*BMC Public Health* 2010,10:517 dol 10.1186/1471-2458-10-517.

Helena C. (2012). Green card training: a new concept introduced to improve patient counselling and knowledge.*S afr Pharm J*,79,8.pp 35-36

Hoang D, Dinh A. T, Groce N, Sulivan L. E, (2011). Knowledge and Perceptions of HIV infected patients regards HIV transmission and treatment as Ho Chi Minh City, Vietnam. Asia Pac *J. Public Health*.2011. http://www.nbci.nih.gov/pubmed.Retrieved 04 August 2012

Home R., Cooper V., Fischer M. (2008).Initiation of therapy with a subcutaneously administered antiretroviral in treatment-experienced HI-infected patients: understanding physician and patient perspectives. *AIDS Care*, 2008 Oct; 20(9):1029-38. http://www.ncbi.nlm.nih.go/pubmed.Retrieved 04 August 2012

Johnson M, Neiland T.B. Neuroticism, Side Effects, and Health Perceptions Among HIV-Infected Individuals on Antiretroviral Medications .*J Clin Psychol Med Settings*. 2007 March; 14(1): 69–77. doi: 10.1007/s10880-007-9056-9

Kallyaperumal K (2004). Guideline for conducting a knowledge, attitude and practice (KAP) study. *AECS Illumina*tion 10 (1), 7-9.

Langlois-Klassen D., Kipp W., and Rubaale T. (2008) .Who's talking? Communication between health providers and HI-infected adults related to herbal medicine for AIDS *t*reatment in western Uganda.*Soc Sci Med* 2008 Jul; 67(1):165-76.Epub 2008 Apr 9.

Lewis R.K., Lasack N.L., Lambert B.L., Connor S.E. (1997).Patient counseling-a focus on maintenance therapy. pp 2094-2098 ol 54(18)

Management Sciences for Health RPM plus (n.d). HIV/AIDS Pharmaceutical Management training. Participants guide. Unpublished notes. Pretoria.pp 193 – 194,209,303-305.

Management Sciences for Health RPM plus. (n.d.).Instructions for completing patient adherence record.version 3.4.Unpublised notes.

Manias E., Claydon-Platt K., McColl G.J., Brand C.A. (2007).Managing complex medication regimens: a perspective of consumers with osteoarthritis and healthcare professionals.*Ann Pharmacother*.2007 May: 41(5):764-71.Epub 2007 Apr 24.

March K., Mak M., Louie S.G. (2007).Effects of pharmacists 'interventions on patient outcomes in an HI primary care clinic. pp 2574-2578.dol 10.2146/*ajhp* 070048.

Matheson C., Bond C.M., Mollison J. (1999).Addiction 1999 Sep; 94(9):1349-59. http://www.ncbi.nlm.gov/pubmed.Retrieved 14 August 2012

Mongan-Rallis H. (2006).Guidelines for writing a literature review. http://.yellowlitreview.html Retrieved 01 April,2012

Monjok E.,Smesny A.,Okokori I.B.,Mgbere O.,Essien E.J.(2010).*Adherence to antiretroviral therapy in Nigeria: an overview of research practice*.HIV AIDS(Auck),2010:2:69-76.

Nachega J.B., Morroni C., Zuniga J.M., Schechter M., Rockstroh J., Solomon S., Sherer R.(2012) .HIV treatment adherence.patient health literacy and health care proider-patient communication.*J Int Assoc Physicians AIDs Care* 2012, 11(2):128-133.

Negi K.S.,Khandpal S.D.,Kumar A.,Kukreti M.(2006).Knowledge,attitude and perception about HIV/AIDS among pregnant women in rural areas of Dehradun.*J K Science* ol 8(3).

Northern Cape Provincial Standard Operating Procedures for Pharmaceutical Services. (n.d.).SOP on dispensing. Unpublished notes.

Northern Cape Province (n.d.). *HIV & AIDS & STI Provincial Strategic Plan 2009-2011. Monitoring and Evaluation framework.* Department of Health, Kimberley. pp 26, 62-63

Northern Cape Province (n.d.). *Provincial Strategic Plan. HIV & AIDS and STI 2009-2011*. Swiftprint Kimberley

Northern Cape Province (n.d.). *Provincial Strategic Plan on HIV, TB & STI 2012-2013.* Operational plan. Department of Health, Kimberley .pp 3,7,25-30,34

Nziengui U., Zamba C., Rev J.L. (2006).Difficulties of the patients to undergo their ARV treatment at the Libreille outpatient health centre, Gabon http://www.ncbi.nlm.nih.go/pubmed.Retrieved 08 August 2012.

Peralta L., Belzer M., Palmer A.L., (2009).Antiretroviral treatment and adherence. http://hicarefor youth.org.Retrieved 08 August 2012

Pharmaceutical Society of South Africa (2011). The Consumer Protection Act. How does it affect pharmacy? *South African Pharmacy Journal*, 78, 3. Pp.8.

Puspitasari H.P.,Aslani P.,Krass I.(2009).A review of counseling practices on prescription medicines in community pharmacies.*Res Social Adm Pharm* 2009 Sep;5(3):197-210.Epub 2009 Jan 31..

Puspitasari H.P.,Aslani P.,Krass I.(2010).Pharmacists' and consumers viewpoints on counselling on prescription medicines in Australian community pharmacies.*Int J Pharm Pract*.2010 Aug;18(4):202-8.

.Ramirez-Garcia P., Cote J. (2009).Development of a nursing intervention to facilitate optimal antiretroviral with HIV. *BMC Health Ser Res*.2009;9:113 dol 10.1186/1472- 6963-9-113.

Republic of South Africa (RSA) (2010). Contract RT 71-2010 MF: Antiretroviral drugs. Begin 1 January 2011 to 31 December 2012. National Treasury.

Republic of South Africa (RSA) (2009). *Antiretroviral therapy in South Africa. A pocket guide on prevention and management of side effects and Drug Interactions South Africa* (2009).National Department of Health. Pretoria. pp 2-24

Republic of South Africa (RSA) (1998).PSSA. *Pharmacy Law Compendium vol 1*.pg PRE 210-213.Lexis Nexis South Africa

Republic of South Africa (RSA) 2010. *Clinical guidelines for the management of HIV & AIDS in Adults and Adolescents.* National Department of Health(pp 1,2,6,7,10,17,25-26).Pretoria

Republic of South Africa (RSA) (2011).Unpublished memo (revision of thresholds for ART initiation of patients-CD4 cell count baseline of 350.

Republic of South Africa (RSA) (2012).Contract number HP13-2013 ARV provision of anti-retroviral medicines to the Department of Health. Period 01 January 20123 to 31 December 2014.

Republic of South Africa (2011).Regulations. Pharmacy Act 53 of 1974.10.pp PRE 177,277,326,327)

Ruud K. W. Srinivas S. L, 8toverud E. L (2012). Healthcare providers experience with adverse drug reacting and adherence challenges in antiretroviral therapy of HIV patients in the Eastern Cape Province, South Africa. *Eur J. ClinPharmacol 2012*. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed.

Sanjobo N.Frich J.C., Fretheim A. (2008).Barriers and facilitators to mpatients'adherence to antiretroviral treatment in Zambia: a qualitative study.*SAHARA J.2008* Sep; 5(3):136-43.

Sheridan J.,Strang J,.Taylor C.Barber N.(1997).HI prevention and drug treatment services for drug misusers: a national study of community pharmacists 'attitudes and their involvement in service specific training.*Addiction*.1997 Dec;92(12):1737-48..

Schumaker L.L., Bond V.A. (2008).Antiretroviral therapy in Zambia: colours,'spoiling','talk' and the meaning of antiretrovirals.*Soc Sci Med*.2008 Dec'67(12):2126-34.Epub 2008 Oct 24.

South Africa. (2012). www.southafrica.info/about/geography/northern-cape.htmNorthern Cape province, South Africa-SouthAfrica.info

South African Pharmacy Council (2012).Patient rights and responsibilities in a pharmacy.*Pharmaciae*, 20, 1.pp16-17.

StatsSA. (2012) www.statssa.gov.za.Midyear pop estimates 2011.Retrieved 02 May 2012.

Steel G, Nwolike J, Joshi M. (2007).Development of a Multi-method tool to ART Adherence in Resource-Constrained Settings: The South African Experience. U. S. Agency for R.P.M. plus, Arlington.

Survey monkey (n.d.). Retrieved 09 April 2012, from http://help.surveymonkey.com

The Global Health Council (nod.). The impact of HIV/AIDS. Retrieved 01,2011 from http://www.globalhealth.org/hiv_aids

Tully M.P.,Beckman-Gyllenstrand A.,Bernsten C.B.(2011).Factors predicting poor counselling about prescription medicines in Swedish community pharmacies. *Patient Educ Couns*.2011 Apr;83(1):3-6.Epub 2010 Jun 3 .Retrieved from http://www.ncbi.nih.gov/pubmed

UNAIDS (2012). Terminology Guidelines(January 2011).Retrieved from www.unaids.org 2011.pp 3

UNAIDS (2012).Web definitions. Retrieved from http://www.unaids.org

Uzochukwu B.S.,Onwujekwe O.E.,Onoka A.C.,Okoli C.,Uguru N.P.,Chukwuogo O.I.(2009).Determinants of non-adherence to subsidized anti-retroviral treatment in southeast Nigeria. *Health Policy Pla*.2009 May;24(3)"189-96.Epub 2009 Mar 10.Retrieved from http://www.ncbi.nlm.nih.go/pubmed

Van Niekerk, A. A. & Kopelman, L. M. (Ends) 2008. *Ethics & Aids in Africa. The challenge to our thinking* (2nd ed, pp 13, 38 42-44). Claremont David Phillip publishers

WHO (2008).Technical guidance for Global und HIV proposals. Pharmacovigilance for antiretroviral drugs. www.who.org.pp 1-3.Retrieved 10 August 2012.

WHO. (2007).Pharmacovigilance for antiretrovirals in resource-poor countries. www.WHO.com .pp 2, 10. Retrieved 08 August 2012.

WHO (n.d). A guide to developing knowledge, attitude and practice surveys. Advocacy, communication and social mobilisation for TB control 20-25.Switzerland.www.WHO.com.Retrieved 04 March 2012.

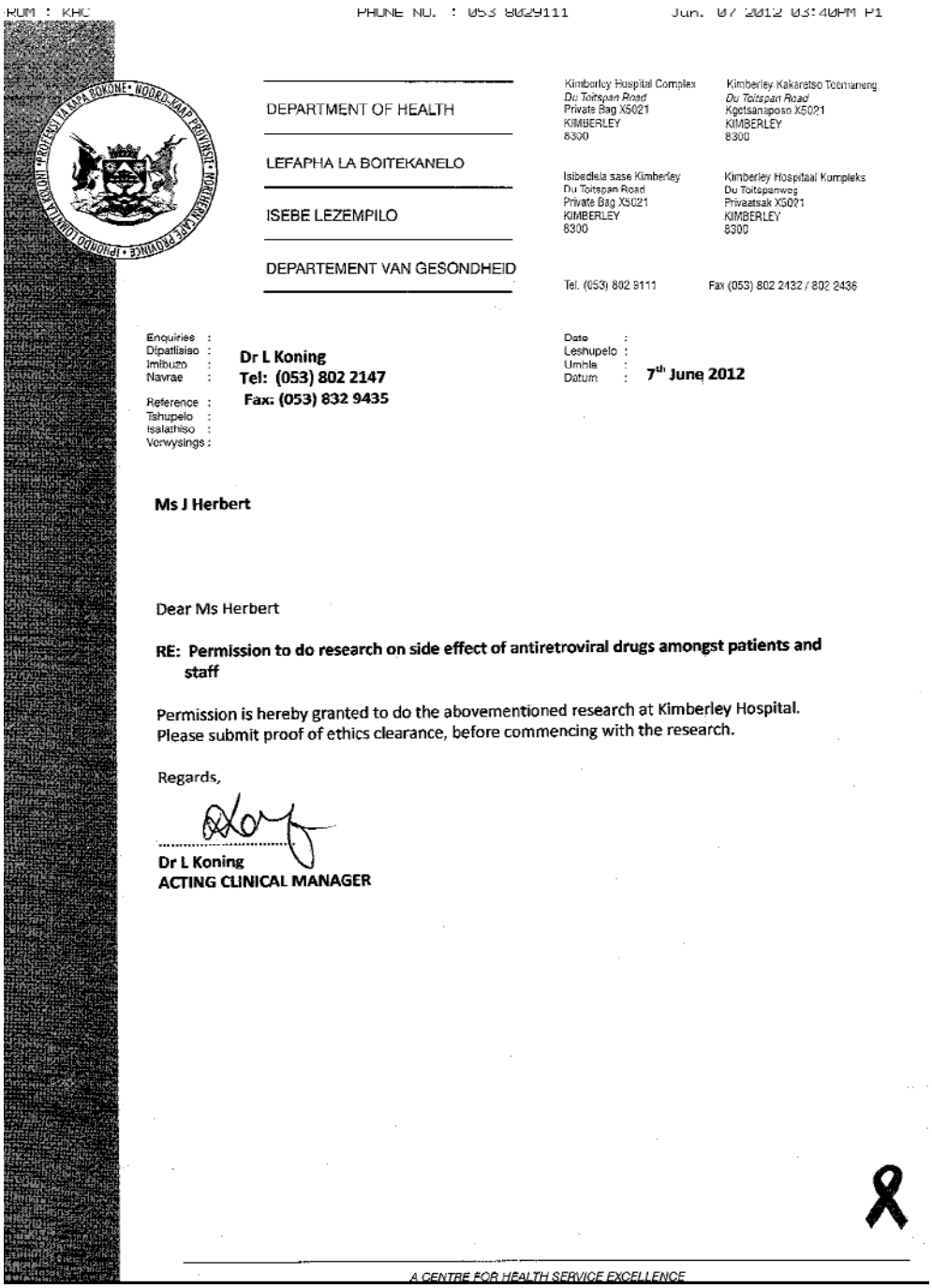
Williams A.F.,Manias E.,Walker R.(2008).adherence to multiple, prescribed medications in diabetic kidney disease: A qualitative study of consumers' and health professionals'perspectives.*Int J Nurs Stud*.2008 Dec ;45(12):1742-56.Epub 2008Aug 13.

Wong I.Y., Lawrence N.., Struthers H., Mcintyre J., Friedland G.H. (2006). Development and assessment of an innovative culturally sensitive educational videotape to improve adherence to highly active antiretroviral therapy in Soweto, South Africa.*J Acquir Immune Def Syndr*, and 2006 Dec 1; 43 Suppl 1: S142-8.

Xuniga J. M. (2006). Results of the International Association of Physicians in AIDS Care Surveys of HIV-positive patients and HIV Treating Physicians in the United States. *JINT Assoc Physicians AIDS* (Care 5/2) 2006 pp. 51-56.

ADDENDA

Addendum A: Letter of permission (Kimberley Hospital Complex)



RUM : KHC PHONE NO. : 053 8029111 Jun. 07 2012 03:40PM P1

DEPARTMENT OF HEALTH
LEFAPHA LA BOITEKANELO
ISEBE LEZEMPILO
DEPARTEMENT VAN GESONDHEID

Kimberley Hospital Complex
Du Toitspan Road
Private Bag X5021
KIMBERLEY
8300

Kimberley Kakaretso Tsamaneng
Du Toitspan Road
Kgetsanaposo X5021
KIMBERLEY
8300

Isibedlela sase Kimberley
Du Toitspan Road
Private Bag X5021
KIMBERLEY
8300

Kimberley Hospitaal Kompleks
Du Toitspanweg
Privaatsak X5021
KIMBERLEY
8300

Tel. (053) 802 9111 Fax (053) 802 2432 / 802 2436

Enquiries : Dr L Koning
Dipatlisiso :
Imibuzo : Tel: (053) 802 2147
Navrae : Fax: (053) 832 9435

Reference :
Tshupelo :
Isalathiso :
Verwysings :

Date :
Leshupelo :
Umhla : 7th June 2012
Datum :

Ms J Herbert

Dear Ms Herbert

RE: Permission to do research on side effect of antiretroviral drugs amongst patients and staff

Permission is hereby granted to do the abovementioned research at Kimberley Hospital. Please submit proof of ethics clearance, before commencing with the research.

Regards,

Dr L Koning
ACTING CLINICAL MANAGER

A CENTRE FOR HEALTH SERVICE EXCELLENCE

Addendum B: Letter of permission (Galeshewe Day Hospital)

DEPARTMENT OF HEALTH
LEFAPHA LA BOITEKANELO
ISEBE LEZEMPILO
DEPARTEMENT VAN GESONDHEID

FRANCES BAARD DISTRICT OFFICE
PRIVATE BAG X5049
KIMBERLEY
8301
TEL – 053 8314695
FAX- 053 8337201
EMAIL – fbrekelmans@ncpg.gov.za

Enquiries / Dipatlisiso / Imibuzo / Navrae: MRS . N.GUMBO

Date / Letsatsi / Umhla / Datum: 2012/06/05

Reference / Tshupelo / Isalathiso / Verwysings: RESEARCH STUDY – GDH

MS J HERBERT

RE: RESEARCH STUDY – GALESHEWE DAY HOSPITAL

1. The above and your correspondence of the 28th May 2012 has reference.
2. Please note that your request to conduct research study at Galeshewe Day Hospital is granted.

Thanking you

MRS N GUMBO
FRANCES BAARD DISTRICT MANAGER

We are commited to achieving our vision through a decentralized, accountable, accessible and constantly improving health care system within available resources. Our caring, multi-skilled, effective personnel will use evidence-based, informative health care and maturing partnerships for the benefit of our clients and patients.

Addendum C: Patient information sheet (English)

FORM 1 - Patient information sheet (To be read by each respondent)

Dear Respondent/Participant

Exploring the knowledge, perceptions and attitudes of Antiretroviral drugs (ARVs) amongst patients at public healthcare institutions in the Frances Baard District of the Northern Cape

In partial fulfilments of the requirements of the Master Philosophy Degree in HIV/AIDS Management from the Africa Centre of HIV/AIDS Management at Stellenbosch University, I am carrying out a study with the above title. The information you will supply is for academic purposes and it is anonymous and will be treated with confidentiality. The purpose of this study is to gather baseline information. Through the questionnaire I intend to ask the following research question- How much knowledge and what perceptions and attitudes do HIV patients have about the side effects of antiretroviral drugs (ARVs)?

The aim of the studyis to collect data on the knowledge, attitudes and perceptions of the side effects of ARVs amongst HIV patients with the hope of using the information to improve practices at the clinic/hospital and to make recommendations in an effort to improve the knowledge, perceptions and attitudes about the side effects of ARVs amongst HIV patients

The study objectives are as follows-

1. To assess the level of knowledge of HIV patients on the side effects of ARVs
2. To determine the perceptions of HIV patients about the side effects of ARVs
3. To establish the attitude of HIV patients towards the side effects of ARVs
4. To recommend interventions to promote knowledge about the side effects of ARVs amongst HIV patients.

Please feel free to contact me should you have any questions or if you need clarification.

Thank you.

Yours sincerely

Addendum D: Patient consent form (English)

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jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Exploring the knowledge, perceptions and attitudes of the side effects (unwanted effects) of Antiretroviral drugs (ARVs) amongst patients and staff at public healthcare institutions in the Frances Baard District of the Northern Cape. This consent form is applicable to **patients.**

You are asked to participate in a research study conducted by Josephine Winley Herbert, B.Pharm. (U.W.C.), from the Africa Centre for HIV/AIDS at Stellenbosch University. The results of this research study will contribute to a research paper. You were selected as a possible participant in this study because you have qualified to participate in this study.

1. **PURPOSE OF THE STUDY**

- To establish the knowledge, attitude and perceptions about the side effects(unwanted effects) of ARVs
- To provide recommendations to improve practices and knowledge

2. **PROCEDURES**

If you volunteer to participate in this study, we would ask you to do the following:

- Read the participant information sheet(Form 1)
- Complete this Consent form and hand the consent form back to the data collector(myself) once you have signed the form
- Complete the attached questionnaire (Form 2) which the data collector hands to you. You need not record your name on any page of the questionnaire. Fill in all the pages

of this questionnaire by ticking your response and once it is completed, hand it back to the data collector. It should take 15-30 minutes of your time to complete. Both these forms will be completed while you are waiting in the queue (by the doctor or pharmacy).The dat collector will be seated in close proximity to you in case there are any queries with the completion of the forms.

- Participants who wish to participate in the study but are illiterate will be interviewed by the data collector(with form 3)

3. POTENTIAL RISKS AND DISCOMFORTS

There are no risks to the participant that will cause the researcher to terminate the study. If any participant does experience any discomfort(due to the personal nature of HIV/AIDS questions or the personal nature of the treatment of HIV and AIDS),the participant can feel free to contact the researcher who will refer him/her to the doctor/nurse/counsellor on duty at the clinic or hospital.

Counselling services are available from:

- The doctor on duty (Galeshewe Day Hospital) - 053 8022165
- The doctor on duty (Kimberley Hospital Employee Wellness Centre) - 053 8029111
- The Psychologist on duty (Kimberley Hospital Complex) – 053 8029111
- The Chief Social worker on duty (Kimberley Hospital Complex) – 053 8029111

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The respondent may benefit indirectly from this research as this research study intends to make recommendations to improve practices at the healthcare institutions so that patients and staff are more knowledgeable about the side effects (unwanted effects) of ARVs. It is hoped that the more knowledgeable the patients and staff become about the side effects(unwanted effects) of ARVs, the more these side effects (unwanted effects) will be reported to the healthcare providers and the Medicines Control Council so that we strive towards quality products and excellent health services.

5. PAYMENT FOR PARTICIPATION

The respondents will not receive any payment for their participation in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. **Confidentiality will be maintained** by means of coding the questionnaires with a unique number. No names are recorded anywhere in the research study. The data will be protected on the computer (laptop) with restricted access via a password (only known to the data collector).No other person has access to the computer (laptop) which will be used to capture the data. The data will be stored on a
removable disk and it will be backed up on a USB stick of the data collector. The completed questionnaires will be stored in a lockable, steel storage cabinet at the office of which there is only one set of keys which I carry. No information will be released to any other person except the statistician who will provide technical assistance to me with the analysis and compilation of the data for the research report.
No activities in this study will be audio or videotaped, even for educational purposes.
The results of this study will be compiled in a report which will be provided to the University of Stellenbosch and the Ministry of Health (Northern Cape) in a confidential and professional manner.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to **participate** in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Ms. Josephine Herbert (Researcher) or Professor J.Augustyn (Supervisor).

Contact details:

Researcher : Ms. Josephine Herbert Kimberley T:+27 0846806958 E:jherbert55@gmail.comor jwherbert55@gmail.com	Supervisor: Professor J.Augustyn Africa Centre for HIV/AIDS Management Stellenbosch University T: +27 083 626 3081 E:jcda@sun.ac.za

9. **RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to meby Josephine Herbertin Afrikaans/English/Xhosa/other and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative (if applicable)

_____ _____

Signature of Subject/Participant or Legal Representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ and /or [his/her] representative _____. [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [Afrikaans/*English/*Xhosa/*other] and [no translator was used/this conversation was translated into _____ by _____].

I declare that I explained and requested permission from the participant_____ and /or [his/her] representative_____ to access information in his/her file (folder) in his/her presence for purposes of this research study only. The file (folder) will be accessed (only if it is necessary) to assist with the anonymous completion of the questionnaire.

_____ _____

Signature of Investigator

Addendum E: Patient questionnaire (English)

FORM 2 - QUESTIONAIRE FOR PATIENTS

Goal: To obtain information on the knowledge, perceptions and attitudes of the side effects (unwanted effects) of Antiretroviral drugs (ARVs) amongst patients

To all participants:

This survey is conducted at this facility to provide us with information. We would like to learn about your knowledge, perceptions and attitudes about the side effects (unwanted effects) of ARVs to improve practices at this health facility.

This in an anonymous survey and it is not required for you to write your name on this questionnaire. Your participation is voluntary and it should take 15-30 minutes to complete this questionnaire.

Please answer all the questions on all the pages**. PLEASE TICK YOUR RESPONSE**.

Institution: …… **Questionnaire no: .....**

Date: …….....

GENERAL QUESTIONS

1. How old are you?

□ 15-19 □ 20-29 □ 30- 39 □ 40-49 □ 50-59 □ 60-69 □ 70-79 □ Above 80 yrs

2. What is your gender?

□ Male □ Female

3. What is the highest level of education you have completed?

□ Std 5 (grd 7) □ Std 10 (grd 12) □ College □ University □ other (please explain).....

KNOWLEDGE QUESTIONS

4. Is there a cure for HIV?

□ Yes □ No

5. What treatment is provided at a clinic/hospital to a person with HIV?

□ARVs and other medicines □ Herbal medicines □ Traditional medicines

□Don't know □Other (please explain) …….....…

6. Are you taking ARVs?

□ Yes □ No

7. How long have you been taking ARVs?
□ 0 yrs □ 1 year □ 2 years □ 3 years □ 4 years □ 5 years □ 6 years
□ other.....

8. Do you know the names of your ARVs?
□ All of them □ Most of them □ some of them . □ none of them

9. How do you take your ARVs? Please explain.
……..
…….

10. Are you taking other medicines or herbs or traditional mixtures with your ARVs?
□ Yes (Please explain)..... □ No

11. Do you think it is important to take your ARVs as you are told at the clinic?
□ Yes (Please explain)..... □ No (Please explain).....

12. When you take your ARVs do you follow the instructions exactly as you are told at the clinic?
□ All of the time □ Most of the time □ Sometimes □ Never

13. Do you know what will happen if you stop taking your ARVs? (More than 1 answer can be ticked)
□ You could die □ You could become resistant to ARVS □ You could develop AIDS □ Nothing will happen □ I don't know

14. Have you been told about the side effects (unwanted effects) of ARVs?
□ Yes □ No

15. What is a side effect (unwanted effect) of an ARV? (Please explain)
.....
.....
16. Who told you about the side effects (unwanted effects) of ARVs? (More than one answer can be ticked here)
□ Doctor □ Nurse □ Pharmacist □ Pharmacist Assistant □ Counsellor
□ Other.....

17. When do they tell you about the side effects (unwanted effects) of ARVs? (More than one answer can be ticked here)
□ When you start ARVs □ Every month □ Every 3 months □ Never □ I don't know

PERCEPTION

18. Do you think the side effects (unwanted effects) of ARVS are something good or something bad?
□ Very good □ Good □ Not good or bad □ Bad □ Very bad
□ I don't know

19. Do you think that the side effects (unwanted effects) of ARVs are serious or something not to worry about?
□ Very serious □ Serious □ A little serious □ Not serious □ Nothing to worry about

20. What do you think causes the side effects (unwanted effects) of ARVs?
.....
.....
21. Do you think that the side effects (unwanted effects) of ARVs can be stopped or discontinued?
□ Yes □ No

22. How many side effects (unwanted effects) do you think can be stopped?
□ All of them □ Most of them □ Some of them □ None of them
□ I don't know

23. Do you think that side effects can change the longer you are on treatment with ARVs?
□ Yes □ No □ I don't know

24. Is it difficult for you to understand the side effects of ARVs?
□ Yes □ No

25. If yes (in no.24 above) please explain your answer.
.....
.....
26. Do you look for the side effects (unwanted effects) or any changes in your body if you take your ARVs?
□ Yes □ No

27. Are you told about the side (unwanted effects) of ARVs at every clinic visit?
□ All the time □ Most of the time □ Sometimes □ Never
□ Don't know

28. Do they tell you about the **same**or **different** side effects every time you visit the clinic?
□ Yes (explain)..... □ No (explain).....

29. Do you think the staff at the clinic know about the side effects (unwanted effects) of ARVs?
□ All of them □ Most of them □ Some of them □ None of them
□ I don't know

30. Do you think that other HIV patients know about the side effects (unwanted effects) of ARVs?

□ All of them □ Most of them □ Some of them □ None of them
□ I don't know

ATTITUDE

31. What do you do when you experience any side effect (unwanted effect) of your ARVs?
□ Stop taking the **specific** ARV that you think is causing the problem □ Stop taking **all** the ARVS □ Don't do anything □ Other.....

32. Do you report the side effects (unwanted effects) of the ARVs?
□ All the time □ Most of the time □ Sometimes □ No, I don't report it □ I don't know how to report it

33. To whom do you report the side effects (unwanted effects) of the ARVs?
□ Doctor □ Nurse □ Pharmacist □ Pharmacist Assistant □ A friend
□ A family Member □ Nobody □ Other.....

34. Do you want to know more about the side effects (unwanted effects) of ARVs?
□ Yes □ No

35. Do you ask questions about the side effects (unwanted effects) of ARVs at your clinic?
□ All the time □ Most of the time □ Sometimes □ Never □ I don't know how to ask

36. Do you read more about the side effects (unwanted effects) of ARVs?
□ All the time □ Most of the time □ Sometimes □ Never □ I don't know where to get information

37. What do you think will assist HIV patients to know more about the side effects (unwanted effects) of ARVs?
□ Posters □ Pamphlets □ Counselling □ Support groups' □ Health talks' □ Patient diaries □ I don't know □ Other.....

38. How many side effects (unwanted effects) of **each ARV** do you think they must tell you about when you visit the clinic?
□ 0 (none) □ 1 □ 2 □ 3 □ 4
□ I don't know

39. When must they tell you about the side effects (unwanted effects) of your ARVs?
□ Every month □ Every 2 months □ Every 3 months □ Every 6 months
□ Never

40. Do you have any suggestions how the clinic can improve its services so that all HIV patients know and understand the side effects (unwanted effects) of ARVs?
.....
.....

THANK YOU FOR YOUR PARTICIPATION

Addendum F: Patient interview schedule for illiterate patients (English)

Form 3-Interview schedule for respondents/participants (e.g. illiterate patients)

Opening

After observing the response and reaction of the respondent in answering the self administered questionnaire, I shall interview the respondent. During the interview I would like to ask some questions about the participant's age, gender, educational background, the knowledge of antiretroviral drugs (ARVs) as well as the perception, the attitudes and knowledge about the side effects of ARVs.

The interview should take 30 to 45 minutes.

The interview will be semi-structured, guided by the following kinds of questions:

A. General demographic information

1. Age
2. Gender
3. Educational background

B. Background information about ARVs

1. How long have you been on the antiretroviral drugs (ARVs)?
2. Do you know about the names of your ARVs?
3. What side effects of ARVs have/do you experience? Please explain your answer
4. Do you report any side effects of ARVs to a healthcare worker? Please explain your answer
5. If yes - when, where and how is this reported?

C. Knowledge strategy

1. What is a side effect of ARVs?
2. During your visits to this clinic do you receive information about the side effects of ARVs?
3. If yes, when, who and how is this provided?
4. Are their other ways that information on the side effects of ARVs can be provided to HIV patients?

D. Perception

1. Are side effects of ARVs good or bad?
2. Do you think the side effects of ARVs can change over time?

E. Attitude

1. Is it easy to understand the side effects of ARVs?

Please explain your answer.

2. What will make it easier for you to understand the side effects of ARVs?

F. Closing

1. Are there any other matters regarding the knowledge, perceptions or attitudes? of the side effects of ARVs that you would like to emphasise?

Addendum G: Staff information sheet (English)

FORM 1 - Staff information sheet (To be read by each respondent)

Dear Respondent/Participant

Re: Exploring the knowledge, perceptions and attitudes of Antiretroviral drugs (ARVs) amongst staff at public healthcare institutions in the Frances Baard District of the Northern Cape

In partial fulfilments of the requirements of the Master Philosophy Degree in HIV/AIDS Management from the Africa Centre of HIV/AIDS Management at Stellenbosch University, I am carrying out a study with the above title. The information you will supply is for academic purposes and it is anonymous and will be treated with confidentiality. The purpose of this study is to gather baseline information. Through the questionnaire I intend to ask the following research question- How much knowledge and what perceptions and attitudes do staff have about the side effects of antiretroviral drugs (ARVs)?

The aim of the studyis to collect data on the knowledge, attitudes and perceptions of the side effects of ARVs amongst staff with the hope of using the information to improve practices at the clinic/hospital and to make recommendations in an effort to improve the knowledge, perceptions and attitudes about the side effects of ARVs amongst staff members.

The study objectives are as follows-

1. To assess the level of knowledge on the side effects of ARVs amongst staff.
2. To determine the perceptions of the side effects of ARVs amongst staff.
3. To establish the attitude of staff towards the side effects of ARVs
4. To recommend interventions to promote knowledge about the side effects of ARVs amongst staff members.

Please feel free to contact me should you have any questions or if you need clarification. Thank you.

Yours sincerely

Addendum H: Staff consent form (English)

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jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Exploring the knowledge, perceptions and attitudes of the side effects of antiretroviral drugs (ARVs) amongst staff at public healthcare institutions in the Frances Baard District of the Northern Cape. This consent form is applicable to staff members.

You are asked to participate in a research study conducted by Josephine Winley Herbert, B.Pharm. (U.W.C.), from the Africa Centre for HIV/AIDS at Stellenbosch University. The results of this research study will contribute to a research paper. You were selected as a possible participant in this study because you have met the criteria to participate in this study.

1. PURPOSE OF THE STUDY

The study is designed to collect baseline information on the knowledge, perceptions and attitudes of the side effects of antiretroviral drugs (ARVs) amongst staff at the Galeshewe Day Hospital and the Kimberly Hospital Complex and to make recommendations in an effort to improve the perceptions, attitudes and knowledge about the side effects of ARVs amongst staff and patients.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:
a. Read the participant information sheet (Form 1)
b. Complete this Consent form
c. Complete the attached questionnaire for staff (Form 2, pgs 1 - 4)
d. Forms 1, 2 and this consent form will be available in English.

Handout of forms

The participant will be provided forms 1, 2 and this consent form by the data collector for him/her to read in a private place at the clinic/hospital. It should take 10-20 minutes for him/her to read through all the forms.

Completion of forms

He/she will complete this consent form, as well as form 2 in a black pen. The consent form must be read and signed by the participant. It should take 5- 20 minutes to complete this consent form.With form 2, all questions must be answered and all pages must be completed .It should take 20 – 30 min to complete form 2.The completed forms will be handed back to the data collector.

All the completed forms will then be collected and securely stored with the data collector.

3. POTENTIAL RISKS AND DISCOMFORTS

There are no foreseen physical or psychological risks to participation that might cause the researcher to terminate the study.

This research study is considered to be classified as a medium risk category as the research questions enquire about his/her knowledge about his/her antiretroviral drugs (ARVs) as well as personal information about the perception, attitude and knowledge about the side effects of antiretroviral drugs (ARVs).

Any discomfort experienced by the participant with the reading and completion of the consent form and forms 1 and 2 will be handled with confidentiality and professionalism. The participant will be referred to the doctor at the clinic or hospital to reduce the impact of the risk of discomfort.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The respondent will not benefit from this research. This research study intends to make recommendations to improve practices at the healthcare institutions so that staff are more knowledgeable about the side effects of ARVs. It is hoped that the more knowledgeable the staff are about the side effects of ARVs, the more these side effects will be communicated to patients and healthcare providers and with time, more side effects of ARVs will be reported

by staff to the Medicines Control Council so that quality ARVS are produced for HIV patients.

5. PAYMENT FOR PARTICIPATION

The respondents will not receive any payment for participation in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of coding the questionnaire (form 2) with a unique number. All completed questionnaires will be safely stored in a secure storage place having a restricted access to these documents. Data from the completed questionnaires will be captured on a laptop of the data collector and it will be stored on a removable disk ad backed up on a USB stick of the data collector and statistician. Access to the laptop of the data collector is restricted and accessible with the use of a pin code (only known to the data collector)

Data that is collected will be released to the statistician only for purposes of analyzing the results of the study and presenting the results in professional, technical and analytical manner for academic purposes.

No activities in this study will be audio or videotaped, even for educational purposes.

The results of this study will be formulated as a report which will be provided to the University of Stellenbosch and the Ministry of Health (Northern Cape) in a confidential and professional manner.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Ms. Josephine Herbert or Professor J.Augustyn.

Contact details:

Researcher : Ms. Josephine Herbert Kimberley T:+27 0846806958 E:jherbert555@gmail.com or jherbert@msh.org	Supervisor: Professor J.Augustyn Africa Centre for HIV/AIDS Management Stellenbosch University T: +27 083 626 3081 E:jcda@sun.ac.za

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without any penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to [*me/the subject/the participant]* by Josephine Herbertin [*Afrikaans/English]* and [*I am/the subject is/the participant is]* in command of this language or it was satisfactorily translated to [*me/him/her*].[*I/the participant/the subject]* was given the opportunity to ask questions and these questions were answered to *[my/his/her]* satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.] I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative (if applicable)

_____ _____

Signature of Subject/Participant or Legal Representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ and /or [his/her] representative _____. *[H*e/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa/*other*] and [*no translator was used/this conversation was translated into* _____ by _____].

_____ _____

Signature of Investigator **Date**

Addendum I: Staff questionnaire (English)

FORM 2 - QUESTIONAIRE FOR STAFF MEMBERS

Goal: To collect data on the knowledge, perception and attitudes of the side effects of antiretroviral drugs (ARVS) amongst staff.

To all participants:

This survey is conducted at this facility to provide us with information. We would like to learn about your knowledge, perception and attitudes of ARVS to improve practices at this health facility. This in an anonymous survey and it is not required for your name to be recorded on this questionnaire. Your participation is voluntary and it should take 15-30 minutes of your time.

Please answer all questions on all 4 pages. Please circle your selected response.

Institution: …… **Questionnaire no: ……**

Date: ……

GENERAL QUESTIONS

1. How old are you?

a. 15-19 b. 20-29 c. 30- 39 d. 40-49 e. 50-59 f. 60-69

2. What is your gender?

a. Male b. Female

3. What is the highest level of education you have completed?

a.Std 5 (grd 7) b. Std 10 (grd 12) c. College d. University e.Other (please explain).....

KNOWLEDGE QUESTIONS

4. Can HIV be cured?

a. Yes b. No

5. What treatment is provided at this clinic/hospital to a person with HIV?

a.ARVs and medicines b. Herbal medicines c. Traditional medicines d. Don't know e.Other (please explain) …….....

6. Do you know the names of ARVS?

a. Yes (explain).....

b.No (explain).....

7. Do you know the dosaging and frequency of ARVS?
a. Yes (explain).....
b.No (explain).....

8. What is a side effect of an ARV? (explain)
.....
.....
.....
9. Have you been told about the side effects of ARVS?
a. Yes b. No

10. Who informed you about the side effects of ARVS? (More than 1 can be circled here)
a. Doctor b. Nurse c. Pharmacist d. Pharmacist Assistant e. Counsellor f.Other.....

11. Do you think that the side effect of ARVS is something serious?
a. Very serious b. Serious c. A little serious d. Not serious e. Nothing to worry about

12 What do you think causes side effects of ARVS?
.....
.....
.....
13. Do you think that the side effects of ARVS can be stopped or discontinued?
a. Yes b. No

14. How many side effects do you think can be stopped?
a. All of them b. Most of them c. Some of them d. None of them e. I don't know

15. Do you think that side effects can change over time with the treatment of ARVS?
a. Yes b.No

16 Did you receive training about the side effects of ARVS?
a. Yes b.No

17. When and where did you receive training about the side effects of ARVs? Please explain.
.....
.....

PERCEPTION

18. Do you think the side effects of ARVS are good or bad?
a. Very good b. Good c. Neutral d. Bad e. Very bad f. Don't know

19. Is it difficult to understand the side effects of ARVS?
a. Yes b.No

20. If yes (in no.19 above) please explain.....

21. Do you think patients know about the side effects of ARVS?

a. All of them b. Most of them c. Some of them d. None of them e. I don't know

22. Do you think patients must know about the side effects of ARVS?
a. Yes (explain).....b.No (explain).....

23. Do you think patients look for the side effects of ARVS or any changes in their body?
a. Yes b.No c. I don't know

24. Do you think that patient knowledge about side effects of ARVS is linked to adherence?
a. Yes b.No c. I don't know

25. When do you think must patients be told about the side effects of ARVS?
a. Never b. Before starting treatment c. Upon initiation of treatment. d. After 1 month on treatment e. After 3 months on treatment f. After 6 months on treatment g. After 1 year on treatment h. With every visit
i. Other (explain).....

26. Do you think staff members at this facility know about the side effects of ARVS?
a. All of them b. Most of them c. Some of them d. None of them e.I don't know

27. Whom do you think must inform patients about the side effects of ARVS?
e.Counsellor b. Doctor c.Pharmacist d.Pharmacist Assistant e. Nurse
f.Other (explain).....

28. Do you think there is enough time spent educating patients about the side effects of ARVS?
a. Yes b.No c. I don't know

ATTITUDE

29. Do you inform patients about the side effects of ARVS?
a. All the time b.Most of the time c. Sometimes d. Never
e. I don't know how to do it

30. Do you tell them the same side effects **each time** they visit the clinic/hospital?
a. Yes (explain)..... b. No (explain).....

31. How many side effects do you tell them of **each** ARV?

a.0 b.1 c.2 d.3 e.4 f.Other.....

32. How do you decide how many side effects you must tell the patient? Please explain.....
.....
.....

33. Do you tell them the general side effects or specific side effects of ARVS?

a. General side affects b.Specific side effects

34. When patients tell you their side effects of ARVS what do you do?
a. Stop the ARVS b. Refer the patient to a doctor c.Dont do anything
d. Report it e. Other.....

35. Do you report the side effects of the ARVS?
a. All the time b. Most of the time c.Sometimes d. No, I don't report it
e. I don't know how

36. To whom do you report the side effects of ARVS?
a. Doctor b. Nurse c. Pharmacist d. Pharmacist Assistant
e. Medicines safety centre f. Nobody g. Other.....

37. Do you want to know more about the side effects of ARVS?
a. Yes b. No

38. Do you ask questions about the side effects of ARVS?
a. All the time b. Most of the time c. Sometimes d. Never
e.I don't know who to ask

39. Do you read more about the side effects of ARVS?
a. All the time b. Most of the time c. Sometimes d. Never
e. I don't know where to get info

40. What will assist HIV patients to know more about the side effects of ARVS?

a. Posters b. Pamphlets c. Counselling d. Support groups e. Health talks
f. Patient diaries g. Don't know h.Other.....

41. Do you have any suggestions how the clinic/hospital can improve its services so that staff know and understand the side effects of ARVS?
.....
.....

THANK YOU FOR YOUR PARTICIPATION