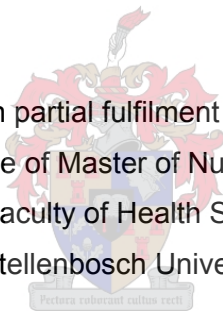


THE KNOWLEDGE ABOUT HIV/AIDS AND ANTIRETROVIRAL TREATMENT OF PATIENTS RECEIVING ANTIRETROVIRAL THERAPY

Lauren Muriel Terblanche (née Baird)

Thesis presented in partial fulfilment of the requirements
for the Degree of Master of Nursing Science
in the Faculty of Health Sciences
at Stellenbosch University



Supervisor: Dr. E.L. Stellenberg

March 2012

DECLARATION

By submitting this thesis 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 explicitly otherwise 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.

Signature:

Date:

Copyright © 2012 Stellenbosch University
All rights reserved

ABSTRACT

Many HIV positive patients are on antiretroviral therapy (ART) to assist in decreasing the replication of the HIV virus within the body. Adherence to this medication is important, as non-adherence can have serious repercussions. Therefore, the patients' knowledge of ART and their disease is crucial in ensuring good adherence.

A range of barriers to patient education were suspected by the researcher in this community of Delft. The high influx of patients into the clinic everyday minimized consultation time and thereby diminished the opportunity for effective patient education. Consequently, adherence to medication which is closely related to the knowledge and understanding of patients about the disease may be affected.

The following research question was therefore explored: What is the knowledge of infected HIV/AIDS patients who are receiving antiretroviral treatment about HIV/AIDS and ART? The objectives set were to evaluate the patient's knowledge of HIV/AIDS, evaluate the knowledge of ART and to determine whether there are statistical differences between the dependant and independent variables within the study. A quantitative descriptive correlational research design was applied and a convenience sample of $n=200$ (8.5%) patients was selected from a population of $N=2349$ at the Delft Community Health Centre.

A multiple choice questionnaire comprising of mainly closed ended questions with multiple responses was used in individual interviews conducted by either the researcher or fieldworker. Reliability and validity was ensured through the consultation of experts in the fields of research methodology, statistics, HIV/AIDS and the Health Research Ethics Committee of Stellenbosch University.

Permission to conduct this study was granted by the Health Research Ethics Committee of Stellenbosch University, the Provincial Regional Head for Primary Health Care Services, as well as the head of the Delft Community Health Centre.

Data revealed that the participants were mainly female ($n=145/72.5\%$), and the mean age was 37.5 years. Participants were mostly Xhosa speaking and literate, and the majority ($n=112/56\%$), of the participants had a highest education level between grade 9 and grade 12. Many ($n=73/36.5\%$) of the participants had been living with HIV for more than 5 years, but had been on ART for between 1 to 3 years. Knowledge was assessed by asking questions about various aspects of HIV and ART throughout the study. Scores for the 14

critical questions revealed that (n=0/0%) of the participants had good knowledge, (n=40/20%) of the participants had average knowledge and (n=160/80%) of the participants had poor knowledge. The average score for all participants for all 20 knowledge testing questions was (12.6/63%).

The findings showed that the overall knowledge (n=160/80%) is poor. Basic terms and principles of HIV/AIDS and ART were not understood and serious misconceptions regarding the disease were revealed.

OPSOMMING

Baie MIV positiewe pasiënte is op antiretrovirale terapie (ART) om te help met die vermindering van die replisering van die HIV virus in die liggaam. Gebruik van hierdie medikasie is belangrik omdat versuiming van inname ernstige gevolge kan hê. Dus, is die pasiënte se kennis van ART en hul siekte van deurslaggewende belang om volgehoue inname te verseker.

'n Reeks van hindernisse om pasiënte te onderrig, is deur die navorser in die Delftgemeenskap vermoed. Die hoë toestroming van pasiënte na die kliniek elke dag het die konsultasietyd tot die minimum beperk en daardeur die geleentheid vir effektiewe pasiëntonderrig laat verminder. Gevolglik, kan die nakoming om die medikasie te neem wat 'n noue verband toon met die kennis en begrip wat pasiënte het oor die siekte, geaffekteer word.

Die volgende navorsingsvraag is gevolglik ondersoek: Wat is die kennis van geïnfekteerde HIV/VIGS pasiënte wat antiretrovirale behandeling ontvang oor HIV/VIGS en ART? Die doelwitte wat gestel is, is om die pasiënt se kennis van HIV/VIGS te evalueer, die kennis van ART te evalueer en te bepaal of daar 'n statistiese verwantskap tussen onafhanklike en afhanklike veranderlikes binne die studie is. 'n Kwantitatiewe beskrywende korrelerende navorsingsontwerp is toegepas en 'n gerieflikheidsmonster van $n = 200$ (8.5%) pasiënte is geselekteer uit 'n bevolking van $N = 2349$ by die Delftgemeenskap Gesondheidssentrum.

'n Veelkeusige vraelys wat hoofsaaklik uit geslote vrae met veelkeusige response bestaan het, is gebruik in individuele onderhoude wat deur of die navorser of veldwerker gevoer is. Betroubaarheid en geldigheid is verseker deur oorlegpleging met spesialiste op die gebied van navorsingsmetodologie, statistiek, HIV/VIGS en die Gesondheidsnavorsing se Etiese Komitee van die Universiteit van Stellenbosch.

Toestemming om die navorsing te doen, is gegee deur die Gesondheidsnavorsing se Etiese Komitee van Stellenbosch Universiteit, die Provinsiale Streekshoof vir Primêre Gesondheidsdienste, asook die hoof van die Delftgemeenskap Gesondheidssentrum.

Data het bewys dat die deelnemers hoofsaaklik vroulik is ($n=145/72.5\%$) en die gemiddelde ouderdom 37.5 jaar. Deelnemers is meestal Xhosasprekend en geletterd en die meerderheid ($n=112/56\%$) van die deelnemers se hoogste opleidingsvlak is tussen graad 9

en graad 12. Baie ($n=73/36.5\%$) van die deelnemers het met HIV geleef vir 5 jaar, maar was op ART vir tussen 1 tot 3 jaar. Kennis is geassesseer deur vrae te stel oor verskeie aspekte van HIV en ART dwarsdeur die ondersoek. Puntetelling vir die 14 kritiese vrae het aan die lig gebring dat ($n=0/0\%$) van die deelnemers goeie kennis het, ($n=40/20\%$) van die deelnemers beskik oor gemiddelde kennis en ($n=160/80\%$) van die deelnemers se kennis is gering. Die gemiddelde puntetelling vir al die deelnemers van al 20 kennisvrae wat getoets is, is ($12.6/63\%$).

Die bevindinge bewys dat die algehele kennis ($n= 160/80\%$) gering is. Basiese terminologie en beginsels van HIV/VIGS en ART word nie begryp nie en ernstige wanopvattinge aangaande die siekte is geopenbaar.

ACKNOWLEDGEMENTS

My sincere thanks and acknowledgements go to:

- The Lord, in Whom all things are possible.
“Now to Him who is able to do far more abundantly than all we shall ask for or think... to Him be the glory.” Ephesians 3:20, The Bible
- My amazing husband Tielman, I don't know how I would've done this without you. You are my inspiration.
- My parents David and Wendy Baird, who supported me at all times.
- My siblings Michelle, Janet and Jason for your support and encouragement.
- My awesome friends for being so encouraging and affirming. Thank you for all the prayers and support.
- My colleagues and friends, Natalie, Ceridwyn and Danine for your help and support. You are amazing.
- My supervisor Dr. Ethelwynn L. Stellenberg for guiding me through this invaluable process.
- Joan Petersen who is so valuable to this masters program.
- Prof. M. Kidd and Dr J. Harvey for the help with the statistical analysis.

TABLE OF CONTENTS

Declaration	ii
Abstract	iii
Opsomming	v
Acknowledgements	vii
List of Tables	xiii
List of Figures	xiv
Abbreviations	xv
CHAPTER 1: SCIENTIFIC FOUNDATION FOR THE STUDY	1
1.1 Background	1
1.2 Rationale	2
1.3 Significance of the study.....	5
1.4 Research problem	5
1.5 Research question.....	5
1.6 Study aim.....	5
1.7 Objectives of the study	6
1.8 Research methodology.....	6
1.8.1 Research design	6
1.8.2 Research Setting.....	6
1.8.3 Population and sampling	6
1.8.4 Specific criteria	6
1.8.5 Data collection tool	7
1.8.6 Pilot study.....	7
1.8.7 Validity and reliability.....	7
1.8.8 Data collection.....	7
1.8.9 Analysis of data	7
1.9 Ethical considerations.....	8
1.10 Limitations	8
1.11 Conceptual framework.....	8
1.11.1 The Innovative Care for Chronic Conditions (ICCC) framework.....	9
1.11.2 Self-care deficit theory of nursing	10
1.12 Definitions	13
1.13 Chapter outline	14

1.14	Summary	14
CHAPTER 2:	LITERATURE REVIEW	15
2.1	Introduction	15
2.2	The human immunodeficiency virus (HIV).....	15
2.2.1	<i>Historical overview</i>	<i>15</i>
2.2.2	<i>Incidence</i>	<i>16</i>
2.2.3	<i>Pathophysiology of HIV</i>	<i>16</i>
2.2.4	<i>The lifecycle of HIV</i>	<i>17</i>
2.2.5	<i>Clinical stages</i>	<i>18</i>
2.2.6	<i>Viral load (VL) and CD4 count.....</i>	<i>19</i>
2.3	Antiretroviral therapy (ART).....	20
2.3.1	<i>Eligibility criteria for ART in South Africa.....</i>	<i>20</i>
2.3.2	<i>ART side-effects.....</i>	<i>21</i>
2.4	Drug resistance	21
2.5	Adherence	22
2.5.1	<i>Factors influencing adherence</i>	<i>22</i>
2.5.1.1	<i>Side effects.....</i>	<i>22</i>
2.5.1.2	<i>Scheduling of appointments.....</i>	<i>23</i>
2.5.1.3	<i>Disclosure.....</i>	<i>23</i>
2.5.1.4	<i>Substance abuse.....</i>	<i>23</i>
2.5.2	<i>Patient literacy and HIV/AIDS knowledge</i>	<i>23</i>
2.5.3	<i>The link between adherence and knowledge of HIV and ART.....</i>	<i>24</i>
2.6	Patient education.....	26
2.6.1	<i>Factors preventing effective patient education.....</i>	<i>27</i>
2.6.2	<i>Factors promoting effective patient education.....</i>	<i>27</i>
2.7	Summary	28
CHAPTER 3:	RESEARCH METHODOLOGY	30
3.1	Introduction	30
3.2	Research design.....	30
3.3	Population and sampling	30
3.3.1	<i>Population</i>	<i>30</i>
3.3.2	<i>Sampling</i>	<i>31</i>

3.3.3	<i>Criteria</i>	31
3.4	Research setting.....	31
3.5	Pilot study	31
3.6	Reliability and validity	32
3.7	Instrumentation.....	33
3.8	Data collection	34
3.9	Data analysis and interpretation	35
3.9.1	<i>Scoring system</i>	36
3.9.2	<i>Mean</i>	36
3.9.3	<i>Median</i>	36
3.9.4	<i>Standard Deviation</i>	36
3.9.5	<i>Pearson Chi-square</i>	36
3.9.6	<i>Analysis of Variance (ANOVA)</i>	36
3.9.7	<i>Fisher's Exact Test</i>	37
3.9.8	<i>T-test</i>	37
3.10	Ethical considerations.....	37
3.10.1	<i>Permission to conduct the study</i>	38
3.11	Limitations	38
3.12	Summary	38
CHAPTER 4: PRESENTATION, ANALYSIS AND INTERPRETATION OF RESULTS		40
4.1	Introduction	40
4.2	Statistical analysis	40
4.3	Section A (demographic data).....	40
4.3.1	<i>Age</i>	40
4.3.2	<i>Gender</i>	41
4.3.3	<i>Home Language</i>	41
4.3.4	<i>Highest Level of Education</i>	42
4.3.5	<i>Literacy Level</i>	43
4.3.6	<i>Length of Time Living with HIV/AIDS</i>	43
4.3.7	<i>Length of Time on Antiretroviral Therapy</i>	43
4.4	Section B (knowledge of HIV/AIDS and ART)	44
4.4.1	<i>What does the HIV virus do in the body?</i>	44
4.4.2	<i>Is HIV spread through any of the following?</i>	45

4.4.3	<i>What is the window period?</i>	47
4.4.4	<i>How long does the window period last?</i>	48
4.4.5	<i>What is a CD4 count?</i>	48
4.4.6	<i>When last was your CD4 count done?</i>	49
4.4.7	<i>How often should you have your CD4 count done?</i>	49
4.4.8	<i>Why is it important to have your CD4 count done?</i>	50
4.4.9	<i>What is a viral load?</i>	51
4.4.10	<i>When last was your blood drawn for viral load?</i>	51
4.4.11	<i>Do you know which stage of HIV/AIDS you are in?</i>	52
4.4.11.1	<i>If yes, which stage are you in?</i>	52
4.4.12	<i>If you are HIV positive, will your children also definitely be HIV positive?</i>	53
4.4.13	<i>Why did the staff at the clinic say that you must start treatment?</i>	53
4.4.14	<i>Can ART cure HIV?</i>	54
4.4.15	<i>What does ART do to the HIV virus in the body?</i>	54
4.4.16	<i>Did the clinic staff say that you can expect any side-effects with your medication?</i>	55
4.4.17	<i>Can ART cause side-effects that can be very dangerous?</i>	56
4.4.18	<i>Can you name two (2) danger signs of ART?</i>	56
4.4.19	<i>What should you do if you experience any of the danger signs?</i>	57
4.4.20	<i>What should you do if you forget to take your medication?</i>	57
4.4.21	<i>What will happen if you stop taking your medication?</i>	58
4.4.22	<i>Where did you learn most of your knowledge about HIV and treatment from?</i>	59
4.5	<i>distribution of obtained scores</i>	59
4.6	<i>Summary</i>	60
CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS		62
5.1	<i>Introduction</i>	62
5.2	<i>Discussion</i>	62
5.2.1	<i>The level of knowledge of patients infected with HIV/AIDS about the disease</i>	62
5.2.2	<i>The level of knowledge of patients infected with HIV/AIDS about ART</i>	64
5.2.3	<i>Determining whether there are statistical differences between the dependant and independent variables within the study</i>	66
5.3	<i>Conclusions</i>	67
5.4	<i>Overall evaluation of participant's knowledge regarding HIV/AIDS and anti-retroviral therapy (ART)</i>	67

5.5	Recommendations.....	68
5.5.1	<i>Continuous patient education</i>	68
5.5.1.1	Language and culture	69
5.5.1.2	Gender	69
5.5.1.3	Age	69
5.5.1.4	Literacy and Education Level	70
5.5.2	<i>Visual techniques and initiatives</i>	70
5.5.3	<i>Continuous professional development</i>	71
5.5.4	<i>Community development</i>	71
5.5.5	<i>Patient acknowledgment</i>	71
5.5.6	<i>Health promotion</i>	72
5.6	Further research	72
5.7	Limitations	73
5.8	Conclusion	73
	List of references	75
	Appendices	83
	Appendix A: Data collection tool.....	83
	Appendix B: Ethical committee approval letter	88
	Appendix C: Ethical committee approval letter.....	89
	Appendix D: PGWC approval letter.....	90
	Appendix E: Letter of informed consent	91
	Appendix F: Afrikaans declaration.....	96
	Appendix G: Xhosa declaration	98

LIST OF TABLES

Table 4.1: Gender	41
Table 4.2: Literacy levels	43
Table 4.3: Length of time living with HIV.....	43
Table 4.4: What does HIV do in the body?	44
Table 4.5: Is HIV spread through any of the following?	47
Table 4.6: What is the window period?	48
Table 4.7: How long does the window period last?	48
Table 4.8: When was your last CD4 count done?	49
Table 4.9: Why is it important to have you CD4 count done?	50
Table 4.10: Do you know what stage of HIV you are currently in?	52
Table 4.11: Which stage are you in?	52
Table 4.12: Can ART cure HIV?	54
Table 4.13: Can ART cause side-effects that can be very dangerous?	56
Table 4.14: Can you name two danger signs of ART?	57
Table 4.15: From where did you learn most of the knowledge about HIV and its treatment from?	59
Table 4.16: Distribution of scores	60

LIST OF FIGURES

Figure 1.1: The HIV positive patient's self-care requisites and the nurse's responsibility to promote self-care, applying to Orem's self-care theory (illustration by researcher).....	12
Figure 2.1: The Life Cycle of HIV (Illustration by Smeltzer & Bare, 2004:1552).	18
Figure 4.1: Age range and mean age of participants.....	41
Figure 4.2: Distribution of home language	42
Figure 4.3: Distribution of Education Levels	42
Figure 4.4: Distribution of participants' years on ART.....	44
Figure 4.5: Distribution of answers for whether kissing can spread HIV correlated with number of years on ART	45
Figure 4.6: Distribution of answers to the question: What is a CD4 count?.....	49
Figure 4.7: Distribution of answers to the question: How often should a CD4 count be done?	50
Figure 4.8: Distribution of answers to the question: What is a viral load?	51
Figure 4.9: Distribution of answers to the question: When last was your blood drawn for viral load?.....	52
Figure 4.10: Distribution of answers to the question: If you are HIV positive, will your children also definitely be HIV positive?	53
Figure 4.11: Reasons for commencing ART	54
Figure 4.12: Distribution of answers to the question: What does ART do to the HIV virus in the body?	55
Figure 4.13: Distribution of years on ART specific answers to: Did the clinic staff say that you could expect any side-effects with the medication you are using?	56
Figure 4.14: Distribution of the answers to the question: What should you do if you experience any of the danger signs?	57
Figure 4.15: Distribution of answers to the question: What must you do if you forget to take your medication?	58
Figure 4.16: Distribution of answers to the question: What will happen if you stop taking your medication?.....	59

ABBREVIATIONS

AIDS:	Acquired immune deficiency syndrome
ANOVA:	Analysis of variance
ART:	Antiretroviral therapy
ARV's:	Antiretrovirals
CD4:	Cluster designation four (4) cells
CHC:	Community Health Centre
CNP:	Clinical nurse practitioner
DNA:	Deoxyribonucleic acid
DOH:	Department of Health
HAART:	Highly active antiretroviral therapy
HIV:	Human immunodeficiency virus
MDR- TB:	Multi- drug resistant tuberculosis
MTCT:	Mother- to- child transmission
RNA:	Ribonucleic acid
STI:	Sexually transmitted infection
TB:	Tuberculosis
UNAIDS:	Joint United Nations Programme on HIV/AIDS
VL:	Viral load
WHO:	World Health Organisation
XDR- TB:	Extensively drug resistant TB

CHAPTER 1: SCIENTIFIC FOUNDATION FOR THE STUDY

1.1 BACKGROUND

The Human Immunodeficiency Virus (HIV) is primarily a sexually transmitted disease which has changed the focus of health care delivery in South Africa dramatically since the 1980's. According to the 2009 AIDS Epidemic update, there were 5.7 million people living with HIV/AIDS in South Africa, out of a global total of 33.4 million. This update therefore indicates that South Africa constitutes 17% of the global HIV/AIDS population. The number of people living with HIV/AIDS has shown a constant increase every year since the first diagnosis of HIV/AIDS in the 1980's despite the call for better co-ordination and monitoring (South Africa, 2007:11). Various interventions have been introduced to reduce vulnerability to HIV infection and the impact of AIDS including:

- prevention of the sexual transmission of HIV through distribution of free condoms,
- increase in coverage for voluntary counselling and testing and
- promotion of regular HIV testing

(South Africa, 2007:13-14).

According to the HIV and AIDS and STI strategic plan for South Africa (2007:19), South Africa's main contributing factors in the spread of this disease are rooted in poverty, underdevelopment, the low status of woman and gender-based violence in the communities.

It is assumed that adherence is directly related to knowledge, amongst other factors (Kip, Ehlers, Van der Wal, 2008:152). By patients' understanding of their disease, it is more likely that they will adhere to the education they are given regarding, how the HI-virus is transmitted and how this can be prevented, what the virus does in the body, how HIV can be treated, how the treatment affects the virus, what the side effects of treatment are and the risks of poor adherence.

The standard treatment of choice for people living with HIV/AIDS is antiretroviral therapy (ART). The pharmacological action of this medication is to suppress the replication of the HI virus (South Africa, 2010:28). Adherence to ART is therefore important to contain the disease because poor adherence may produce serious complications like medication resistance, which could even lead to death.

The virus is transmitted through the exchange of bodily fluids during sexual intercourse, blood transmission, mother to child transmission (MTCT) as in during pregnancy, birth and breast feeding (Evian, 2008:13-17). The underlying pathophysiology which results when the HIV virus enters the body is to destroy or cause dysfunction in the helper T cells or CD4 cells, which are known as the immune response cells in the body (Evian, 2008:7). These cells are required to signal the immune system to any pathogens which enter the body which may result in a disturbance of the normal physiology of the body. The body may respond with signs of infection.

Unfortunately, there is still no cure for HIV/AIDS, but antiretroviral therapy (ART), is the treatment of choice to contain the disease. In layman's terms, ART suppresses the virus and thereby prevents the cells to 'make copies' or 'replicate' themselves (Evian, 2008:79). ART therefore lowers the viral load of the HIV in the blood, and by doing so prevents CD4 cells from being destroyed.

1.2 RATIONALE

Many HIV positive patients are on ART to assist in decreasing the replication of the HI-virus within the body. Adherence to this medication is of crucial importance, as serious side effects can be caused by non-adherence. Therefore, the patient's knowledge of ART and HIV disease is crucial to ensure that adherence is improved and maintained.

Adherence can be defined as, 'the process in which a person follows rules, guidelines or standards especially as a patient follows a prescription and recommendations for a regimen of care.' (Anderson, Keith, Novak & Elliot, 2002:42).

According to Bangsberg (2006:939), adherence of more than 90% needs to be achieved, in order for ART to be effective. If ART is not correctly adhered to, the HIV virus is not optimally controlled within the body and the viral load in the blood increases.

HIV is known to rapidly spread by multiplying itself; therefore this uncontrolled virus replicates itself within the body if not adequately suppressed by lifelong ART, which could lead to resistance to medication (Evian, 2008:79).

According to previous studies adherence rates are not optimal. In a study conducted by Bhat, Ramburuth, Singh, Titi, Antony, Chiya, Irusen, Mtyapi, Mofoka, Zibeke, Chere-Sao, Gwadiso, Sethathi, Mbondwana, & Msengana (2010:948), the results indicated that only 62.5% had an adherence rate of more than 90% and therefore 37.5% of the participants were at risk of developing resistance due to unacceptable adherence levels.

In a study conducted in Botswana, adherence rates were strongly influenced by misconceptions regarding the virus. Out of 400 participants, male and female, 40.3% did not believe that they could be re-infected with HIV/AIDS through sexual intercourse or other means. Another misconception is that some people believe that HIV could be cured by ART. In the same study it was indicated that 9.3% of the participants believed that HIV did not really even exist (Kip, Ehlers, Van der Wal, 2008:152).

A study conducted in Soweto, South Africa, revealed that just below 60% of the participants believed that HIV could be transmitted through mosquitoes (Nachega, Lehman, Hlatshwayo, Mothopeng, Chaisson, Kardtaedt., 2005:189). In Brazil, Almeida and Vieira (2009:184) showed in their studies that 55% of the HIV positive participants on ART did not know the mode of action of the antiretrovirals (ARV's) in suppressing the virus and preventing rapid replication. The study also indicated that 36% did not know that they would be taking medication for life, and only 14% of the participants knew and gave the correct answer on what to do if a dose is skipped.

Nachega *et al.* (2005:189), in their studies conducted in Soweto revealed a relatively high understanding of HIV disease progression and transmission by the participants, as well as the importance of adherence to medication. This could be attributed to the fact that the study took place in a specialized HIV treatment clinic within the township, where all patients were HIV positive. Nevertheless, this indicates that there was much attention given to maintaining a high level of patient education and ensuring patient understanding in this facility, which is reassuring.

Molassiotis, Nahas-Lopez, Chung, Lam, Li, Lau (2002:305), revealed the importance and value of regular and ongoing patient education, in their study conducted in China. This study found a 97% adherence rate. Patients who participated in the study showed good knowledge and understanding concerning medication and related knowledge regarding the importance of drug resistance and decreasing the risk of drug resistance. These patients all received regular individual patient education regarding their illness and the researchers identified that there was strong trusting relationship between the patients and the nursing staff.

The above studies show that, by providing regular education by healthcare professionals to patients, the better the understanding the patients will have of their disease. With an improved understanding, insight and knowledge about the disease and management, thereof, an improvement in adherence may result.

Patients may adhere to education given to them regarding preventing HIV transmission through safe sex practices, taking medication as prescribed and taking responsibility for their own health. It is important for patients to understand the importance of attending all follow-up appointments, understanding and having their CD4 and viral loads monitored regularly.

Knowledge and understanding of HIV/AIDS will in turn reduce the amount of HIV cases in the community, in the country and eventually globally. However, as experienced by the researcher in practice, serious misconceptions also exist in communities about HIV/AIDS as described above which may influence adherence to medication.

Furthermore, overcrowded clinics aggravate the management of patients daily. An average number of 1200 patients attend a particular comprehensive health clinic daily with a variety of conditions. The researcher in her daily practice as a primary health care practitioner observed that due to a minimal number of nursing and medical staff, health education given to especially patients faced with a debilitating disease such as HIV/AIDS are inadequate. This is very serious as a lack of knowledge and understanding will lead to ignorance and will maintain the rapid spread of HIV/AIDS in South Africa.

According to Kozier, Erb, Berman and Burke (2000:461), emotions, prognosis, language and culture are factors inhibiting patients from learning. Emotions such as fear, anger, depression and anxiety result in an inability of the patients to concentrate and focus on what they are being educated about. If patients are preoccupied by their prognosis, they will not concentrate on the information being conveyed to them and if they do not understand what is being said due to a language barrier, the education given will therefore be unprofitable. Cultural barriers may have an important effect on learning. Values of the Western culture may be in conflict with the cultural values of these patients and lead to poor adherence to advice and treatment offered or recommended.

The researcher observed that there were a range of suspected barriers to patient education in this community. The high influx of patients daily into the clinic minimizes consultation time and thereby diminishes the opportunity for effective patient education regarding HIV/AIDS. Possible illiteracy of the HIV positive patients on ART in this community may lead them not to understand what they are taught by healthcare workers and patients that are unable to read would be unable to acquire and understand knowledge from educational material distributed by various institutions which promote HIV/AIDS education.

According to Kozier *et al.* (2000:466), nurses should assess a patient's physical, emotional and cognitive readiness prior to educating the patient. This will result in effective education.

In addition, a threat exists in developing drug resistance and possibly dangerous and fatal side effects of ART if patients are not educated about the side-effects, these side-effects could cause serious irreparable harm (Zuniga, van Cutsem and Saranchuk, 2010:215).

Therefore, health education is especially required when treating a patient infected with HIV/AIDS as it comprises of many facets that need constant attention. Patients are required to have a complete understanding of their disease in order to adhere to treatment and contain the disease. Ultimately, this may contribute to an improvement in the quality of life of HIV/AIDS infected patients and prevent the spread of the disease.

1.3 SIGNIFICANCE OF THE STUDY

The study served to determine the knowledge of HIV positive patients being treated with anti-retroviral drugs, regarding HIV/AIDS and ART as well as to determine if there are any statistical differences between independent and dependent variables within the study. By determining this, insight into the patient's knowledge of the disease and the patient's management would be gained, including whether this knowledge is influenced by certain variables. Scientific evidence obtained in this study would assist policy makers in health when developing strategies to improve patient education and compliance.

1.4 RESEARCH PROBLEM

In the light of the above, it was identified that problems such as the high influx of patients daily as well as an inadequate number of nursing staff in the clinical environment may prevent health professionals in providing adequate health education to patients infected with HIV/AIDS and receiving ART. Consequently, knowledge of HIV and ART is affected negatively and adherence to medication which is closely related to the knowledge of patients about the disease and ART is affected.

1.5 RESEARCH QUESTION

The question that the researcher explored in this study was: What is the knowledge of infected HIV/AIDS patients receiving antiretroviral treatment about HIV/AIDS and antiretroviral therapy (ART)?

1.6 STUDY AIM

The aim of this study was to determine the knowledge of infected HIV/AIDS patients who are receiving ART about HIV/AIDS and anti-retroviral therapy ART

1.7 OBJECTIVES OF THE STUDY

The specific objectives set for this study were to:

- evaluate the level of knowledge of patients infected with HIV/AIDS about the disease
- evaluate the level of knowledge of patients infected with HIV/AIDS about ART
- establish whether there is a statistical differences between the independent and dependant variables within the study.

1.8 RESEARCH METHODOLOGY

In this chapter a brief overview is described about the methodology applied in the study, a more in-depth approach is described in chapter 3.

1.8.1 Research design

A quantitative descriptive correlational research design was applied to evaluate the knowledge of HIV infected patients receiving ART about the disease HIV/AIDS and ARTs.

1.8.2 Research Setting

The study was conducted at the Delft Community Health Centre (CHC) in Delft, Cape Town, South Africa, which is a low socio-economic area where there is a high level of poverty, low literacy levels, as well as a fairly large HIV population (Statistics South Africa, 2001). Delft CHC is a comprehensive primary health care clinic offering a wide range of services to the community such as HIV and TB care, chronic disease care, antenatal care, integrated management of childhood illnesses as well as family planning, to name a few. Two private consultation rooms were provided by the CHC for the conduction of the structured interviews.

1.8.3 Population and sampling

According to statistics given by the manager of the ARV clinic, the HIV population of Delft CHC was 3429 excluding children under 18, of which 2349 patients were on ART. For the purpose of this study and in consultation with a statistician and to improve validity, a fairly large convenience sample of $n = 200$ (8.5%) patients was selected from a population of $N = 2349$ at the Delft CHC.

1.8.4 Specific criteria

Specific criteria set for the purpose of this study for each participant were the following:

- HIV positive and receiving ART
- eighteen years and older
- either male or female

- receiving ART for at least three months

1.8.5 Data collection tool

A multiple choice questionnaire (Appendix A) consisting of closed-ended questions with multiple responses was developed by the researcher and used for data collection. The questionnaire consisted of 20 questions which tested HIV/AIDS and ART knowledge. 14 of the 20 questions were critical questions on which the scoring of the patients would be based. The questionnaire was in English, but structured interviews took place in, English, Afrikaans or Xhosa (with the help of a Xhosa and English speaking fieldworker), depending on the participant's preference.

1.8.6 Pilot study

A pilot study was conducted using 10% (n=20) of the sample of the actual study. This was done to determine the feasibility of the study and to test the methodology amongst others also the questionnaire. The results of the pilot study were not included in the study data.

1.8.7 Validity and reliability

Reliability and validity was ensured through the consultation of experts in the fields of research methodology, statistics, HIV/AIDS and the Health Research Ethics Committee of Stellenbosch University. The questionnaire was revised by various professionals in the field and proved to be valid and reliable in the pilot study. The pilot study also added to the overall reliability and validity of the study

1.8.8 Data collection

The English and Afrikaans speaking researcher and a trained fieldworker fluent in both Xhosa and English conducted structured interviews in two (2) private consultation rooms within the Delft CHC. These structured interviews were conducted in the language preferred by the participant as the fieldworker and researcher were able to provide in this need.

1.8.9 Analysis of data

The researcher had been in consultation with Professor Martin Kidd from the Centre for statistical analysis, as well as Dr Justin Harvey, who assisted with the data analysis and interpretation.

All data collected was captured on an excel spreadsheet by the researcher. Thereafter, the data was analysed by a statistician using the computerised data analysis programme STATISTICA Version 9. For descriptive purposes frequency tables, graphs and means were used. For comparison of variables, the types of analyses depended on the types of data

compared, but typically included cross tabulation (with the Pearson Chi-square test), correlation analyses, t-tests or ANOVA.

1.9 ETHICAL CONSIDERATIONS

Permission to conduct this study was requested and granted (Appendix B) from the Health Research Ethics Committee of Stellenbosch University, from the Provincial Regional Head for Primary Health Care Services (Appendix C), as well as the head of the Delft Community Health Centre where the data collection took place. Informed consent was obtained from each of the participants in English, Afrikaans or Xhosa depending on the participant's choice (Appendix D, E & F). The participants had a choice whether or not to take part in the study. Anonymity was ensured. For this purpose the participants were not required to fill in their names, identification or folder numbers anywhere on the questionnaire.

1.10 LIMITATIONS

A limitation experienced was that of obtaining permission from the Department of Health which was delayed by three months due to internal delays within the department. In addition, due to the low socio-economic levels and suspected low literacy rates, structured interviews had to be conducted personally with each participant to ensure that they understood what was required of a question. The data collection took place over 3 weeks and approximately 13 participants were interviewed per day. The researcher continued her daily occupation during the data collection period and only went to the CHC for a few hours per day during this period. The fieldworker also continued her daily work in the CHC, and could not dedicate full days to the research. Therefore, the data collection period was much longer than expected as each interview took approximately 20 minutes and there was a large sample group.

1.11 CONCEPTUAL FRAMEWORK

A conceptual theoretical framework explains either graphically, or in the narrative form, the main aspects to be studied, the key factors, constructs, or variables and the presumed relationships among them (Miles & Huberman, 2003:45).

According to Mouton (2005:175), conceptual frameworks bring conceptual clarity. A well structured conceptual analysis makes conceptual categories clear, explicates theoretical linkages and reveals the conceptual implications of different viewpoints.

When statements are organised according to certain interests or objectives and become integrated into conceptual frameworks, familiar structures of science are found (Mouton, 2002:195).

1.11.1 The Innovative Care for Chronic Conditions (ICCC) framework

In 2003, the WHO developed the ICCC which highlights the need for comprehensive health system design or change in order to achieve effective care (Epping-Jordan, Pruitt, Bengoa & Wagner, 2004:299). The framework consists of 3 levels including the micro (patient and family), meso (healthcare organization and community) and macro (policy) levels.

The micro level emphasizes that there is a critical role that is played by leaders and caregivers in the community (Epping-Jordan *et al.*, 2004:301). It highlights that there is an active triad partnership between patients, families, healthcare teams and community partners. It is explained that this partnership will function optimally if all members are informed, motivated and prepared with skills necessary to manage chronic conditions (Epping-Jordan *et al.*, 2004:301).

The meso level emphasizes the importance of the greater community in playing a supportive role to the health care system as well as the patients and families within the community (Epping-Jordan *et al.*, 2004:301). The role of the community is to support by 'bridging the gap' between the health care system and the world of the patients and their families by repeating and emphasizing messages about prevention and management of chronic conditions (Epping-Jordan *et al.*, 2004:301).

The macro level stipulates the responsibility of policy-makers and governments to provide a positive environment (Epping-Jordan *et al.*, 2004:301). This can be achieved by providing advocacy and leadership, integrating policies, supporting legislative frameworks, promoting consistent finances, developing and allocating human resources and strengthening partnerships within the community (Epping-Jordan *et al.*, 2004:302).

In light of the above, it can be seen that health care leaders and providers need to play an active role in care amidst the increasing burden of chronic conditions within the communities they serve. By equipping health care providers, community members and patients, it is envisioned that an effective and positive impact will be made on the community and patients. In order to have informed, motivated and prepared health care providers, community members and patients, increased provision and time for learning and motivating is crucial within the clinical setting.

1.11.2 Self-care deficit theory of nursing

Dorothea Orem's theory of self-care is based on the philosophy that 'all patients wish to care for themselves' (Orem, 1971:25). Orem (1991:35) describes self-care as 'care that is performed by oneself when one has reached a state of maturity that is enabling for consistent, controlled, effective and purposeful action'. She describes that it is the 'practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and wellbeing' (Orem, 1985:84).

Taylor (2002:191), defines self-care as *'the practice of activities that maturing and mature persons initiate and perform within time frames, on their own behalf, and in the interest of maintaining life and healthful functioning and continuing personal development and well being'*.

It is assumed that patients can recover quicker and holistically if they are allowed to perform their own self-care. It can therefore also be assumed that patients suffering from HIV/AIDS will maintain health if they understand their disease and are able to make informed decisions regarding their own self-care.

Orem (1985:90-100) identified self-care requisites, which are groups of needs or requirements for all people. There are 3 categories namely:

- **Universal Self-care requisites:** Needs that people have such as; air, water, food, elimination, activity and rest, solitude and social interaction, hazard prevention and promotion of normality. For the HIV/AIDS patient, as the immune system is compromised, good nutrition, regular exercise and preventing exposure to infections is essential to maintain health and wellbeing.
- **Developmental Self-Care Requisites namely:**
 - Maturational: progressing towards a higher level of maturation through knowledge and understanding of HIV/AIDS and its treatment.
 - Situational: preventing of negative effects due to development by receiving support and acceptance by various people in the community.
- **Health Deviation Requisites:** Those needs which arise due to a person's condition which involves seeking medical assistance, medical care and learning to live with the disease and complying with prescribed medical regimes, therapeutic and rehabilitative measures. Taylor (2002:193) explains that disease does not only affect specific physiological or psychological structures, but also integrated human functioning and self-care ability.

In the case of the HIV/AIDS patient, the patient is required to understand and adhere to the treatment regime, knowing what necessary blood tests are needed, what side-effects may present with ART, what to do in the case of side-effects and how to prevent the transmission of HIV/AIDS.

Orem explains that a self-care deficit occurs when a person is not able to meet their own self-care requisites. Here, it is the nurse's responsibility to identify these deficits and see which support modality the patient is grouped into. In the case of an HIV/AIDS patient, nurses are to identify deficits knowledge and understanding of HIV/AIDS preventing self-care, and to educate appropriately. The three support modalities identified by Orem are:

- *Wholly compensatory*: The nurse is expected to accomplish all the patient's therapeutic self-care or when the patient needs continuous guidance in self-care (Taylor, 2002:195). If the HIV/AIDS patient has no or little knowledge of his/her disease or is very ill, it is the nurse's responsibility to provide and decide on the appropriate and best treatment option for the client. She should also guide and educate as much as possible in order for the patient to gain knowledge and understanding. This will in turn help the patient to gain the ability to practice self-care.
- *Partly Compensatory*: The nurse compensates for self-care limitations and the patient performs some self-care measures to meet the self-care needs (Taylor, 2002:195). When the HIV/AIDS patient has some knowledge regarding his or her disease, it is still the nurses responsibility to identify which deficits in self-care there are and how to assist the patient, however supporting the patient by educating him at all times to reach complete self-care.
- *Supportive- educative*: The patient accomplishes self-care and the nurse promotes and supports self-care (Taylor, 2002:195). HIV/AIDS patients who have good knowledge and understanding, and who are able to practice self-care, must at all times be supported as well as encouraged to support and educate other HIV/AIDS patients who have not reached self-care.

Dorothea Orem's theory on self-care can appropriately be applied to patients suffering from HIV/AIDS. As HIV/AIDS is a life threatening and life changing disease, it is important that patients are able to regain a feeling of control in their lives. By having informed, motivated and prepared nurses continuously educating, supporting and making resources available to them, as per the ICCC framework, it will aid patients to regain compliance and ultimately the ability of self-care. This relationship between patient's needs and nurse's responsibility towards the patient is key in attaining the ability for self-care by the patient. The role of the nurse in patient education is of absolute importance, as it will be the nurse who will

continuously be in the position to identify self-care deficits (Stellenberg, 1995:70). It is however ultimately the patient's choice whether to follow or not follow advice or suggestions given by the nurse (Figure 1.1).

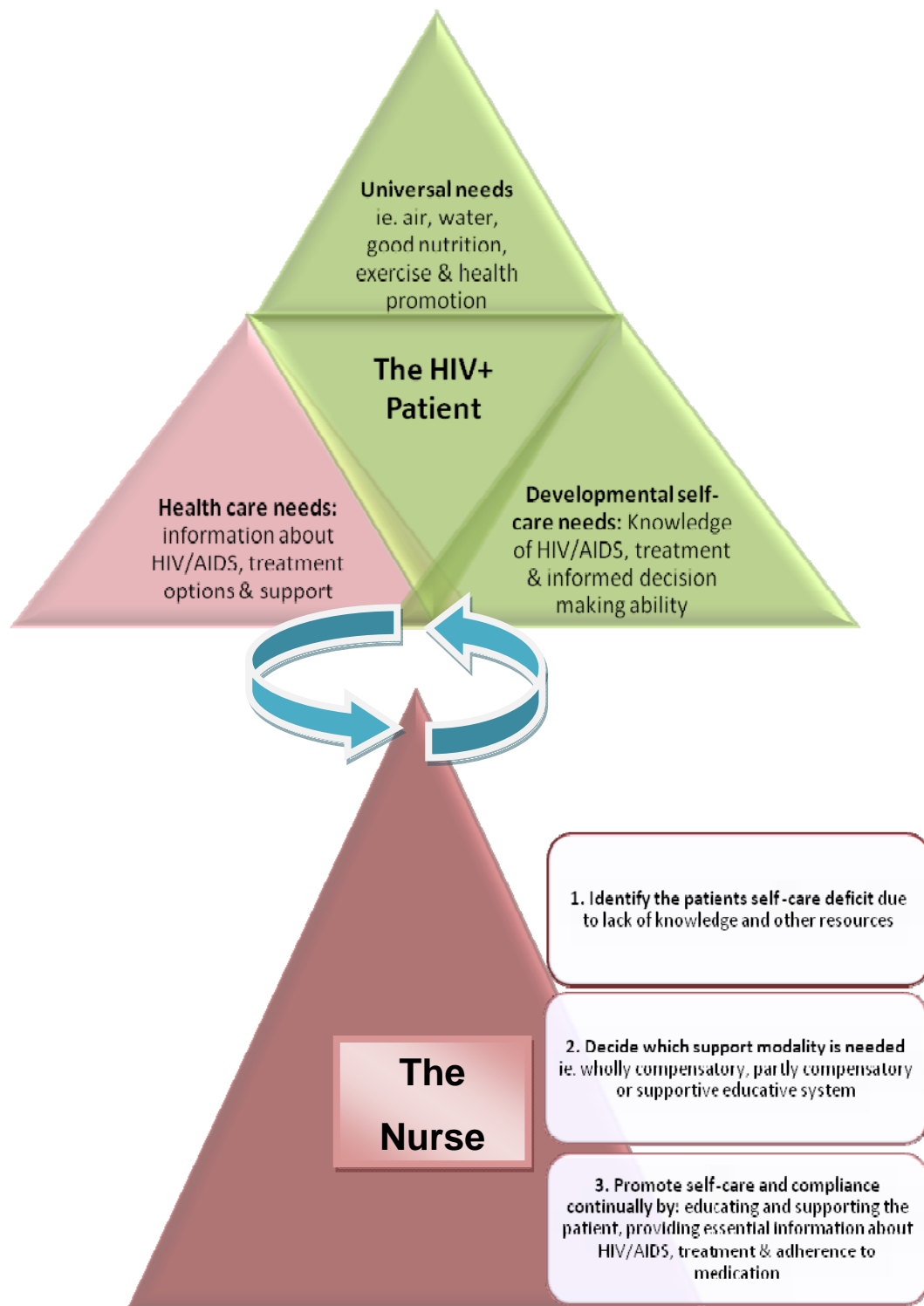


Figure 1.1: The HIV positive patient's self-care requisites and the nurse's responsibility to promote self-care, applying to Orem's self-care theory (illustration by researcher).

1.12 DEFINITIONS

Acquired immune deficiency syndrome (AIDS)

A syndrome involving a defect in cell-mediated immunity that has a long incubation period, follows a protracted and debilitating course, is manifested by various opportunistic infections, and without treatment has a poor prognosis (Anderson, Keith, Novak & Elliot, 2002:22).

Antiretroviral therapy (ART)

The purpose of ART (highly active ART- HAART) is to achieve HIV viral suppression and reduce the level of RNA of HIV to as low as possible for as long as possible. It is the medication therefore that is effective in delaying the onset of AIDS (Evian, 2008:79).

Cluster designation four (4) cells

Cells which are important indicators/ predictors of the risk for acquiring opportunistic infections and when to start ART (Evian, 2008:73).

Human immunodeficiency virus (HIV)

A retrovirus that causes acquired immunodeficiency syndrome (Anderson, Keith, Novak & Elliot, 2002:830).

Mother-to- child transmission (MTCT)

Transmission of HIV from a mother to child via pregnancy, childbirth or breastfeeding (Evian, 2008:223).

Sexually transmitted infection (STI)

A contagious infection usually acquired by sexual intercourse or genital contact (Anderson, Keith, Novak & Elliot, 2002:1572).

Tuberculosis (TB)

A chronic infection caused by an acid-fast bacillus, *Mycobacterium tuberculosis*. It is usually transmitted by inhalation or ingestion of infected droplets and usually affects the lungs, although infection of multiple system organs can also occur (Anderson, Keith, Novak & Elliot, 2002:1761).

World Health Organization (WHO)

An intergovernmental organization within the United Nations system whose purpose it is to aid in the attainment of the highest possible level of health by all people (Anderson, Keith, Novak & Elliot, 2002:1835).

1.13 CHAPTER OUTLINE

Chapter 1: Scientific foundation for the study

In chapter 1 the background, rationale, significance, research question, goal and objectives for the study are described. A brief overview of the research methodology and the conceptual framework which guided the study is also described.

Chapter 2: Literature Review

In chapter 2 literature regarding HIV/AIDS, the treatment thereof, the importance of patient education and gaps in education identified by various studies in the field are discussed.

Chapter 3: Research Methodology

In chapter 3 the research methodology as applied in the study is discussed.

Chapter 4: Data Analysis and Interpretation

In chapter 4 the results of the study is revealed, analysed, interpreted and discussed.

Chapter 5: Conclusions and Recommendations

In chapter 5 the conclusions and recommendations based on the results are described.

1.14 SUMMARY

In most of the literature studied, it was observed that the general knowledge level of HIV is not what it should be and there are a number of misconceptions regarding HIV/AIDS. According to the literature a lack of knowledge and understanding is aiding in non-adherence of the patients towards their prescribed treatment regimen which is described in the rationale. As HIV/AIDS is constantly changing and new information is regularly published about the disease, it is important that patients get regular and ongoing education about their disease by informed, motivated and prepared nursing staff. This area was researched in order to see what the knowledge level of patients is, where the deficits lie and to make recommendations what can be done to improve their level of knowledge and understanding. Improving their knowledge and understanding is believed to aid them in becoming autonomous, which will lead them to self-care by making informed decisions regarding their health, their illness and their treatment. In this chapter the researcher described the rationale, as well as the goals and objectives of the study. A brief description of the research methodology applied to the research study was also presented. In the next chapter an in depth literature review based on various studies in the field of HIV, patient education and the influences of patient literacy are described and a conceptual framework is established on which to base the research.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter, the literature review sets out to explore the various aspects of HIV/AIDS, as well as the treatment and management thereof. Strategies by various stakeholders, including the National Department of Health (DOH), and various studies conducted in this field will be explored. According to Burns and Grove (2009:91), the purpose of a literature review is to convey what is currently known regarding a specific topic and to obtain a broad background and understanding of what is already known about a particular problem and the knowledge gaps that exist in the situation. A literature review is a summary of theoretical and empirical sources to generate a picture of what is known and not known about the particular area of research (Burns & Grove 2007:545). It is conducted to direct the planning and execution of a study (Burns & Grove, 2007:137) and provides one with the current theoretical and scientific knowledge about the particular problem (Burns & Grove, 2007:135).

Areas that need to be researched could be gaps that have been identified from previous research that has been conducted, but the need arises for it to be conducted in another country or institution. Literature was searched for in the Google search engine, medical journals, PubMed, the Stellenbosch University Library and other resources available.

2.2 THE HUMAN IMMUNODEFICIENCY VIRUS (HIV)

2.2.1 Historical overview

HIV is primarily a sexually transmitted disease which was first 'discovered' in the United States of America in 1981, after a number of homosexual men developed a rarely seen pneumonia caused by a bacterium called pneumocystis carinii. These previously well homosexual men between the ages of 20 and 45 years had developed a severe immune deficiency, which helped this pneumonia to develop. Not long after that, health workers in Central Africa, started seeing heterosexual patients representing with a disease called Slims disease, which was marked by severe weight loss and diarrhea. The spread of the disease was assisted by various means such as; people having unprotected sex and exposure to HIV positive body fluids and this is how the disease began to spread throughout the world (Evian, 2008:3). Cefrey (2001:24) states that HIV is a virus referred to as acquired, because a person has to perform a certain behaviour to become infected by this virus. Many myths have been spread about AIDS. There is no cure for HIV/AIDS and while treatment may help and some people manage their disease, the condition is still fatal (Jackson, 2002:13).

2.2.2 Incidence

HIV/AIDS is considered a manageable chronic condition (Mukona, Charumbira, Nyamakura, Zvinavashe & Manwere, 2011:17), which according to the 2009 AIDS Epidemic Update, South Africa constituted 17% of the global HIV/AIDS population and this number is continuously increasing. In 2009, 5.7 million people were living with HIV/AIDS in South Africa out of 33.4 million people living with HIV/AIDS globally (UNAIDS AIDS Epidemic Update, 2009:11).

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), reasons for the rapid and continual spread of HIV/AIDS is as result of:

- Lack of understanding about AIDS and the HIV transmission,
- Lack of enough counselling
- Lack of testing services,
- The effects that stigma and discrimination attached to AIDS has, which often results in rejection and violence against people who are HIV positive

(Pendukeni, 2004:16-17).

2.2.3 Pathophysiology of HIV

The virus is transmitted through the exchange of fluids during sexual intercourse, blood transmission, mother to child transmission (MTCT) as in during pregnancy, birth and breast feeding (Evian, 2008:13-17). The impact of HIV on the human immune system depends on various factors, including the age of the person, health status and wellbeing, as well as any previous diseases or illnesses. Whether or not the person is healthy, the virus will eventually affect the person's immune system so that the function of immune protection is hindered. Consequently, it will no longer be able to protect the person from various diseases..

Rapid multiplication of the HIV virus occurs especially in the first three (3) months (Cefrey, 2001:8 - 9), known as the window period. The window period is the gap of approximately three months between the time when a person becomes infected with HIV and the time when antibodies first appear in the blood (Jehuda-Cohen, 2011:179). During this period seronegative individuals are an increased threat to others, as they can spread the virus although they test negative (Jehuda-Cohen, 2011:179).

The underlying pathophysiology which results when the HIV virus enters the body, is to destroy or cause dysfunction in the helper T cells or CD4 cells, which are known as the

immune response cells in the body (Evian, 2008:7). These cells are required to alert the immune system to any pathogens which enter the body which may result in a disturbance of the normal physiology of the body. These cells are the primary target of the HIV virus. Normal CD4 counts range from 700-1000 cells/mm³, but a CD4 count as low as 500 cell/mm³ could be considered as normal (Wyatt & Sodroski in Smeltzer & Bare, 2004:1553). Therefore, the higher the CD4 count the more optimal for the patient.

2.2.4 The lifecycle of HIV

The life cycle of the HIV virus consists of a number of stages (Figure 2.1) namely:

1. Attachment: The HIV virus firstly attaches itself to the CD4 cell receptor
2. Fusion: The virus then fuses with the CD4 cell wall and the virus then empties its content (reverse transcriptase and Deoxyribonucleic acid [DNA]) into the CD4 host cell
3. Reverse transcription: The virus then produces an exact copy of its viral ribonucleic acid (RNA) within the host cell to form a double stranded DNA
4. Integration: The Viral DNA then joins with the host cells' DNA
5. Protein production and proteas function: The cell then makes new viral proteins within itself which become functional proteins
6. Maturation: This eventually results in cell replication and starts the whole process again

(Porth in Smeltzer & Bare, 2004:1552).

This process results in more viruses being produced and more CD4 cells infiltrated and destroyed. The patient's immune response is lowered when HIV destroys the T cells (CD4) and consequently patients infected with HIV are more susceptible to infections as the body has difficulty defending itself (Evian 2008: 7).

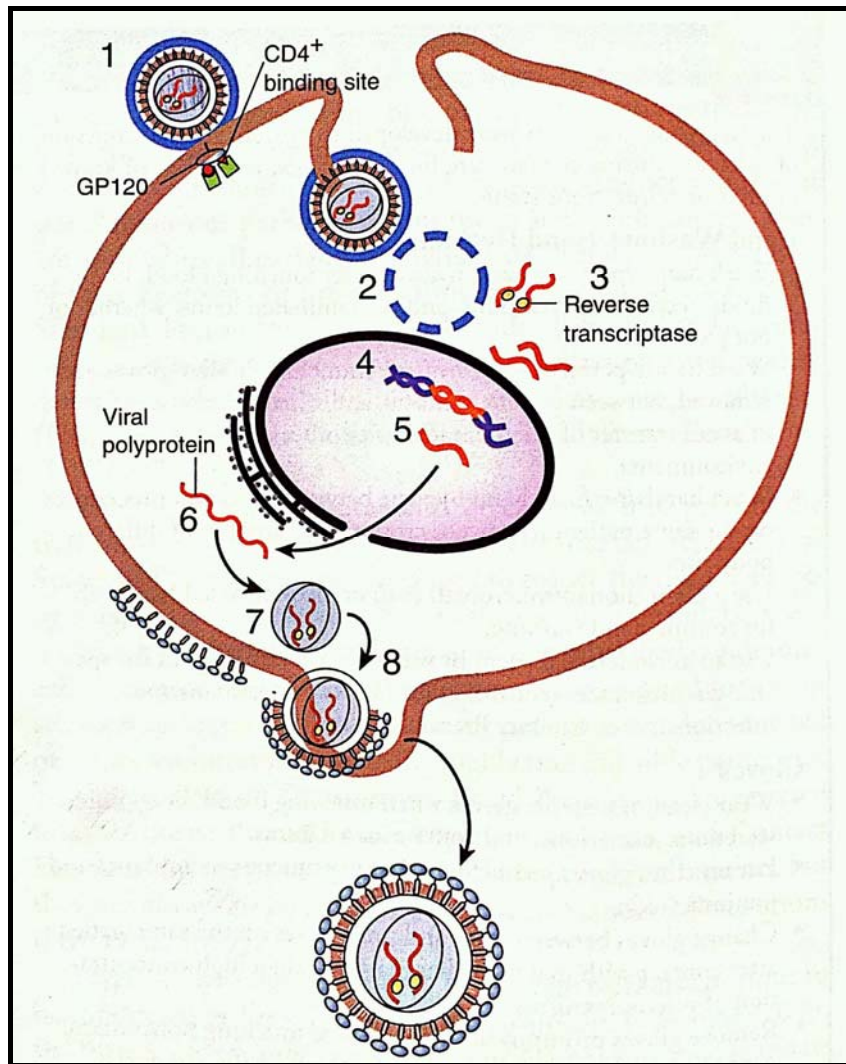


Figure 2.1: The Life Cycle of HIV (Illustration by Smeltzer & Bare, 2004:1552).

2.2.5 Clinical stages

According to the WHO (2004), there are four clinical stages in this disease which are based on clinical criteria. Patients are allocated to a stage based on the clinical symptoms, signs and diseases with which they may present, such as pulmonary tuberculosis (TB), a prevalent lung disease in South Africa (Harries *et al.*, 2004:32).

- HIV Stage 1:
Patients present with either no symptoms or painless swollen lymphnodes (South Africa, 2010:27).
- HIV Stage 2:
Patients present with symptoms such a recurrent sinusitis, recurrent tonsillitis, mouth ulcers, fungal nails infections and unexplained weight loss, to name a few (South Africa, 2010:27).

- HIV Stage 3:
Patients are classified to be stage 3 if they have current pulmonary TB or TB within the last 12 months, oral thrush, diarrhea for more than 1 month, pneumonia and meningitis, to name a few (South Africa, 2010:27).
- HIV Stage 4:AIDS
Patients are classified to have AIDS if they fall into stage 4, which is characterised with current extrapulmonary TB, herpes simplex of the mouth, Kaposi's sarcoma, recurrent severe pneumonia and invasive cervical cancer to name a few (South Africa, 2010:27).

2.2.6 Viral load (VL) and CD4 count

Regular monitoring of certain blood levels has proven to be very valuable in managing and controlling this disease. There are two main blood tests to measure immune status, including CD4 count and viral load.

Viral load 'explains the measurement of the amount of HIV in the blood expressed which assists in monitoring the response to treatment' (Anderson, Keith, Novak & Elliot,, 2002:1813), it measures the quantity of HIV RNA in the blood (Smeltzer & Bare, 2004:1548). The viral load usually rises to very high levels just after the person has contracted HIV due to white blood cells which respond by increasing after identifying the virus in the body (van Dyk, 2008:50). As soon as the body's immune system recognizes the virus in the blood, it develops an immune response by forming antibodies which then lowers the viral load (Evian, 2008:27). A higher viral load is inversely proportionate with a low CD4 count. According to van Dyk (2008:50) a viral load and CD4 count have a high inverse 'seesaw' relationship. A viral load is the best indicator of the development speed of the disease. The higher the viral load in the blood, the sooner the patient is likely to develop an immune deficiency, and a high risk to spread the disease through sexual intercourse, pregnancy or breastfeeding (Evian, 2008:27).

By observing the state of the patient's immune system, it is easier to predict the patient's risk of developing a symptomatic disease caused by opportunistic infections. The CD4 count is thus an important test in monitoring the immune status of the patient (Evian, 2008:26). According to the HIV/TB guidelines for the Western Cape (2010:27), prior to starting ART, a CD4 count must be done every 6 months, however, the CD4 and viral load count must be monitored at 4 months, 12 months and then 12 monthly after commencing ART. This very important test is also crucial in monitoring the response of the patient to ARV treatment.

2.3 ANTIRETROVIRAL THERAPY (ART)

According to Ewings, Bhaskaran, McLean, Hawkins, Fisher, Gilson, Nock, Brett, Johnson, Phillips and Porter (2008:90), 50% of people start ART between 2 and 10 years after infection. Although not a cure, many HIV positive patients are on ART to assist in decreasing the replication of the HIV virus within the body and usually results in near-complete suppression of HIV replication (Harries *et al.*, 2004:137). The ultimate goal of ART is to prolong life, prevent progression to AIDS, and to improve quality of life for the patient (Hammer, Saag, Schechter, Montaner, Schooley & Jacobsen, Thompson, Carpenter, Fischl, Gazzard, Gatell, Hirsch, Katzenstein, Richman, Vella, Yeni, and Volberding, 2006:832). Determining the stage of the disease is key to routine HIV care, as health workers are then able to follow the HIV/AIDS guidelines to decide which treatment option the patient should commence with (South Africa, 2010:27-28).

Unfortunately, there is still no cure for HIV/AIDS, but ART, is the treatment of choice to contain the disease. In layman's terms, ART suppresses the virus and thereby prevents the cells to 'make copies' or 'replicate' themselves (Evian, 2008:79). ART therefore lowers the viral load of the HIV in the blood, and by doing so prevents CD4 cells from being destroyed. In addition, with the help of ART, the risk of MTCT of HIV is also reduced by reducing the mother's viral load (Zuniga *et al.*, 2010:145).

According to the Department of Health (2010:6), there are various factors which influence the patient's eligibility for ART.

2.3.1 Eligibility criteria for ART in South Africa

According to the new 2010 South African Guidelines, patients are eligible for ART if they meet any of the following criteria:

- A CD4 count ≤ 200 cells/mm³ irrespective of clinical stage **or**
- A CD4 count ≤ 350 cells/mm³
 - In HIV positive patients with tuberculosis (TB)
 - In pregnant women or according to
- WHO stage IV irrespective of CD4 count **or**
- Multi drug- resistant (MDR)/ Extensively drug- resistant (XDR) TB irrespective of CD4

(DOH, 2010:6)

2.3.2 ART side-effects

Most ARV drugs are potentially toxic and may cause side-effects. Most patients tolerate ARV drugs well, but the patient and practitioner must always be sensitive for potential development of side-effects. Side-effects are usually minor in the first 4-8 weeks of treatment but are considered more severe if they develop later (Evian, 2008:88). According to Bhengu, Ncama, McInerney, Wantland, Nicholas, Corless, McGibbon, Davis, Nicholas and Ros (2011:5), there are many different side-effects which patients experience after commencing ART, but not all patients experience the same side-effects.

Side-effects experienced by patients include: Fatigue, tiredness, skin rashes, headaches, insomnia, depression, disturbing dreams and numbness of the feet (Bhengu *et al.*, 2009:5). For both the professional nurse in the clinical field and the patient, all side effects of ART are important to monitor and to be aware of (South Africa, 2010:32).

It is also therefore important that patients know the side-effects of the specific drugs which they are on, which side-effects are 'danger signs' (i.e. skin rash, jaundice and vomiting) (South Africa, 2010:31) and how to react to the side-effect. Depending on the side-effect, patients should stop all drugs immediately and consult the nurse practitioner as soon as possible (Zuniga *et al.*, 2010:171).

2.4 DRUG RESISTANCE

Drug resistance is 'the ability of disease organisms to resist the effects of drugs that were previously toxic to them' (Anderson, Keith, Novak & Elliot, 2002:553).

ART is an ongoing, life- long treatment and should be taken as prescribed, every day. If ART is not correctly adhered to, the HIV virus is not optimally controlled within the body. As HIV is known to rapidly spread by multiplying itself, this uncontrolled virus replicates itself within the body in the presence of three (3) ARV drugs and resistance will develop, which is very serious (Zuniga *et al.*, 2010:163).

This condition could lead to the rapid spreading of HIV within the patient causing patients not to react or respond to treatment and therefore possibly becoming extremely ill. As there are currently only two (2) lines of drug treatment in South Africa, it is important that patients adhere to their treatment (DOH, 2010:20), as patients who fail second line therapy have few treatment options left available to them (DOH, 2010:20).

2.5 ADHERENCE

Adherence can be defined as, ‘*the process in which a person follows rules, guidelines or standards especially as a patient follows a prescription and recommendations for a regimen of care*’ (Anderson, Keith, Novak & Elliot, 2002:42).

Adherence to this medication is of cardinal importance, as this is serious there can be repercussions due to non-adherence. Incomplete adherence can lead to poor treatment outcomes and an increased risk for mortality (Racey, Zhang, Brandson, Fernandes, Tzemis, Harrigan, Montaner, Barrios, Toy & Hogg, 2010:816). Therefore, patients’ knowledge of ART and their disease is crucial when it comes to treating and managing their disease as patients’ understanding and use of health care information can affect their decisions regarding treatment (Racey *et al.*, 2010:816).

Successful management depends on patient understanding and the ability to act on treatment information (Wolf, Davis, Arozullah, Penn, Arnold, Sugar & Bennett, 2005:863). Adherence to highly active antiretroviral therapy (HAART) medication is the greatest patient enabled predictor of treatment success and mortality for those who have access to ART (Mills, Nachega, Bangsberg, Singh, Rachlis, Wu, Wilson, Buchan, Gill & Cooper, 2006:2040).

2.5.1 Factors influencing adherence

Adherence is crucial in the treatment and maintenance of the HIV virus. By adhering to medication it ultimately prevents the patient from becoming ill and eventually leading to AIDS which will ultimately lead to death. According to Bangsberg (2006:939), an adherence rate of more than 90% needs to be maintained in order for ART to be effective in achieving and maintaining viral suppression. If adherence is not maintained, drug resistance may develop which leads to a loss of potentially effective drugs and/or entire drug classes and limits the patient’s treatment options (Racey *et al.*, 2010:816-817).

2.5.1.1 Side effects

In studies conducted by Rougemont, Stoll, Elia and Ngang (2009:10), it is observed that the initial phase or first 6 months of treatment is the most crucial. This is when the patient is ill at his/her worst and when ART is initiated, side-effects occur which could make the patient despondent, and therefore not adhere to the medical regimen. It was explained that most losses to follow-up and death occurred in this initial phase. Studies conducted by Guimarães, Rocha, Campos, de Freitas, Gualberto, Teixeira, de Castilho (2008:167)

showed that patients' main reason for finding ART use difficult was because of the severe side-effects of the drugs.

2.5.1.2 *Scheduling of appointments*

Scheduling of appointments was sometimes a problem to patients. Many could not take time from their jobs to go to the clinic for their appointment, and consequently miss the appointments, which could have a negative effect on adherence (Rougemont *et al.*, 2009:10).

2.5.1.3 *Disclosure*

Disclosure is an important part of ART adherence (Rougemont *et al.*, 2009:10). By disclosing the patient's status to a close person or family member, it places less strain on the patient to hide his medication and think of excuses as to why he goes to the clinic often. By disclosing the information, the patient allows him/herself to be supported by this person. The person can also help then to remember their medication times and support the patient when this is necessary. This helps the patient and should have a positive effect on adherence (Rougemont *et al.*, 2009:10). Studies conducted by Mills *et al.* (2006:2056), indicate that fear of disclosure was a patient related barrier to adherence to ART.

2.5.1.4 *Substance abuse*

It is said that high alcohol consumption or a co-existing substance addiction decreases adherence (Mills *et al.*, 2006:2056). Mills *et al.* continues to explain that the lack of understanding treatment benefits, as well as difficulty understanding treatment instructions is a barrier to adherence. Adherence in women seems to be slightly lower than that of men in some studies. Women have explained that they sometimes miss their medication due to being busy or just simply forgetting (Bhat *et al.*, 2010:948).

2.5.2 **Patient literacy and HIV/AIDS knowledge**

The ability to read and write, which results from formal education, plays an important role in HIV/AIDS management as studies indicate that patients with limited literacy skills may lack essential knowledge related to HIV/AIDS and treatment (Wolf *et al.*, 2005:863). Limited literacy skills affect a person's ability to use health services effectively, take medications and understand additional information related to health (King & Taylor, 2010:24). Weiner (2005:57) states that there is a strong relationship between literacy and poverty, and that those who have higher reading skills in general, make more money than those who do not. Wolf *et al.* (2005:871), state that there is link between literacy and HIV/AIDS knowledge. The

lower the literacy levels are, the poorer the understanding, which results in poorer adherence.

HIV/AIDS has increasingly become an infection of poverty (Smith Fawzi, Jagganathan, Cabral, Banares, Salazar, Farmer & Behforouz, 2006:764). Therefore HIV/AIDS progression can also be associated with low literacy and low health literacy skills which as identified by Neyhart (2008:409) present as barriers to patient education. Health literacy is defined as the problem solving and decision making skills that enable a person to apply new information in order to navigate their way through the health care system and function successfully as a health care consumer (Cutilli, 2007:43). This is one of the strongest predictors of health status and well being (Nath, 2007:44). According to Racey *et al.* (2010:822), higher education, employment, income and living in stable housing are all predictors of being able to define the development of HIV drug resistance in a community.

Dewalt, Berkman, Sheridan, Lohr and Pignone (2004:1229), state that patients with low literacy skills are generally 1 to 3 times more likely to experience poor health outcomes. In studies conducted by Smith Fawzi *et al.* (2006:770), it was observed that a great lack of knowledge regarding HIV transmission was found especially among vulnerable individuals affected by combinations of extreme poverty, lack of access to HIV medications and a history of abuse. Studies conducted by Wolf *et al.* (2005:870), revealed that there was a lack of understanding of common HIV/AIDS terms such as CD4 count and viral load found in the sample of patients with limited literacy skills. It was observed by Racey *et al.* (2010:816), that having higher school education was predictive of HIV/AIDS knowledge such as the ability of a person to define the term 'HIV resistance'.

Patients need to understand the nature of their treatment, the implication of incomplete adherence and the consequences of developing drug resistance (Racey *et al.*, 2010). Programmes directed at HIV positive patients coping with poverty and problems need to ensure that adequate knowledge is transferred to the patient in order to reduce the overall burden of HIV in resource poor communities (Smith Fawzi *et al.*, 2006:770).

2.5.3 The link between adherence and knowledge of HIV and ART

In numerous studies conducted, there were some clear misconceptions noted regarding the HIV/ AIDS and the treatment of choice which influence adherence levels. In a study conducted in Botswana, adherence rates were strongly influenced by misconceptions regarding the virus. Out of 400 participants, male and female, 40.3% did not believe that they could be re-infected with HIV/ AIDS through sexual intercourse or other means. Kip *et*

al., (2008:152) substantiates that in their study, 9.3% of the participants believe that HIV did not really even exist.

Another misconception is that some people believe that HIV could be cured by ART. Odu and Akanle (2008:86) confirms this by indicating in their study that youth had misconceptions that HIV/AIDS could be cured by spiritual, traditional or medical means.

It was also observed in Soweto, that just below 60% of the participants believe that HIV could be transmitted through mosquitoes (Nachega *et al.*, 2005:189). Adequate HIV transmission knowledge among HIV positive patients is necessary to reduce the risk of secondary infections and to protect the uninfected from transmission (Smith Fawzi *et al.*, 2006:764). Odu and Akanle (2008:85), found in their study that 62.6% of the participants understood that a mother can transmit HIV to her unborn baby.

In Brazil, Almeida & Vieira (2009:184) showed in their studies that 55% of the HIV positive participants on ART did not know how ARV's worked in suppressing the virus and preventing rapid replication. The study also indicates that 36% did not know that they would be taking medication for life, and only 14% of the participants knew and gave the correct answer on what to do if a dose is skipped. This was also confirmed in studies conducted by Mukona *et al.* (2011:19), which indicated that only 69.4% of the participants understood the functioning of ART.

Nachega *et al.* (2005:189), showed in Soweto, a relatively high understanding of HIV disease progression and transmission, as well as the importance of adherence to medication. This could be attributed to the fact that the study took place in a specialized HIV treatment clinic within the township, where all patients were HIV positive. Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kebaabetswe, Dickenson, Mompati, Essex and Marlink (2003:283), indicated in their study that participants were well informed regarding modes of transmission such as through blood transfusion, sexual intercourse and exchange of body fluids. This indicates that there may be a high level of attention given to patient education and, making sure that patients understand their disease and treatment, which is reassuring.

Molassiotis *et al.* (2002:305), revealed the importance and value of regular and ongoing patient education, in their study conducted in China. This study showed a 97% ART adherence rate. Patients who participated showed good knowledge and understanding about medication and related knowledge regarding the importance of adherence in preventing drug resistance and how to decrease the risk of drug resistance. These patients

had all received regular individual patient education regarding their illness and the researchers identified a strong trusting relationship between the patients and the nursing staff.

Patients with inadequate knowledge of HIV/AIDS and transmission are more likely to report not taking ART (Smith Fawzi *et al.*, 2006:769).

2.6 PATIENT EDUCATION

The above studies show that, by providing regular education by healthcare professionals, to patients, the better the understanding the patients have of their disease. Patient education can be most meaningful for patients when they are faced with numerous, complex, healthcare needs and are expected and required to make challenging and life changing choices (Cook, Castrogiovanni, David, Stephenson, Dickson, Smith & Bonney 2008:306). According to Racey *et al.* (2010:822), the goal of patient education is to provide people with adequate information about their treatments, in order to ensure optimal treatment outcomes.

Patient education is a key to disease management, convalescence and overall wellness management (Cook *et al.*, 2008:309).

It is said that patient education can enhance patients' feelings of confidence and control, help build a partnership between the patient and the health care professional. It enables patients to participate actively in their own care (Griffin, McKenna & Tooth, 2003:170).

An important partnership of responsibility is to be developed between the health care provider and the patient in order to ensure proper health education (Salmon & Young, 2005:226). Consideration of education and literacy level is important when educating patients, but according to Cook *et al.* (2008:309), consideration for the afore-mentioned is often missed. Patients may adhere to education given to them regarding preventing HIV transmission through safe sex practices, taking medication as prescribed and taking responsibility for their own health. It is essential that patients completely understand the therapeutic plan, as well as the potential consequences deriving from it (Racey *et al.*, 2010:822), as lack of knowledge has a strong link to adherence (Wolf *et al.*, 2005:864) and low adherence with increased risk for drug resistance and therefore mortality (Racey *et al.*, 2010:816).

Knowledge and understanding of HIV/AIDS will in turn reduce the amount of HIV cases in the community, in the country and eventually globally. However, serious misconceptions

may also exist in communities about HIV/AIDS as described above which may influence adherence to medication.

2.6.1 Factors preventing effective patient education

According to Kozier *et al.* (2000:461), emotions, prognosis, language and culture are factors inhibiting patients from learning. Emotions such as fear, anger, depression and anxiety result in an inability for the patients to concentrate and focus on what they are being educated about. If patients are preoccupied by their prognosis, they will not concentrate on the information being conveyed to them. Neyhart (2008:409) suggests that information overload can prevent effective patient education, as well as language barriers. This is aggravated by medical language which can be challenging for people with low literacy levels (King & Taylor, 2010:28). If the patient does not understand what is being said due to a language barrier, the education given will also be unprofitable. Cultural barriers may have an important effect on learning (Neyhart, 2008:409). Values of Western culture could conflict with the cultural values of the patients and lead to poor adherence to advice and treatment offered or recommended.

Furthermore, overcrowded clinics aggravate the management of patients daily. The high influx of patients into clinics every day increases time compression, which minimizes consultation time and thereby diminishes the opportunity for effective patient education regarding HIV/AIDS (Neyhart, 2008:409). Possible illiteracy (Neyhart, 2008:409), of HIV positive patients on ART in low socio-economic areas may lead patients not to understand what they are taught by healthcare workers. In addition patients who are unable to read will be unable to acquire knowledge from education material distributed by various institutions which promote HIV/AIDS counselling and education.

2.6.2 Factors promoting effective patient education

Most health information patients receive is through patient education (King & Taylor, 2010:24). Counselling is the process that helps people understand and deal with their problems as well as communicate better with those whom they are emotionally involved with (Evian, 2008:279). Counselling does not involve just giving advice or taking over the patient's problem. Counselling is when one encourages the patient to find his/her own solutions to problems, helping him/her thus to become an independent and confident person (Evian, 2008:279). The deficit in available time for patient education could play a major role in the self-care and autonomy of the patient. A patient who is autonomous can make informed decisions based on knowledge and experience.

According to Kozier *et al.* (2000:466), nurses should assess a patient's physical, emotional and cognitive readiness prior to educating the patient. Clinicians can assess literacy skills prior to HAART enrolment and provide additional information and support (Wolf *et al.*, 2005:871). This may result in effective education. In addition, a threat exists in developing drug resistance and possibly dangerous and fatal side-effects of ART. If patients are not educated about the side-effects they need to be aware of, these side-effects could cause serious irreparable harm.

Therefore, health education is especially required when treating a patient infected with HIV/AIDS as it comprises many facets that need constant attention. Patients are required to have a complete understanding of their disease in order to adhere to treatment and contain the disease. Ultimately this may contribute to an improvement in the quality of life of HIV/AIDS infected patients and prevent the spread of the disease. Knowledge of ART and HIV/AIDS will empower the HIV positive individual. The individual will consequently be motivated to be part of the collaborative process because initiation of ART is a clinical decision, which should always be made jointly between the informed patient and the healthcare provider (Mukona *et al.*, 2011:19).

By educating HIV positive people in such a way that it leads to full understanding of their disease and treatment thereof, it is believed that this will lead to patients being able to take control of their own self-care and assist in making informed decisions based on what they know, understand and have been educated on (Cook *et al.*, 2008:309). Epping-Jordan, Pruitt, Bengoa and Wagner (2004:299) state that creative ideas and solutions are needed to address the increasing healthcare demands of chronic conditions, especially in countries with limited or stressed primary healthcare infrastructure.

2.7 SUMMARY

HIV/AIDS is a serious disease and the incidence is increasing daily. According to the literature discussed, it is a complex disease which needs to be understood by patients in order for proper management to be conducted as the patient has a high risk of spreading the HIV virus to other people as well as compromising their own health status should they not adhere to treatment.

As reported in this chapter, studies show that there are few HIV positive people who show full understanding of HIV, due to various factors. Those, however, who have adequate adherence to and knowledge of the management of HIV/AIDS, have shown to flow from good patient education by medical staff as well as regular follow-up, which has led to more

effective treatment and prevention. Patient education plays an essential role in the management of patients, as regular and ongoing education promotes knowledge and understanding which lead to patients successfully making informed decisions and good choices regarding their self-care and health.

An overview of the objectives of this study was thus provided by investigating the literature. This study further investigated whether similar problems or situations were present in the Delft community and the results thereof are discussed in chapters 4 and 5.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

Chapter 3 outlines the research methodology being applied during this study. Included in this chapter is a discussion of the research design, the research problem, the study population, the sampling procedure, data collection methods, data analysis and limitations of the study.

3.2 RESEARCH DESIGN

A descriptive quantitative correlation research design was applied to obtain important information of HIV positive patients on ART. A descriptive correlation design describes variables and examines relationships among these variables. This design facilitates the identification of interrelationships in a situation (Burns & Grove, 2007:249). According to Mouton (2005:55), a research design is a plan or a blueprint of how one conducts the research. A research design ensures that research is conducted in a logical and organized manner in order to ensure reliability and integrity. Polit and Beck (2008:765), confirm this by stating that a research design is the overall plan for addressing a research question, including specifications for enhancing the study's integrity. Quantitative research is a formal, objective and systematic process used to describe variables, test relationships between them and examine cause-and-effect interactions among variables (Burns & Grove, 2007:551). Brink and Wood (2001:83), explain that a variable is anything that varies, or any property that takes on different values. These can be characteristics of people, things or situations which can change or vary and they are manipulated or measured in research (Burns & Grove, 2007:559). The aim of this study was to evaluate HIV positive patients' knowledge of HIV/AIDS and the treatment thereof.

3.3 POPULATION AND SAMPLING

3.3.1 Population

A study population can be described as the entire set of individuals or objects having some of the same characteristics (Polit & Beck, 2008:761). Burns and Grove (2007:549), explain that a population is all the elements that meet the sample criteria for inclusion in a study, sometimes referred to as the target population. The specific target population for this study included all HIV positive patients on ART above the age of 18 at the Delft Community Health Centre. The total number of patients who met the specific criteria for this study was (N=2349).

3.3.2 Sampling

Sampling is described by Loisel, Profetto-McGrath, Polit and Beck (2010:208), as the process of selecting a portion of the population to represent the entire population. It is the subset of the population and is made up of elements which are usually humans (Loisel *et al.*, 2010:208). It involves selecting a group of people, events, behaviours, or other elements with which to conduct a study (Burns & Grove, 2007:324). In this study a convenience sampling method was used. Convenience sampling is also known as 'accidental sampling', as the subjects are included in the study because they happen to be at the right place at the right time (Burns & Grove, 2007:337). For the purpose of this study, guided by a statistician, a convenience sample of n=200 (8.5%) patients was selected from the Delft CHC. It was decided that the first 200 patients who voluntarily gave consent to participate in the study would be included in the sample to improve the validity of the study. A large sample adds to the validity of the study. Convenience sampling was best suited for this study due to the profile of the patients attending this clinic. The clinic is situated in a low socio-economic environment within which poverty and low literacy levels dominate. Therefore, various factors influence the regular attendance of patients to the clinics such as the availability of transport, unemployment and finances.

3.3.3 Criteria

The following criteria were set for this study:

Specific Criteria

All HIV positive male or female patients above the age of eighteen who have been on ART for at least three months attending Delft CHC, qualified to take part in this study.

3.4 RESEARCH SETTING

The study was conducted at the Delft CHC, which is situated in a low socio-economic area characterized by high levels of poverty and low literacy levels (Statistics South Africa, 2001), as well as a fairly large HIV population. Delft CHC is a comprehensive primary health care clinic offering a wide range of services to the community such as HIV and TB care, chronic disease care, antenatal care, integrated management of childhood illnesses as well as family planning, to name a few. Two private consultation rooms were provided by the CHC in order for structured interviews to take place.

3.5 PILOT STUDY

A pilot study was conducted to test the feasibility of the study, as well as the validity and reliability of the data collection tool. It was conducted in order to ensure that aspects, such

as the correct methodology and data collection procedure were followed, including reviewing the questionnaire for any errors. Burns and Grove (2007:28), explain that a pilot study is frequently defined as a smaller version of the proposed study, and it is conducted to refine that study. Mouton (2005:103) explains that failure to conduct a pilot study, is one of the most common errors which researchers make. The sample for the pilot study in this study was ($n = 20/10\%$) of the actual number of participants proposed for the sample of the main study. The pilot study was also conducted at Delft CHC. All participants from the pilot study were excluded from the actual study. All participants responded well to the questionnaire by answering honestly and giving of their time, and only a minor adjustment was made to the questionnaire afterwards, i.e. including the answer 'I don't know' for the multiple choice questions for the main study, as some participants were unable to make a choice from the multiple choice answers provided.

3.6 RELIABILITY AND VALIDITY

Reliability refers to the consistency of the measures obtained in the use of a particular instrument and indicates the extent of random error in the measurement method (Burns & Grove, 2009:377). Consistency is an ideal strived for by every researcher, as this ensures that the research outcomes are accurate (Neuman, 2006:188). The reliability of a measurement procedure is the stability of the measurement. It can be increased by clearly conceptualising constructs, using a pilot study and using multiple indicators of a variable (De Vos, Strydom, Fouche & Delport, 2007:163). According to Brink (2006:163) reliability is the degree to which the instrument could be depended upon to yield consistent results, specifically if it is used repeatedly over time by the same person, or another researcher. To ensure reliability and validity, a pilot study was conducted to test the instrument, as well as the feasibility of the study. Rubin and Babbie (2011:195) state however, that reliability does not ensure accuracy, as bias may also occur. Therefore, attempts to reduce bias were made by the researcher by allowing voluntary participation by the study participants in a private room.

Validity of an instrument determines the extent to which it actually reflects the abstract construct being examined (Burns & Grove, 2009:381) and face validity verifies that the instrument looked like it was valid and gave the appearance of measuring what it is supposed to measure (Burns & Grove, 2009:381). A pilot study was conducted in order to test for face validity and the instrument presented as a professional typed document which was simple to complete.

Validity will vary from one sample to another and from one situation to another; therefore validity testing evaluates the use of the instrument for a specific group or purpose rather, than the instrument itself (Burns & Grove, 2007:365). Content validity examines the extent to which the measurement tool includes all the major elements relevant to the construct being measured (Burns & Grove, 2009:381). The questionnaire was designed after an extensive literature review was conducted on various aspects of the subject. The content validity was validated by the study supervisor, an expert in the field of research methodology and nursing, as well as by three (3) other experts in the fields of nursing, HIV and research. The questionnaire was then also reviewed by an expert in statistics to ensure the suitability of the questionnaire for data analysis. The questionnaire proved to be reliable and valid through the pilot study.

3.7 INSTRUMENTATION

Instrumentation of this study was applied by means of a questionnaire (Appendix A). A questionnaire is a printed, self report form, designed to elicit information through written verbal responses of the subject (Burns & Grove, 2007:382). Questionnaires are used to gather a broad spectrum of information from subjects. These include demographic facts about the subject, as well as information regarding beliefs, attitudes or knowledge (Burns & Grove, 2007:382). The questionnaire may consist of open-ended questions, which requires written responses from the subject or closed-ended questions, which only have answers selected by the researcher (Burns & Grove, 2007:382).

In this study, a questionnaire with 26 multiple choice questions and 3 closed-ended questions was designed by the researcher. The questionnaire was used and completed by the researcher and fieldworker during individual structured interviews. The researcher trained the fieldworker by means of allowing her to sit in 5 interviews which the researcher conducted, so that she was able to observe how questions were to be asked. The fieldworker then conducted 2 individual interviews in the presence of the researcher before she was allowed to conduct interviews on her own.

There were 20 questions which tested knowledge of HIV/AIDS and ART of which 14 of the questions were marked as 'critical questions', as these were the basic questions that all HIV positive patients should know. Participants were scored according to the number of correct answers to the critical questions. Participants were considered as good if they had all 14 critical questions correct, average if they had 11-13 correct and poor if they had 10 or less correct. The advantage of a questionnaire is that it offers the possibility of complete anonymity, which is crucial in obtaining truthful responses and it prevents interviewer bias,

since there is an absence of an interviewer (Polit & Beck, 2008:424). In the case of the questionnaire used in this research, interviewer bias was prevented by allowing the researcher or fieldworker only to read a question and read out the set answers in the questionnaire. The instrument was also ethically approved by the Health Research Ethics Committee. The questionnaire designed consisted of two sections, i.e. A and B.

Section A comprised of demographic data such as:

- Age
- Gender
- Home language
- Highest level of education achieved
- Ability to read and write
- Period living with HIV
- Period receiving treatment.

Section B covered an overall testing of knowledge regarding HIV/AIDS and ART, as well as an indication of where each participant learnt most of his/her knowledge about the subject.

These include:

- Mechanism of action of the HIV virus
- Transfer of HIV
- Meanings of various terms and the importance of testing them, such as 'window period', 'CD4 count' and 'viral load'
- Knowledge of ART, side effects, dosages and stopping medication.

Multiple choice questions were used as it allowed the researcher and fieldworker to read out the question and the choice of answers to each participant. This ensured minimal influence by the interviewer and assisted the participant by limiting the amount of answers that they could choose from.

3.8 DATA COLLECTION

Data collection is the process of acquiring the subjects and collecting the data for the study (Burns & Grove, 2007:391). The data for this study was collected over a period of three (3) weeks by means of structured interviews by the researcher and fieldworker, with the use of the questionnaire in private consultation rooms. Each participant had their own questionnaire; therefore 200 questionnaires were printed for individual structured interviews. During the interview, each participant was provided with an information leaflet explaining the purpose of the study as well as an informed consent form which was available in English,

Afrikaans and Xhosa (Appendix E, F & G). Once consent was obtained, the researcher (in English or Afrikaans) or fieldworker (in English or Xhosa) conducted the interview by reading questions in a language which the participant understood, as well as providing all possible answers from the questionnaire (Appendix A) from where the participant could select answers. Thereafter, the answer chosen by the participant was clearly marked with a tick on the questionnaire by the interviewer. Questionnaires were kept by the researcher or fieldworker at all times and participants were not able to see the questionnaire. The duration of each structured interview was 20-25 minutes in total. Participants were selected according to availability and the willingness of each participant present at the ART clinic on the particular day and who complied with the specific criteria set for the study. If a participant declined, the next person was approached. A total of (n=200/8.5%) of the population (N=2349) formed the sample. Only 2 people declined to take part in the study due to time restraint.

3.9 DATA ANALYSIS AND INTERPRETATION

Data analysis is conducted to reduce, organize and give meaning to data (Burns & Grove, 2009:695). It involves breaking up the data into manageable themes, patterns, trends and relationships (Mouton, 2005:108). Accuracy is very important when capturing the data on the computer as it can threaten the validity of measures and cause misleading results (Neuman, 2006:346). The aim of analysis is to understand the various constitutive elements of one's data through an inspection of the relationships between concepts, constructs or variables and to see whether there are any patterns or trends that can be identified or isolated (Mouton, 2005:108). Statistics are often used not only to describe some characteristics of a sample group, but also to test for similarities, or differences between groups (de Vos *et al.*, 2007:218).

After each interview, the completed questionnaires were placed in a file as well as informed consent forms were placed in a separate file. Questionnaires and informed consent forms were collected from Delft CHC on a daily basis by the researcher.

The data from each questionnaire was captured by the researcher on an excel spreadsheet. The researcher had been in consultation with two statisticians from the Centre for statistical analysis. The excel spreadsheet was then sent to one of the statisticians who assisted with the data analysis and interpretation. For descriptive purposes frequency tables, histograms, means and standard deviations were used. For comparison of variables, the types of analyses depended on the types of data compared, but typically included cross tabulation

(with the Chi-square test), correlation analyses or ANOVA. Descriptions of each term and test follow which was applied in the study and presented in chapter 4.

3.9.1 Scoring system

As discussed in paragraph 3.6, the questionnaire consisted of a total of 29 questions of which 20 tested HIV/AIDS and ART knowledge. Certain questions in the questionnaire were identified as critical questions and it was expected that participants would be able to answer these questions whereas the others were seen as 'good to know'. In consultation with various professionals in the field of HIV/AIDS, 14 critical questions were identified to be the basis for deciding whether or not the participants in the study had good, average or poor knowledge of HIV/AIDS and ART.

The scoring is as follows:

- Good knowledge: The participant has all 14 critical questions correct
- Average knowledge: The participant has 11-13 critical questions correct
- Poor knowledge: The participant has 10 or less critical questions correct.

3.9.2 Mean

The mean is the value obtained by summing up all the scores and dividing the total by the number of scores being summed (Burns & Grove, 2009:708).

3.9.3 Median

The median is the score at the exact centre of the ungrouped frequency distribution (Burns & Grove, 2007:546). According to Burns and Grove (2009:472), it is the most appropriate measure of central tendency for ordinal data but is also used for interval and ratio data.

3.9.4 Standard Deviation

Standard deviation is a measure of dispersion that is the square root of the variance (Burns & Grove, 2009:474).

3.9.5 Pearson Chi-square

According to Polit and Beck (2008:749), the chi-square test is a statistical test, which assesses the difference in proportions and Polit and Beck (2008:749) describe the chi-square test, symbolized by X^2 , as a statistical test, used to assess differences in proportions.

3.9.6 Analysis of Variance (ANOVA)

A statistical test used to examine differences among two or more groups by comparing the variability between groups with the variability within each group (Burns & Grove, 2007:530).

3.9.7 Fisher's Exact Test

A statistical test used to determine if there are nonrandom associations between two categorical variables (Weisstein, 2011).

3.9.8 T-test

A parametric analysis technique used to determine significant differences between measures of two samples (Burns & Grove, 2007:558).

3.10 ETHICAL CONSIDERATIONS

According to Terre Blanche and Durrheim (2004:65), ethics is defined as the study of moral standards. It is the branch of philosophy that deals with morality (Burns & Grove, 2009:61). As research in nursing not only requires expertise and diligence but also honesty and integrity (Burns & Grove, 2009:184), conduct and research designs should always reflect careful attention to the ethical issues embodied in research projects. Ethical issues must be considered when presenting research sources. The content from other studies must always be presented honestly and not be distorted (Burns & Grove, 2007:156). Three principles have been identified with which to approach ethical issues in research. These include autonomy, non-maleficence and beneficence.

i. Autonomy

The principle of autonomy states that people should be allowed to be self-governing and make decisions for themselves (Kerridge, Lowe & McPhee, 2007: 46). All participants participated voluntarily during this study and it was explained to each participant that they could discontinue their participation at any time should they feel to do so.

ii. Non-maleficence

Non-maleficence can be defined as 'above all, do no harm' (Kerridge et al., 2007: 46). This principle is also important with regards to the way data is stored and who will have access to the data (Watson, McKenna, Cowman & Keady, 2008:131). All participants were assured that only the researcher, fieldworker and supervisor would have access to the data they provided.

iii. Beneficence

The principle of beneficence may be described as active well-doing, altruism or conduct aimed at the good and well-being of others (Kerridge et al., 2007: 46). All participants were handled in an honest and open way, which allowed for them to ask

as many questions as they desired in order to have obtained clarity on what was needed of them for the research.

In addition, principles of justice and confidentiality were adhered to at all times. All participants were treated equally in a fair and just manner. All information given by the participants was available only to the researcher and fieldworker. Information was reported in such a manner that responses could not be linked to the identities of the participants.

3.10.1 Permission to conduct the study

Permission to conduct this study was obtained in writing from the Health Research Ethics Committee of Stellenbosch University on 8 April 2011 (Appendix B) and from the Provincial Regional Head for Primary Health Care Services on 8 August 2011 (Appendix C). Verbal permission was obtained on 9 August 2011 from the head of the Delft Community Health Centre where the data collection took place. Written informed consent was obtained from each of the participants, where a form (Appendix D, E & F) was available in English, Afrikaans or Xhosa depending on the participant's choice. The participants had a choice whether or not to take part in the study. Anonymity was ensured at all times. For this purpose the participants were not required to fill in their names, identification or folder numbers anywhere on any of the data forms.

3.11 LIMITATIONS

There were two (2) main limitations identified during the course of the study namely:

- Obtaining permission from the Department of Health was delayed by 3 months which prevented the researcher from beginning with data collection, despite having obtained ethical approval by the Health Research Ethics Committee of Stellenbosch University.
- As the questionnaire was only available in English, a possibility of bias may have been present due to the translation process during each individual structured interview despite efforts by the researcher and fieldworker to prevent this.

3.12 SUMMARY

A descriptive, quantitative correlation research design was applied to this study on a population of (N=2349). A sample size of (n=200/8.5%) was selected from Delft Community Health Centre ART clinic by means of convenience sampling. The criteria for the study included any HIV positive male or female, above the age of eighteen, who had been on ART for more than three (3) months. A pilot study was conducted with (n=20/10%) of the sample (n=200) participants of the main study. The instrument was thereafter analysed and a few

small alterations were made to the questionnaire. The questionnaire consisted of 26 multiple choice questions and 3 closed-ended questions. The information covered on the questionnaire ranged from the participant's demographic data to knowledge of HIV/AIDS and ART. The data was then collected over a period of three weeks by means of structured private interviews by the researcher or trained Xhosa fieldworker with each participant, which lasted approximately 20-25 minutes each. Each participant was required to give written consent should they be willing to participate in the study. Thereafter, interviews were conducted with each participant by asking them questions on the questionnaire and providing the answers from which to choose in a language of their choice. With the help of a statistician, the data was analysed and interpreted by the researcher. Ethical principles of autonomy, non-maleficance, beneficence, justice and confidentiality were at all times considered and applied. Written permission to conduct the study was obtained from the Health Research Ethics Committee of Stellenbosch University, as well as from the Provincial Regional Head for Primary Healthcare Services. The data analysis, interpretation of the data and related discussions of the results are presented in chapter 4

CHAPTER 4: PRESENTATION, ANALYSIS AND INTERPRETATION OF RESULTS

4.1 INTRODUCTION

In this chapter, the analysed results from this study are interpreted, discussed and presented in tables and graphs. Results are predominantly quantitative in nature and will be presented by means of figures and tables. Numbers and percentages were used to simplify interpretation and understanding.

4.2 STATISTICAL ANALYSIS

The data was analysed with the help of a statistician, using the computerised data analysis programme, STATISTICA Version 9. The p-value is the measure which is reported from all tests of statistical significance. This value shows the probability that one variable is dependent on another or if an effect will happen by chance. In medical research, various statisticians and researchers have agreed that if the p-value is more than 5% ($p > 0.05$) there was an insignificant difference between the variables tested. If the p-value is less than 5% ($p \leq 0.05$), there is a statistically significant difference between variables (Attia, 2005:78). In medical research a 95% confidence is usually used (Attia, 2005:79), therefore, a 95% confidence interval with a significance level of ($p \leq 0.05$) was used to establish statistically significant associations between variables as discussed. The data is presented completely in a quantitative form.

A full description of the tests used during the data analysis was discussed in section 3.8 of chapter 3.

The discussion of the results and interpretation of all the variables covered in the questionnaire follows hereafter.

4.3 SECTION A (DEMOGRAPHIC DATA)

4.3.1 Age

The response rate to this question was ($n=200/100\%$) with a mean age of 37.5 and a median age of 36.5. The minimum age was 19 years and the maximum age was 62 years (Figure 4.1).

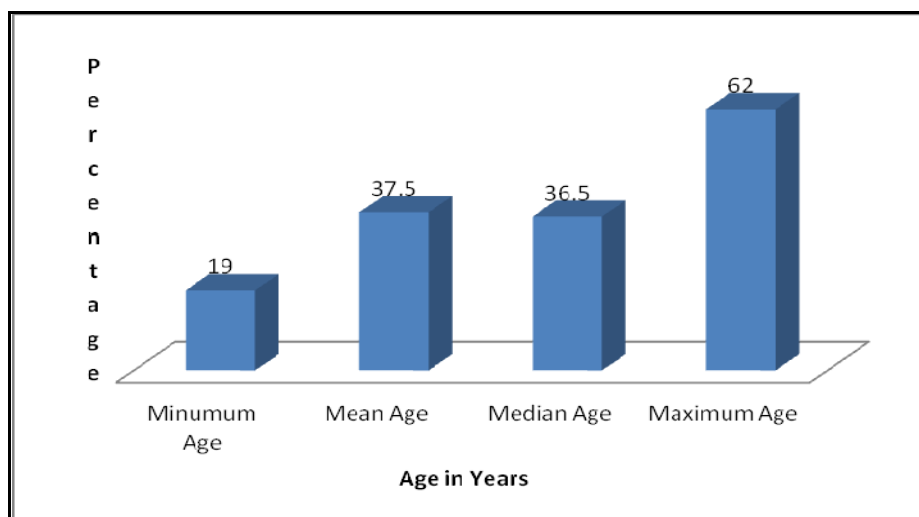


Figure 4.1: Age range, mean, median and age of participants

4.3.2 Gender

According to the data, (n=145/72.5%), the majority of the participants were female (Table 4.1). These results are supported by the 2007 AIDS Epidemic Update (2007:8), which indicates that more women are living with HIV/AIDS than men. In 2007, 61% of the HIV/AIDS population in Sub-Saharan Africa were women. It is also stated in the Second National HIV Communication Survey 2009 - findings from the Western Cape (2009:8), that men are more likely to have multiple sex partners as opposed to women. This may result in multiple women being infected by one male.

Table 4.1: Gender

Gender	n(%)
Female	145(72.5)
Male	55(27.5)
TOTAL	200(100)

4.3.3 Home Language

The dominant language spoken by the participants was Xhosa (n=150/75%), followed by Afrikaans (n=36/18%) and English (n=7/3.5%) (Figure 4.2). These results are aligned with the Western Cape Provincial Languages Act, which states that these three languages are the official languages of the Western Cape (South Africa, 1998:3).

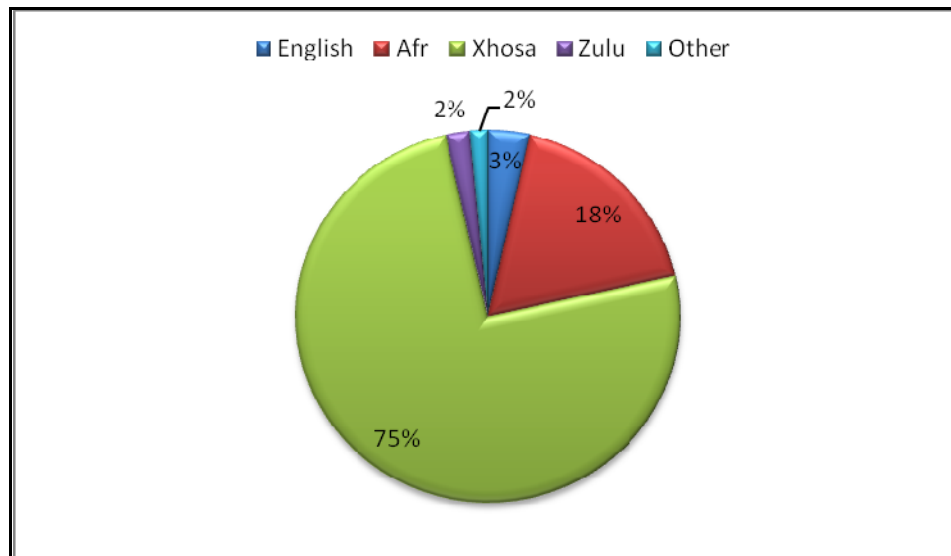


Figure 4.2: Distribution of home language

4.3.4 Highest Level of Education

Racey *et al.* (2010:816) state that higher education is predictive of HIV/AIDS knowledge. According to Africa, Budlender and Mpetsheni (2001:14), it was found that 22% of people in South Africa above the age of 26 years had no formal schooling or education. In this study however, results show more than 50% ($n=112/56\%$) of the participants in Delft had an education level higher than grade 9 (Figure 4.3) and that ($n=48/24\%$) of the participants had achieved grade 12. It was also found that only ($n=41/20.5\%$) had a primary school achievement and only ($n=2/1\%$) had no schooling at all. This is also an improvement of the statistics given by the census in 1996 which stated that 6% of all people between 16 and 26 years had no formal schooling (Africa *et al.*, 2001:1).

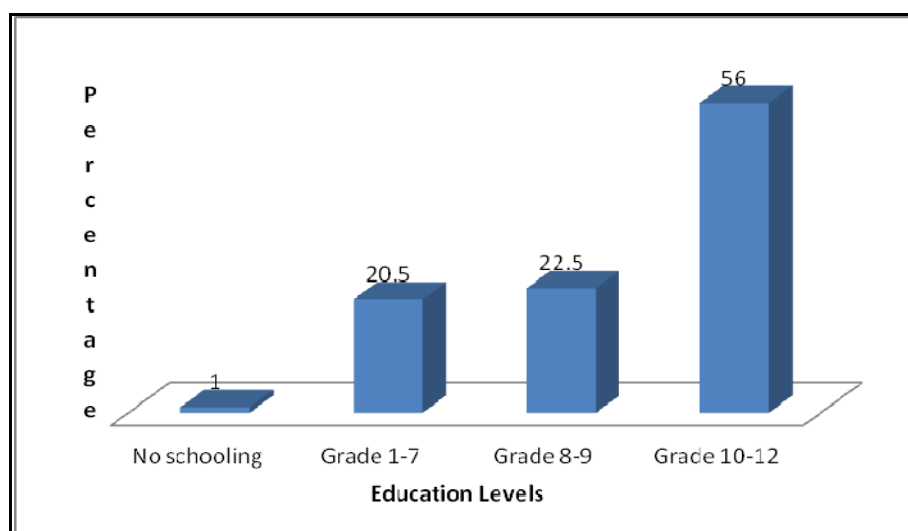


Figure 4.3: Distribution of Education Levels

4.3.5 Literacy Level

According to Neyhart (2008:409), low literacy and low health literacy skills present frequent barriers to patient education. The data revealed that (n=196/98%) of the participants were literate and that only (n=3/1.5%) of the participants were completely illiterate, they could not read or write (Table 4.2). According to Wolf *et al.* (2005:863), the ability to read and write, which results from formal education, plays an important role in HIV/AIDS management as studies indicate that patients with limited literacy skills may lack essential knowledge related to HIV/AIDS and treatment. Nath (2007:44) confirms this by stating that health literacy is one of the strongest predictors of health status and well being.

Table 4.2: Literacy levels

Literacy level	n(%)
Cannot read or write	3(1.5)
Can read only	1(0.5)
Can read and write	196(98)
TOTAL	200(100)

4.3.6 Length of Time Living with HIV/AIDS

The data revealed that (n=15/7.5%) of the participants had been living with HIV/AIDS for less than one year while (n=73/36.5%) had been living with HIV/AIDS for more than five (5) years (Table 4.3).

Table 4.3: Length of time living with HIV

Length of Time	n(%)
<1 year	15(7.5)
1-3 years	60(30)
3-5 years	51(25.5)
>5 years	73(36.5)
Don't know	1(0.5)
TOTAL	200(100)

4.3.7 Length of Time on Antiretroviral Therapy

The data revealed that (n=78/39%) of the participants had been on treatment for 1-3 years (Figure 4.4) and that only (n=35/17.5%) had been on treatment for more than five (5) years. However, as described in paragraph 4.3.6 the majority of participants (n=73/36.6%) indicated that they have been living with HIV for more than five (5) years. It can therefore be concluded that most people lived with HIV/AIDS for approximately two (2) years or more

before starting treatment. This is confirmed by Ewings *et al.* (2008:90), who stated that 50% of HIV positive people start ART between 2 and 10 years after infection.

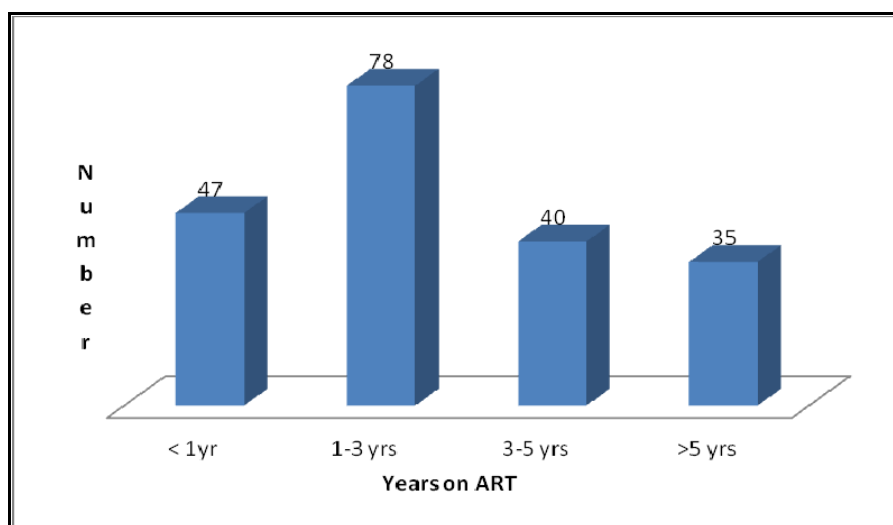


Figure 4.4: Distribution of participants' years on ART

4.4 SECTION B (KNOWLEDGE OF HIV/AIDS AND ART)

4.4.1 What does the HIV virus do in the body?

The results showed that only (n=114/57%) correctly indicated, 'kills the immune system' (Table 4.4). This is basic information regarding HIV/AIDS, and patients suffering from HIV/AIDS should have a basic understanding of the pathophysiology. According to literature, irrespective of the individual's health status, the HIV virus does eventually affect the person's immune system to such an extent that the immune function is hindered, resulting in the person becoming more susceptible to various diseases (Cefrey, 2001:8-9). This was a critical question.

Table 4.4: What does HIV do in the body?

What does HIV do in the Body?	n(%)
Kills the immune system	114(57)
Destroys your organs	57(28.5)
Causes TB	16(8)
Makes you stronger	2(1)
I don't know	11(5.5)
TOTAL	200(100)

4.4.2 Is HIV spread through any of the following?

Kissing

The HIV virus is transmitted through the exchange of fluids during sexual intercourse, blood transmission, MTCT during pregnancy, birth and breast feeding (Evian, 2008:13-17).

The results showed that (n=193/96.5%) of the participants indicated that HIV is not spread through kissing (Table 4.5). The results further indicated that there was a significant statistical association between literacy level and whether kissing could spread HIV (Pearson Chi-square, $df=2$, $p = 0.02$). The higher the education levels the more likely the correct answer was given. Furthermore, a statistical association was also found between the years on antiretroviral therapy and whether kissing spread HIV (Figure 4.5). The longer the participants were receiving ART therapy the more likely they would give the correct answer (Pearson Chi-square, $df=2$, $p=0.02$). This was a critical question.

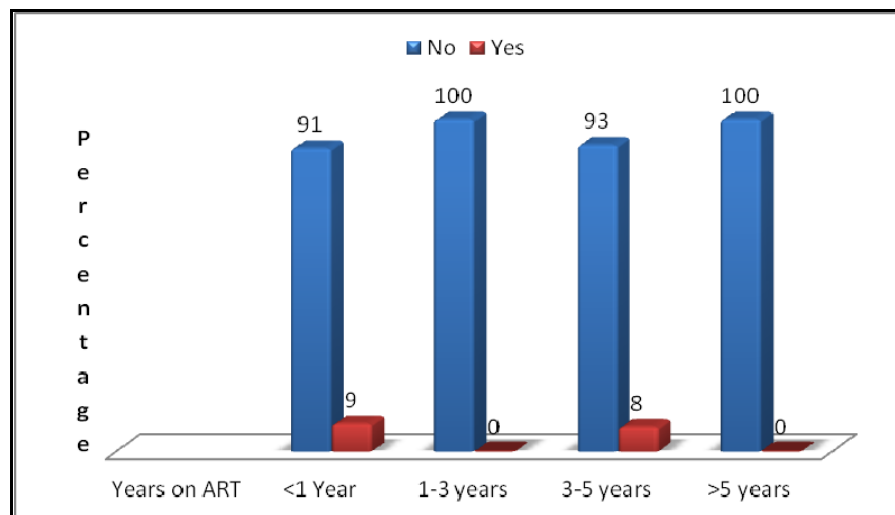


Figure 4.5: Distribution of answers for whether kissing can spread HIV correlated with number of years on ART

Hugging

Data analysis indicated that (n=198/99%) of the participants confirmed that HIV could not be spread through hugging (Table 4.5). A significant association between education and hugging was found (Pearson Chi-square, $df=12$, $p \leq 0.01$). T-tests for independent groups found that the mean age of those participants who incorrectly answered 'yes' was 50.5 years and those that correctly stated 'no' was 37.4 years which is statistically significant ($p=0.04$).

Sexual intercourse

The analysis indicated (n=198/99%) of the participants chose the correct answer that sexual intercourse can spread HIV (Table 4.5), which corresponds with the study conducted by Odu and Akanle (2008:85), where 98.8% of the participants indicated that HIV could be spread through sexual intercourse.

Wesier *et al.* (2003:283), substantiates the results of this study who also found that 98% of their participants indicated that HIV could be spread through sexual intercourse. Although statistically insignificant, T-tests for independent groups found that the mean age of those participants who correctly stated 'yes' was 37.5 years and those who incorrectly stated 'no' was 47 years. Further analysis showed that there was also a significant statistical relationship between educational level and whether or not sexual intercourse could spread HIV (Pearson Chi-square, df=12, p=0.01).

Mosquitoes

The results showed that (n=180/90%) of participants correctly indicated that mosquitoes do not spread HIV and that only (n=20/10%) indicated that they do spread HIV (Table 4.5). In contrast, these results do not compare to the study conducted by Nachega *et al.* (2005:189) in Soweto, in which 60% of the participants in the study indicated that HIV could be spread by mosquitoes.

There was also a statistically significant association found between education level and whether HIV could be spread by mosquitoes. Those who had lower education levels were more likely to choose the correct answer (Pearson Chi-square, df=12, p=0.02).

Coughing

Data showed that (n=177/88.5%) of the participants answered correctly by indicating that HIV cannot be spread by coughing and that only (n=20/10%) indicated that it could be spread by coughing (Table 4.5).

The patients' immune response is lowered when HIV destroys the CD4 cells and consequently patients infected with HIV are more susceptible to infections (Harries *et al.*, 2004:32) such as pulmonary tuberculosis. HIV/AIDS and TB are closely connected, and often described as a "dual-epidemic" (WHO, 2004). WHO (2004) also states that TB is one of the main causes of death in HIV positive patients. An estimated one-third of the 40 million people living with HIV/AIDS worldwide are co-infected with TB and most of them live in Sub-Saharan Africa (WHO, 2004).

Further analysis showed that a statistical association was identified between whether coughing spreads HIV and education level (Pearson Chi-square, $df=12$, $p=0.01$).

Blood transfusion

The question of whether or not HIV could be spread through blood transfusion was chosen well with ($n=200/100\%$) correctly indicating that it can (Table 4.5). This result indicated that participants were well informed regarding the possible risk for HIV transmission through blood transfusion.

This corresponds with a study conducted by Odu and Akanle (2008:85), where 90% of the participants understood the risk for transmission through a blood transfusion. In a study conducted by Wesier *et al.* (2003:283), results also indicated that patients had a good understanding of HIV transmission through blood transfusion.

Infected bodily fluids

The results showed that the majority ($n=188/94\%$) of the participants correctly indicated that HIV can be spread through infected body fluids (Table 4.5). Further analysis showed that there was a statistical significant association between gender and whether or not HIV could be spread through infected bodily fluids and that males were more likely to indicate correctly (Pearson Chi-square, $df=1$, $p=0.03$, Fisher's Exact test one tailed ($p=0.02$) in the one tailed and two tailed ($p=0.04$)).

This corresponds with the study by Wesier *et al.* (2003:283), in which results showed that participants understood the risk for HIV transmission through infected body fluids.

Table 4.5: Is HIV spread through any of the following?

Variable	Yes: n(%)	No: n(%)	Total: n(%)
Kissing	7(3.5)	193(96.5)	200(100)
Hugging	2(1)	198(99)	200(100)
Sexual activity	198(99)	2(1)	200(100)
Mosquitoes	20(10)	180(90)	200(100)
Coughing	23(11.5)	177(88.5)	200(100)
Blood transfusion	200(100)	0(0)	200(100)
Contact with HIV positive blood or body fluids	188(94)	12(6)	200(100)

4.4.3 What is the window period?

The window period is the gap of approximately 3 months between the time when a person becomes infected with HIV and the time when antibodies first appear in the blood (Harries *et*

al., 2004:19). At this time there is a rapid multiplication of the HIV virus which occurs (Cefrey, 2001:8-9) especially in these first three (3) months (Jehuda- Cohen, 2011:179) which increases the risk for transmission to others through sexual intercourse or other ways.

Data revealed that (n=85/42.5%) knew that it was 'the period when the HIV virus is not seen in the blood', but (n=107/53.5%) did not know what the window period was at all. A few participants (n=5/3%) indicated that the window period is the time 'when it is safe to have unsafe sex' (Table 4.6). A further analysis showed that there was a statistically significant difference between distribution of answers for the window period and language (Pearson Chi-squared, df=12, p=0.02). This was a critical question.

Table 4.6: What is the window period?

What is the window period?	n(%)
When you get HIV through the air	2(1)
When HIV is not seen in the blood	85(42.5)
When it is safe to have unsafe sex	6(3)
I don't know	107(53.5)
TOTAL	200(100)

4.4.4 How long does the window period last?

In this particular question, results indicated that (n=106/53%) did not know how long the window period lasts. As stated in the 4.4.3, the window period lasts approximately 3 months (Jehuda- Cohen, 2011:179). Lack of knowledge for this question could be attributed to the fact that (n=115/57.5%) did not know what the window period was or did not answer correctly (as discussed in paragraph 4.4.3). Only (n=82/41%) of the participants knew that it lasted for three (3) months (Table 4.7). This was a critical question.

Table 4.7: How long does the window period last?

How long does the window period last?	n(%)
3 months	82(41)
6 months	10(5)
2 years	2(1)
I don't know	106(53)
TOTAL	200(100)

4.4.5 What is a CD4 count?

Although being an important test in monitoring the immune status of the patient (Evian, 2008:26), data showed that (n=142/71%) chose correctly by indicating that a CD4 count is

the number of 'fighter cells' in the body (Figure 4.6). This corresponds with the study by Wolf *et al.* (2005:870), which revealed that there was a lack of understanding of common HIV/AIDS terms such as a CD4 count. A further analysis showed that there is a statistically significant difference between the answers to "What is a CD4 count" and language (Pearson Chi-square, $df=12$, $p=0.03$). This was a critical question.

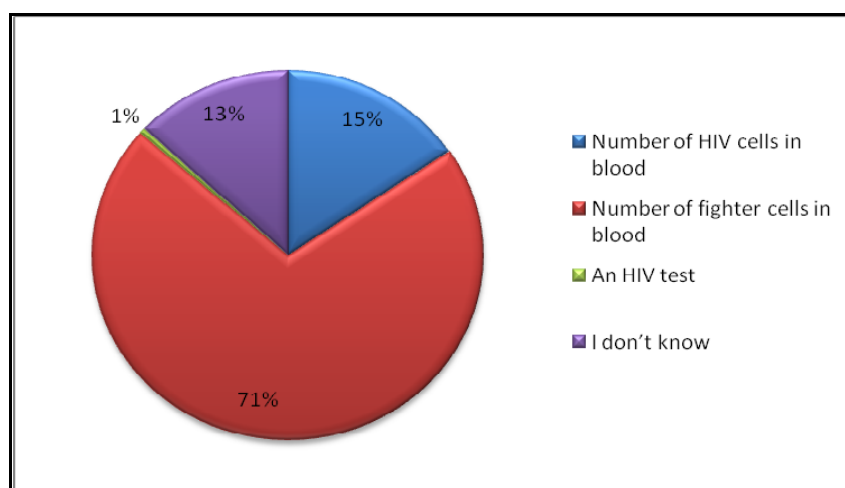


Figure 4.6: Distribution of answers to the question: What is a CD4 count?

4.4.6 When last was your CD4 count done?

Data indicated that most ($n=159/79.5\%$) participants indicated that their last CD4 count was done less than 6 months before, ($n=26/13\%$) indicated 6-12 months before and ($n=12/6\%$) did not know when their last CD4 count was done (Table 4.8). Statistically significant associations were found between literacy level and when last their CD4 count was done. It showed that literate participants were most likely to indicate that their CD4 count was drawn less than six (6) months ago (Pearson Chi=quare, $df=6$, $p=0.01$).

Table 4.8: When was your last CD4 count done?

Time period	n(%)
<6 months ago	159(79.5)
6-12 months ago	26(13)
12-24 months ago	3(1.5)
I don't know	12(6)
TOTAL	200(100)

4.4.7 How often should you have your CD4 count done?

The CD4 count is a good test in monitoring the immune status of HIV positive patients (Evian, 2008:26). A CD4 count should be done every 6 months prior to starting ART (South

Africa, 2010:27). However, the CD4 count must be monitored at 4 months, 12 months and then 12 monthly after commencing ART (South Africa, 2010:31). The data revealed that only (n=23/11.5%) indicated correctly that a CD4 should be drawn 12 monthly (Figure 4.7). This was a critical question.

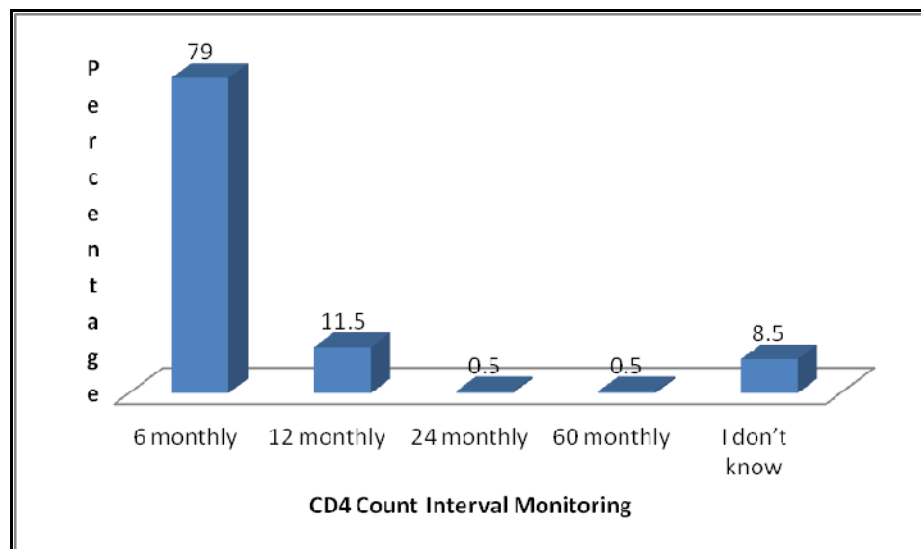


Figure 4.7: Distribution of answers to the question: How often should a CD4 count be done?

4.4.8 Why is it important to have your CD4 count done?

The pharmacological action of ART is to suppress the virus and prevent rapid replication thereof (Almeida and Vieira, 2009:184). Consequently, the viral load is decreased in the blood and CD4 counts are increased (Evian, 2008:79). Data revealed that (n=139/69.5%) participants indicated correctly that it is important to do your CD4 count 'to see if the ART is working', while (n=39/19.5%) indicated incorrectly that it was important so that one could 'monitor the HIV cells in the blood' (Table 4.9). Further analysis showed a significant statistical association between language and why it is important to have your CD4 count done (Pearson Chi-square, df=12, p=0.02).

Table 4.9: Why is it important to have you CD4 count done?

Reasons for CD4 Count	n(%)
To monitor how many HIV cells you have in your blood	39(19.5)
To see if you have been cured of HIV	2(1)
To see if the treatment is working	139(69.5)
Do not know	20(10)
TOTAL	200(100)

4.4.9 What is a viral load?

Viral load 'explains the measurement of the amount of HIV in the blood expressed which assists in monitoring the response to treatment' (Anderson, Keith, Novak & Elliot, 2002:1813).

The data revealed that (n=120/60%) of the participants indicated correctly that a viral load is 'the number of HIV cells in the blood', and that (n=69/34.5%) did not know what a viral load was (Figure 4.8). This corresponds with the study by Wolf *et al.* (2005:870), which revealed that there was a lack of understanding of common HIV/AIDS terms such as viral load.

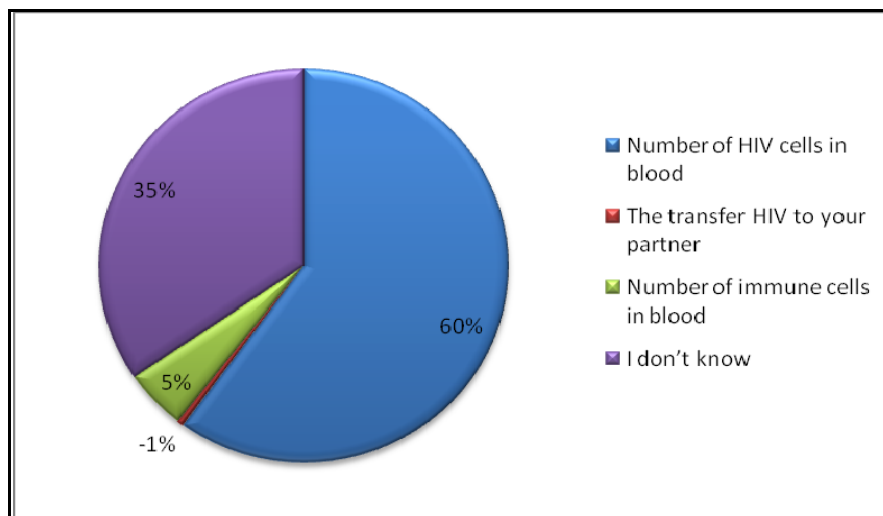


Figure 4.8: Distribution of answers to the question: What is a viral load?

4.4.10 When last was your blood drawn for viral load?

The response to this question indicated that (n=106/53%) of the participants said that their blood for viral load was drawn less than 6 months prior to the interview and (n=77/38.5%) of participants did not know when last theirs were drawn (Figure 4.9). Further analysis showed a significant statistical association between gender and when last blood was drawn for viral load. Women were more likely to know when last their viral load was done, as opposed to men (Pearson Chi-square, df=2, p=0.03).

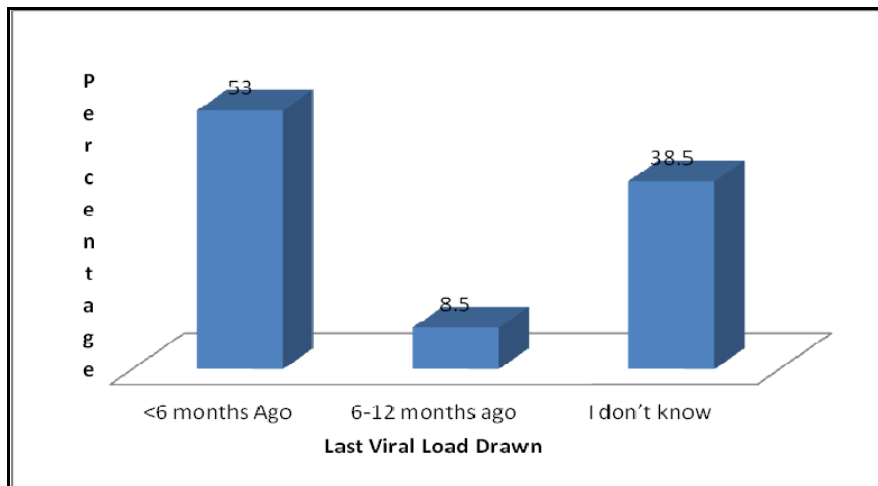


Figure 4.9: Distribution of answers to the question: When last was your blood drawn for viral load?

4.4.11 Do you know which stage of HIV/AIDS you are in?

According to Harries *et al.* (2004:32), the stages of HIV are based on clinical symptoms and signs of the disease. The data for this question revealed that only (n=17/8.5%) knew which stage they were in and (n=183/91.5%) did not know (Table 4.10). In the researcher's experience, patients are not often educated on their HIV stage in clinical appearance.

Table 4.10: Do you know what stage of HIV you are currently in?

Do you know which stage of HIV you are currently in?	n(%)
Yes	17(8.5)
No	183(91.5)
TOTAL	200(100)

4.4.11.1 If yes, which stage are you in?

Of the total number of participants (n=200/100%), (n=7/3.5%) indicated that they were in stage 1; (n=3/1.55%) indicated stage two and (n=7/3.5%) stage 4 (Table 4.11).

Table 4.11: Which stage are you in?

Which stage are you in?	n(%)
Stage 1	7(3.5)
Stage 2	3(1.5)
Stage 4	7(3.5)
I don't know	183(91.5)
TOTAL	200(100)

4.4.12 If you are HIV positive, will your children also definitely be HIV positive?

This question was answered well with the data revealing that only (n=13/6.5%) of the participants incorrectly indicated 'yes' and that (n=187/93.5%) indicated correctly by choosing 'no' (Figure 4.10). According to literature, HIV can be transmitted from mother- to-child inter-uterine (Evian, 2008:13-17). However, with the help of ART, the risk of mother -to-child transmission of HIV is reduced by suppressing the mother's viral load (Zuniga *et al.*, 2010:145). During pregnancy, women who are not eligible for ART all become eligible from 14 weeks into the pregnancy (Zuniga *et al.*, 2010:145). This was a critical question.

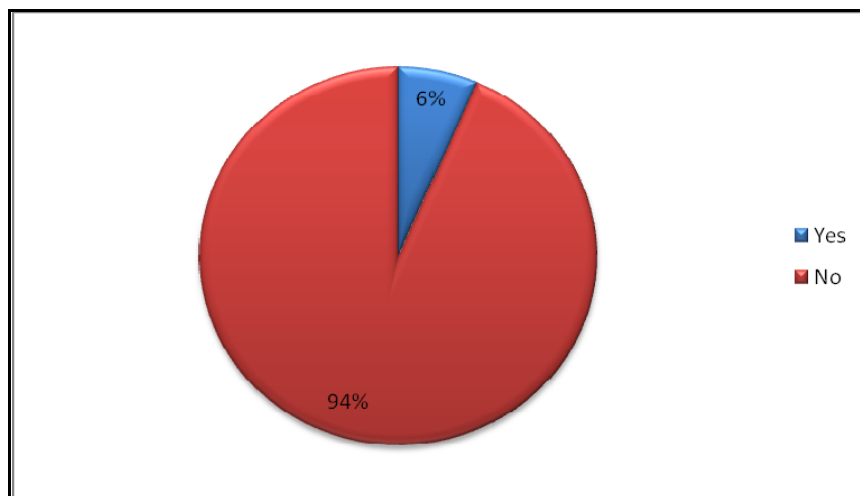


Figure 4.10: Distribution of answers to the question: If you are HIV positive, will your children also definitely be HIV positive?

4.4.13 Why did the staff at the clinic say that you must start treatment?

As this was an open-ended question, five (5) themes were identified in the analysed data as to the various reasons that participants indicated they had to start ART (Figure 4.11). All reasons were valid in layman's terms except for the answer 'because I am HIV positive'. As discussed in paragraph 2.3.1, there are certain criteria for initiating ART based on clinical signs and symptoms of the disease or other evidence of disease progression such as the CD4 count (Harries *et al.*, 2004:32) and not just merely for being 'HIV positive'.

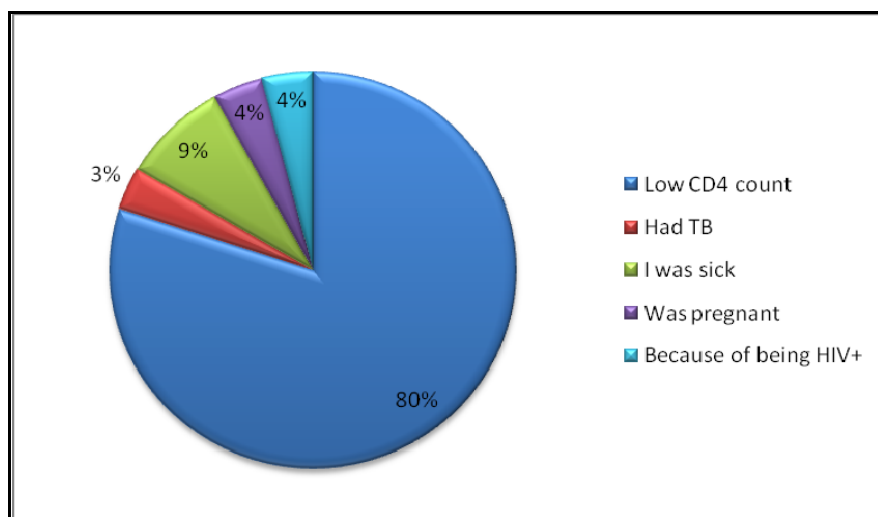


Figure 4.11: Reasons for commencing ART

4.4.14 Can ART cure HIV?

The data indicated that (n=197/98.5%) chose correctly by indicating 'no' and that only (n=3/1.5%) indicated 'yes', ART can cure HIV (Table 4.12). Studies conducted by Kip *et al.* (2008:152), identified in contrast that there were misconceptions in that some people believed that HIV could be cured by ART. Odu and Akanle (2008:85), found that participants in their study were confused as to whether or not HIV/AIDS could be cured by spiritual, traditional or medical practitioners. This was a critical question.

Table 4.12: Can ART cure HIV?

Can ART cure HIV?	n(%)
Yes	3(1.5)
No	197(98.5)
TOTAL	200(100)

4.4.15 What does ART do to the HIV virus in the body?

Although not a cure, antiretroviral therapy (ART) is used to assist in decreasing the replication of the HIV virus within the body and usually results in near-complete suppression of HIV replication (Harries *et al.*, 2004:137).

Data showed that (n=189/93.5%) of the participants indicated correctly by choosing 'lowers the viral load' (Figure 4.12). In contrast, studies conducted by Mukona *et al.* (2011:19), indicated that only 69.4% of their participants understood the function of ART. Similarly to the latter, Almeida and Vieira (2009:184), showed in their studies that 45% of the HIV positive participants on ART knew how ARVs worked. It raises a concern that (n=2/1%)

stated that ART makes it 'safe to have unsafe sex' (sex without a condom). This was a critical question.

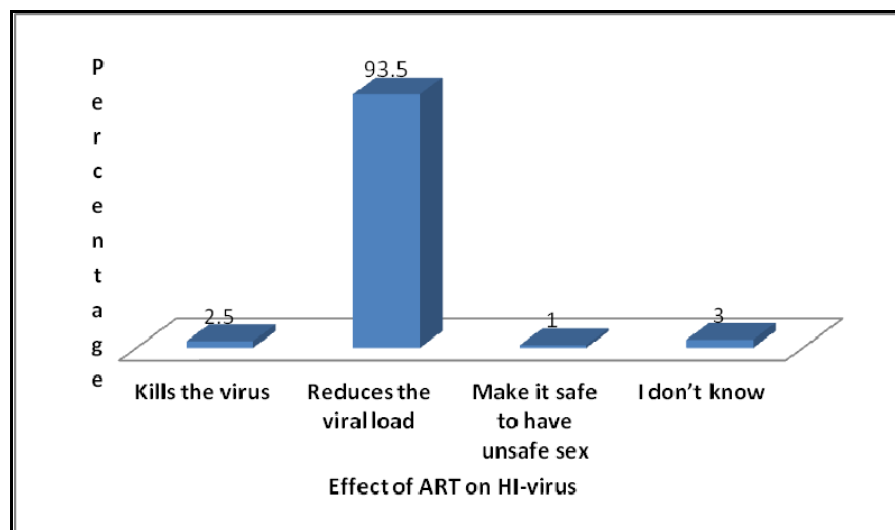


Figure 4.12: Distribution of answers to the question: What does ART do to the HIV virus in the body?

4.4.16 Did the clinic staff say that you can expect any side-effects with your medication?

The data analysis showed that (n=122/61%) of the participants indicated that they had been educated on side-effects while (n=78/39%) indicated that they have not received any education on side-effects. According to the HIV/TB guidelines for the Western Cape (2010:31), routine care given at every follow-up visit includes asking about any drug related side-effects. This should be done at every visit. A statistically significant difference between gender and whether the clinic staff told the participants that they could expect any side-effects with the medication was shown. Females were more likely to indicate 'yes' to receiving education on side-effects as opposed to males (Pearson Chi-square, df=1, p=0.01 and Fisher exact, 1 tailed, p=0.05, and 2 tailed, p=0.01).

In addition, further analysis also showed a statistically significant difference between the length of time on ART and whether the clinic staff told the participants that they could expect any side-effects with the medication. Data indicated that the longer the person was on ART, the more likely they would indicate that they did receive education on side-effects (Pearson Chi-square, df=3, p=0.04) (Figure 4.13).

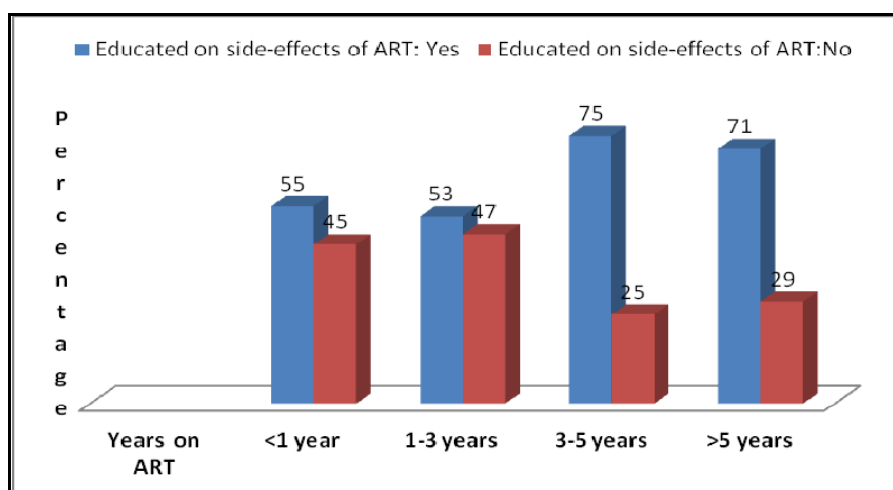


Figure 4.13: Distribution of years on ART specific answers to: Did the clinic staff say that you could expect any side-effects with the medication you are using?

4.4.17 Can ART cause side-effects that can be very dangerous?

Data revealed that only (n=73/36.5%) correctly indicated that ART could cause dangerous side-effects and that (n=127/63.5%) of the participants indicated that they could not (Table 4.13). According to the HIV/TB guidelines for the Western Cape (2010:31), routine care given at every follow-up visit includes asking about any drug related side-effects which also include the dangerous side-effects such as skin rash, vomiting and jaundice. In such cases, these patients are immediately referred to the doctor or to the hospital. This was a critical question.

Table 4.13: Can ART cause side-effects that can be very dangerous?

Can ART cause side-effects that can be very dangerous?	n(%)
Yes	73(36.5)
No	127(63.5)
TOTAL	200(100)

4.4.18 Can you name two (2) danger signs of ART?

The data revealed that only (n=21/10.5%) of the participants could name two (2) danger signs of ART either skin rash, jaundice or vomiting. Table 14.4 indicates how many of the total (n=200/100%) participants could name each of the following as danger signs. This was a critical question.

Table 4.14: Can you name two danger signs of ART?

Danger Sign	Could identify n(%)	Could not identify n(%)	Total n(%)
Skin Rash	60(30)	140(70)	200(100)
Jaundice	1(0.5)	199(99.5)	200(100)
Vomiting	26(13)	174(87)	200(100)

4.4.19 What should you do if you experience any of the danger signs?

In the researcher's experience, patients are educated to stop all medication and go to the clinic as soon as possible, as danger signs could be an indication of potentially life threatening side-effects of ART. These patients (depending on severity) should immediately be referred to the doctor (Zuniga *et al.*, 2010:223-229). However, the data revealed that the majority (n=126/63%) correctly indicated that they 'must stop their medication immediately' and 'go to the clinic as soon as possible' (Figure 4.14). However, (n=7/3.5%) indicated that they must 'carry on taking the medication until the symptoms go away' and (n=66/33%) did not know what they should do in such a case. Further analysis indicated that there was a statistically significant association between 'what should you do if you experience danger signs' and language (Pearson Chi-square, df=12, p=0.03). This was a critical question.

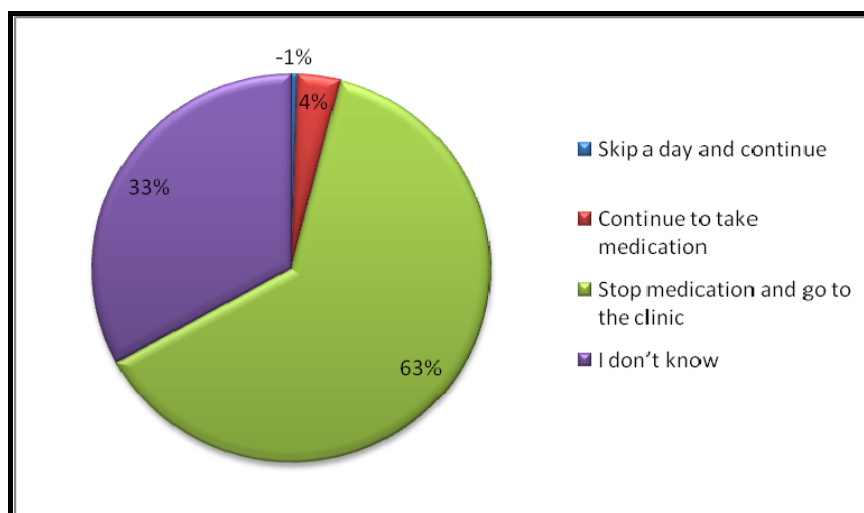


Figure 4.14: Distribution of the answers to the question: What should you do if you experience any of the danger signs?

4.4.20 What should you do if you forget to take your medication?

According to the data, (n=153/76.5%) correctly indicated that they should drink the skipped dose immediately when they remember (Figure 4.15). However, (n=26/13%) of the participants incorrectly indicated that they should throw the skipped medication away and carry on as usual and (n=20/10%) stated that they should take the skipped dose together

with the next dose. According to Bangsberg (2006: 939), an adherence rate of more than 90% needs to be maintained in order for ART to be effective in achieving and maintaining viral suppression.

When compared with studies by Almeida and Vieira (2009:184) in Brazil, it was found that only 14% of their participants did not know what to do if a dose was skipped, which indicates a higher level of understanding by the participants in Brazil than those in this study. Further analysis showed a statistical significant difference between the 'years on ART' and what should be done if medication was forgotten. The longer the patients were on ART the more likely they were to know what to do if they had forgotten their medication (Pearson Chi-square, $df=9$, $p=0.01$). This was a critical question.

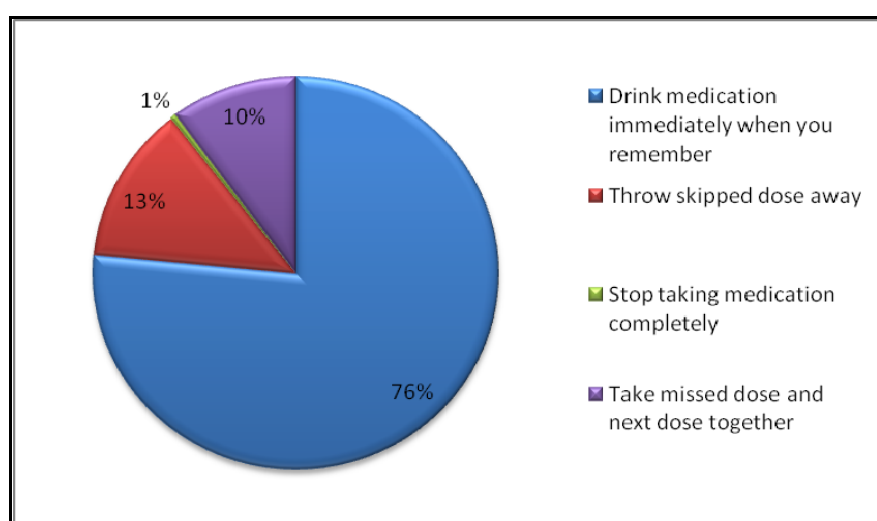


Figure 4.15: Distribution of answers to the question: What must you do if you forget to take your medication?

4.4.21 What will happen if you stop taking your medication?

Data for this specific question revealed that ($n=189/94.5\%$) of the participants correctly indicated that 'the ART will become less effective and the HIV will increase in your blood' (Figure 4.16). This result is in contrast to the results in studies conducted by Mukona *et al.* (2011:19), which revealed that participants' knowledge of the effects of poor adherence was low. This was a critical question.

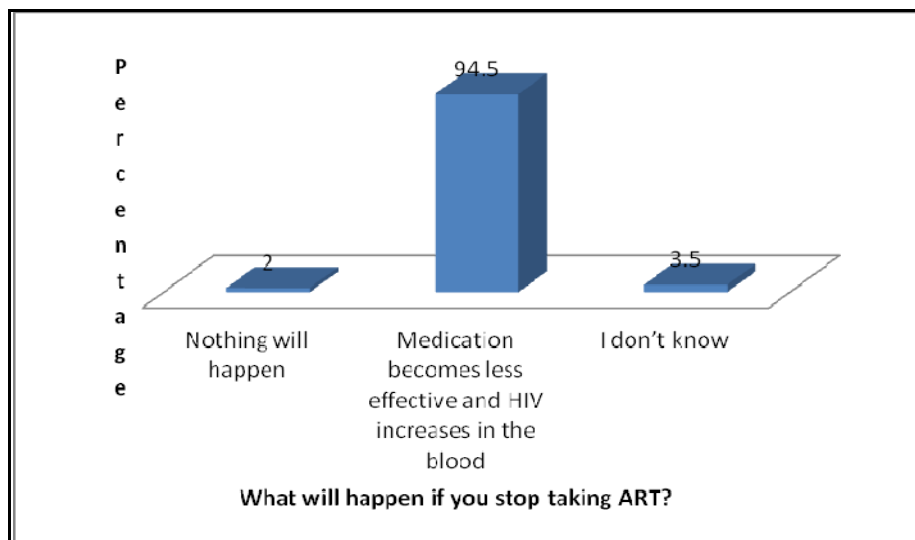


Figure 4.16: Distribution of answers to the question: What will happen if you stop taking your medication?

4.4.22 Where did you learn most of your knowledge about HIV and treatment from?

Data revealed (Table 4.15) that (n=167/83.5%) learnt most of their knowledge from the “clinic sister”, as opposed to the doctor (n=11/5.5%). This corresponds with previous studies by Weiser *et al.* (2003:284), who revealed that nurses and physicians were the primary source of support for patients suffering from HIV/AIDS.

Table 4.15: From where did you learn most of the knowledge about HIV and its treatment from?

Source of knowledge about HIV and treatment	n(%)
The HIV sister at the clinic	167(83.5)
Posters in the clinic	6(3)
TV and radio	9(4.5)
Books in the clinic	3(1.5)
A family member or friend	1(0.5)
The doctor	11(5.5)
Other	3(1.5)
TOTAL	200(100)

4.5 DISTRIBUTION OF OBTAINED SCORES

Scores for the 14 critical questions (Table 4.16: y-axis) revealed that (n=0/0%) of the participants had good knowledge, (n=40/20%) of the participants had average knowledge and (n=160/80%) of the participants had poor knowledge. The average score for all

participants for all 20 knowledge testing questions, including the 'good to know' questions (Table 4.16: x-axis), was (12.6/63%). All scores are represented in Table 4.16.

Table 4.16: Distribution of scores

Number of critical answers correct	Number of participants								Scoring legend	
	0	0	0	0	0	0	0	0		
14	0	0	0	0	0	0	0	0	Good	
13	0	0	0	0	0	8	0	0	Average	
12	0	0	2	0	1	6	0	0	Poor	
11	0	0	5	0	3	14	1			
10	0	0	1	7	9	13	3			
9	0	0	4	2	8	19	0			
8	0	0	6	5	8	10	2			
7	0	0	4	10	6	7	1			
6	0	3	4	6	2	5	1			
5	0	2	3	3	2	0	0			
4	0	1	1	1	0	1	0			
3	0	0	0	0	0	0	0			
2	0	0	0	0	0	0	0			
1	0	0	0	0	0	0	0			
0	0	0	0	0	0	0	0			
	0	1	2	3	4	5	6			
	Number of non-critical answers correct									

4.6 SUMMARY

The participants in this study were mainly female (n=145/72.5%), and the mean age was 37.5 years. Participants were mostly Xhosa speaking and literate, and the majority (n=112/56%), of the participants had an education level between grade 9 and grade 12. The majority (n=73/36.5%) of the participants had been living with HIV for more than 5 years, but had been on ART for between 1 to 3 years. The researcher assessed the participant's knowledge by asking questions about various aspects of HIV and ART throughout the study.

All the data collected during this research study was analysed, interpreted and discussed. The researcher succeeded in exploring, investigating and addressing the research question, i.e.: "What is the knowledge of infected HIV/AIDS patients who are receiving ART about HIV/AIDS and ART?"

By using scientific, investigative techniques, the participant's knowledge of HIV/AIDS and its treatment were tested and determined and independent and dependent variables were correlated to determine significant statistical associations between these variables. The goal and the objectives set for this study were therefore reached.

The results showed that participant's knowledge of HIV/AIDS is poor, as revealed by the scoring system, and that there are also some misconceptions regarding HIV/AIDS and ART. The ability for self-care is thus compromised and by not having knowledge and regular education, HIV positive people in the community will not be motivated, prepared and informed (Epping-Jordan *et al.*, 2004:301) enough to apply to the ICC framework in caring for chronic conditions such as HIV/AIDS.

The following objectives were therefore successfully identified and examined namely, to

- evaluate the level of knowledge of patients infected with HIV/AIDS about the disease
- evaluate the level of knowledge of patients infected with HIV/AIDS about ART
- establish whether there were statistical differences between the independent and dependant variables within the study..

In the final chapter, recommendations are made, based on the findings, as well as the study outcomes being generated during this research.

CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter, conclusions, based on the scientific evidence being obtained during this study, are drawn, with reference to the outcomes from similar studies. The conclusions are discussed according to the purpose, research question and objectives set for the study, based on the findings. Areas for further research and the limitations of the study are discussed. Recommendations to facilitate improved knowledge of HIV/AIDS and its treatment of those HIV positive patients on ART, are also presented.

5.2 DISCUSSION

5.2.1 The level of knowledge of patients infected with HIV/AIDS about the disease

The participant's knowledge of HIV/AIDS was tested on various levels which will be discussed in turn.

The majority of the participants were female (n=145/72.5) (paragraph 4.3.2) which is supported by the UNAIDS 2007 AIDS Epidemic Update (2007:8) which states that more women are living with HIV/AIDS than men are, and that (n=150/75%) (paragraph 4.3.3) of the participants who attended the clinic in which data collection was being conducted, were Xhosa speaking. The mean age was 37.5 years and although the study was conducted in a low socio-economic area, (n=196/98%) were literate (paragraph 4.3.5) and most (n=157/78.5%) had a highest education level between grade 8-12 (paragraph 4.3.4).

Knowledge regarding the action of HIV compromising the immune system was only answered correctly by (n=114/57%) of the participants (paragraph 4.4.1), and many of the participants thought HIV merely destroys your organs. This reveals that this basic knowledge of HIV is not fully understood by these participants suffering from HIV/AIDS.

The spread of the HI-virus was relatively well understood by most of the participants (n=160/88%) in that the correct answer was chosen most times. However, the only mode of transmission which was answered (n=200/100%) correctly was transmission through blood transfusion (paragraph 4.4.2). This corresponds with a study conducted by Odu and Akanle (2008:85), where 90% of the participants understood the risk for transmission through a

blood transfusion, as well as studies conducted by *Weiser et al.* (2003:283), in which results also indicated that patients had a good understanding of HIV transmission through blood transfusion.

What is a concern however, is that (n=2/1%) of the participants indicated that HIV cannot be spread through sexual intercourse (paragraph 4.4.2) this included a male and female, and (n=12/6%) stated that HIV cannot be spread through HIV infected body fluids (paragraph 4.4.2), of which females were more likely to give the incorrect answer (p=0.03). This is an important finding as females must know the risk when breastfeeding their babies, as breast milk is a bodily fluid, which places the baby at risk of being infected with HIV if not breast fed exclusively. *Weiser et al.* (2003:283), also indicated that results from their studies showed an understanding for risk of HIV transmission through infected bodily fluids. According to *Evian* (2008:13-17), sexual intercourse, blood transfusion, mother to child transmission (MTCT) as in during pregnancy, birth and breast feeding are the modes of transmission of HIV.

A significant association (p=0.04) was found between hugging and HIV transmission (paragraph 4.4.2). The older participants were under the impression that HIV could be spread through hugging as the mean age for the incorrect answers given was 50.5 years (p=0.04). Many (n=23/11.5%) indicated that HIV could be spread through coughing (paragraph 4.4.2), which could be influenced by the link between HIV/AIDS and TB (WHO 2004). Furthermore, (n=20/10%) of the participants believed that HIV could be spread through mosquitoes (paragraph 4.4.2), which differs from the study conducted by *Nachega et al.* (2005:189) in Soweto, where 60% of the participants indicated that HIV could be spread by mosquitoes.

The knowledge of the window period was poor, only (n=85/42.5%) of the participants knew what it was (paragraph 4.4.3), and (n=107/53.5%) did not know at all. As the window period is a very high risk period just after transmission of the HIV virus, it is important for individuals to know what it is and to also know that just because a sexual partner's test is negative it does not necessarily mean that they are HIV negative, as they could be in the window period. This 3 month period is the most risky to an HIV negative partner as there is a high risk of the virus to be transferred to them by an undiagnosed infected partner (*Jehuda-Cohen*, 2011:179).

Patients get very confused with the difference between a CD4 count and a viral load. Only (n=142/71%) of the participants knew what a CD4 count was and (n=31/15.5%) of the participants confused it with the viral load (paragraph 4.4.5). When the viral load knowledge

was tested, only (n=120/60%) of the participants indicated it correctly (paragraph 4.4.9). The majority (n=159/80%) of the participants knew when last their CD4 count was done (paragraph 4.4.6), and many during the interviews could tell the researcher what their last count amount was (although not recorded for data collection purposes). Most participants (n=159/79%) indicated that their CD4 count should be done 6 monthly (paragraph 4.4.7), which does not correspond with the Western Cape HIV/TB Guidelines (2010:31), which state that it should be done 12 monthly after being on ART for more than a year.

It is important that a CD4 count and viral load should be done, as the result gives a good indication of the progression of the disease of the immune system (Evian, 2008:26) and also whether or not the ART is effective. Only (n=139/69.5%) of the participants knew why it is important to have a CD4 count done (paragraph 4.4.8). The researcher believes that if patients do not know what a CD4 count or viral load is, they will not fully understand the importance of monitoring it regularly.

In the researchers experience, patients are not often educated about their HIV stage which was confirmed in this study, as (n=183/91.5%) of the participants did not know which HIV stage they were in (paragraph 4.4.11).

Participants were mostly aware that HIV could be transferred inter-uterine, however (n=187/93.5) also knew that they could still have HIV negative children with the help of ART (paragraph 4.4.12). According to literature, HIV can be transmitted from mother-to-child inter-uterine (Evian, 2008:13-17). However, by taking ART as prescribed, the risk of mother-to-child transmission of HIV is reduced by reducing the mother's viral load (Zuniga *et al.*, 2010:145).

In conclusion, the objective was scientifically investigated and the knowledge of participants about HIV/AIDS was successfully evaluated. The study results show that there are some misconceptions regarding HIV/AIDS. In paragraph 5.4 the levels and scores obtained about their knowledge are discussed.

5.2.2 The level of knowledge of patients infected with HIV/AIDS about ART

Themes were identified for reasons why participants commenced on ART, such as a low CD4 count, they were sick, TB, pregnancy and because of being HIV positive (paragraph 4.4.13). It is interesting to note that as mentioned in paragraph 4.4.5, (n=142/71%) knew what a CD4 count was, and that (n=160/80%) said that they were placed on ART due to a low CD4 count (paragraph 4.4.13).

Participants knew ($n=197/98.5\%$) that ART could not cure HIV/AIDS and treatment was most likely to be lifelong (paragraph 4.4.14). People with higher education levels were more likely to indicate the question correctly ($p=0.02$). Studies conducted by Kip *et al.* (2008:152) identified in contrast that there were misconceptions in that some people believed that HIV could be cured by ART. Odu and Akanle (2008:85), found that participants in their study were confused as to whether or not HIV/AIDS could be cured by spiritual, traditional or medical practitioners.

Almeida and Vieira (2009:184) found that 55% of the participants in their study did not know that ART suppresses viral replication and thereby reducing the viral load in the blood and the progression of the disease. This study showed however that ($n=189/93.5\%$) of the participants understood the function of ART (paragraph 4.4.15). What is a point of concern is that, although minimal, ($n=2/1\%$) of the participants indicated ART has the function of making unprotected sex, safe (paragraph 4.4.15).

Education on side-effects seemed to be lacking in that ($n=78/39\%$) of the participants indicated that they had not had any education on the side-effects of ART (paragraph 4.4.16) and that ($n=127/63.5\%$) indicated that ART does not cause any dangerous side-effects (paragraph 4.4.17) which showed a statistical difference with gender ($p=0.01$). Further analysis showed that participants were more likely to know that ART caused dangerous side-effects marked by danger signs and that there was a statistical difference with number of years on ART ($p=0.04$), indicating the longer participants were on ART, the more likely participants were to know that ART had dangerous side-effects marked by danger-signs. Studies have shown that there are numerous side-effects as identified by Bhengu *et al.* (2009:5), however in this study only ($n=21/10.5\%$) could name two danger signs (paragraph 4.5.18). Although not all participants could name danger signs, ($n=126/63\%$) they knew that if danger signs did occur that they should stop the medication and go to the clinic as soon as possible (paragraph 4.4.19), however ($n=66/33\%$) did not know what to do at all. This is important as skin rash, vomiting and jaundice are indications of serious complications of ART to the degree that if not identified and managed, any of these could be fatal (Zuniga *et al.*, 2010:163).

As mentioned in paragraph 4.4.20, medication needs to be completely adhered to no less than 90% of the time (Bangsberg, 2006:939), and therefore needs to be taken as prescribed, as poor adherence could lead to ART drug resistance. Patients must understand what to do should they forget to take a tablet at the right time. Fortunately, most ($n=153/76.5\%$) of the participants knew that if they forget their medication (paragraph 4.4.20), that they should

take it as soon as they remember. Results also showed that there were statistical differences between action if medication was forgotten and length of time on ART. Data revealed the longer the participants were on ART, the more likely they were to know what they should do if they forget to take their medication ($p=0.01$).

However, ($n=47/23.5\%$) of the participants did not know what to do if they skipped a dose of their medication (paragraph 4.4.20). With only 76.5% knowing how to react on a skipped dose, it indicates that 23.5% of the population studied is at high risk for developing drug resistance (Zuniga *et al.*, 2010:163). When compared with the study conducted by Almeida and Vieira (2009:184) in Brazil, it was found that only 14% of their participants did not know what to do if a dose was skipped, it indicates a different level of knowledge by the participants in Brazil than those in this study.

The majority ($n=197/98.5\%$) of participants indicated that ART did not cure HIV (paragraph 4.4.13). When given the question 'what will happen if you stop taking your medication?' ($n=189/94.5\%$) of the participants correctly indicated that 'the ART will become less effective and the HIV will increase in your blood' (paragraph 4.5.21). Mukona *et al.* (2011:19) in their study found that participant's knowledge regarding the effects of failing to adhere to medication was low.

When asked where they had received most of their HIV/AIDS knowledge, most ($n=167/83.5\%$) of the participants indicated that they received it from the "HIV sister in the clinic" (paragraph 4.4.22). This corresponds with the study by Weiser *et al.* (2003:284), who stated that the nurse is one of the primary sources of support for patients suffering from HIV/AIDS.

In conclusion, the objective was scientifically investigated and the knowledge participants had about ART was successfully evaluated. Study results indicated that misconceptions regarding ART do exist. In paragraph 5.4 the levels and scores obtained about their knowledge are discussed.

5.2.3 Determining whether there are statistical differences between the dependant and independent variables within the study

Statistically significant associations were made between the independent and dependant variables within the study i.e. the longer the participants had been on ART, the more likely they were to take the correct action if they forgot to drink their medication ($p=0.01$). Differences were determined between genders, language, education level, literacy level,

period of time living with HIV, as well as length of time on ART which have been reported on in paragraphs 5.2.1 and 5.2.2.

In conclusion, results indicated that variables such as gender, language, education level, literacy level, period of time living with HIV and length of time on ART did have an influence on how much knowledge and understanding participants had of HIV/AIDS and ART.

5.3 CONCLUSIONS

The specific objectives set for this study were to

- evaluate the level of knowledge of patients infected with HIV/AIDS about the disease
- evaluate the level of knowledge of patients infected with HIV/AIDS about ART
- establish whether there are statistical differences between the dependant and independent variables within the study.

These objectives were met through an in-depth research study which aimed at evaluating what the knowledge is of infected HIV/AIDS patients who are receiving antiretroviral treatment, regarding HIV/AIDS and antiretroviral therapy (ART).

5.4 OVERALL EVALUATION OF PARTICIPANT'S KNOWLEDGE REGARDING HIV/AIDS AND ANTI-RETROVIRAL THERAPY (ART)

Analysis of the data revealed that the average score of all participants for all 20 knowledge testing questions in the questionnaire, including the 'good to know' questions, was (12.6/63%). Analysis of the 14 critical questions revealed that (n=0/0%) of the participants had good knowledge, only (n=40/20%) of the participants had average knowledge and (n=160/80%) of the participants had poor knowledge as explained in paragraph 4.5.

According to Smith Fawzi *et al.* (2006:769), patients with inadequate knowledge of HIV/AIDS and transmission thereof are more likely to report not taking ART in order to be effective in achieving and maintaining viral suppression, which needs an adherence rate of no less than 90% (Bangsberg, 2006: 939). Health knowledge is one of the strongest predictors of health status and wellbeing (Nath, 2007:44) and the lower the literacy, the poorer the understanding which results in poorer adherence (Wolf *et al.*, 2005:864). It is clearly indicated in the results as stated above that the knowledge of basic HIV/AIDS and ART information is poor and therefore nurses need to pay more attention to patient education.

5.5 RECOMMENDATIONS

The recommendations are presented according to the results that have emerged from the study.

What has emerged from this study is that the patient HIV/AIDS education which is currently being performed at this CHC is ineffective. The scores for the study revealed that out of a total of (n=200) participants not one participant was able to achieve a good score for basic questions regarding HIV/AIDS and ART. Due to the fact that some participants believed that HIV/AIDS can be transmitted by mosquitoes and hugging a HIV positive individual, including that ART makes unsafe sex safe, are clearly indicative of the lack of knowledge in the spread and management of HIV/AIDS. These are serious misconceptions which need to be addressed.

The researcher has observed in her practice that due to the large amount of patients coming into CHCs daily and the low staff capacity to treat all of these patients, nurses are not able to spend quality time in educating and supporting patients as they need to. Nurses are required to see many patients in minimum time, with limited resources at times

Education should be continuous from the day the individual is diagnosed with HIV onwards. The study showed (as discussed throughout chapter 4) that it should not be assumed that patients are well informed as they have had HIV for a long time or have been on treatment for a long time.

Patient education can be rendered in various ways within the community setting. The following are recommendations for how various patient education methods can be implemented in the community namely:

5.5.1 Continuous patient education

Education needs to start in the consultation room and needs to continue outside the consultation room. Patients need to have adequate time to ask questions and raise any concerns during a consultation and nurses need to be able to give that education, support and attention to patients without feeling pressed for time. More nurses need to be employed by the state in order to reduce the workloads within the CHCs. In this way more time can be dedicated to educating patients. As stated by Mash, Blitz, Kitshoff and Naudé (2010:107), the communicator or nurse within the clinical context, is there to promote a healthy lifestyle by explanation and being an advocate for the individual, thereby helping individuals and groups to improve and protect their own health.

5.4.1.1 Language and culture

The PHC nurses should be aware of the dominant language, culture and religion of the communities they serve as these factors play a role in patient education. Services provided in the clinic should meet the needs of all patients. Nurses should therefore be able to educate and communicate with all people who enter the consultation room or the CHC. In this study, a wide range of languages and cultures were represented within one community and it was identified that knowledge differed in the different language groups. Nurses and educators need to identify and take cognizance of the language differences of the patients they educate. Patients should be provided with the opportunity to be educated in their own language, even if that includes relying on a reliable translator to ensure that knowledge is sufficiently transferred from the nurse or educator to the patient. All educational material should be available in all languages represented in the community.

5.5.1.2 Gender

It was observed that men and women often differed in the way they answered questions. Men and women have diverse roles within the relationship context. Nurses need to take note of who they are educating and what role each individual plays within relationships. Thus they need to educate appropriately and give the necessary support.

Males may learn more effectively from other males instead of a female, therefore it is recommended that if an opportunity for education is arranged in group form, males and females could be divided into separate groups with a facilitator of their own gender. Different modes of learning can be presented in these different groups such as visual, aural or reading and writing, suited to the needs of the patients. This is substantiated by studies conducted by Wehrwein, Lujan and DiCarlo (2006:155), who observed that males and females preferred different modes of learning. Males preferred multi-modal ways of learning whereas females, uni-modal. This can be applied in the various groups. Various modes of learning can be applied to the male group and single modes of learning to the female group.

Separate groups may consequently also provide a secure environment, where men and women can voice their concerns and ask sensitive questions separately, which they may not have asked if the other sex was in the group. However, caution should be taken by facilitators that all information given to patients must be coherent.

5.5.1.3 Age

It should be taken into consideration when educating patients that the age of the patient plays a role. Younger individuals may learn differently from older individuals. Physical

abilities such as hearing and vision may be affected with age and therefore, younger individuals may learn quicker while the older ones may learn slower. More time might need to be spent with older individuals in repeating and making sure they understand the information being conveyed to them. Factors such as hearing and vision may play an increasing role in patient education of the older patient.

5.5.1.4 Literacy and Education Level

Measures need to be implemented to accommodate the education levels of the patients and whether patients are literate or not. It may be beneficial to use visual materials, such as pictures and videos to demonstrate and explain various aspects of HIV/AIDS and ART. Information should be presented in a visual and audible manner in addition to pamphlets given to patients of low education and literacy level.

5.5.2 Visual techniques and initiatives

Patient education needs to be implemented in all areas of the CHC, such as in all the waiting room areas. Most times patients and their companions sit for many hours in the waiting room on the days they come for a consultation. This presents an ideal opportunity for education in the form of videos or presentations.

Rosters can be compiled for daily presentations of basic HIV/AIDS education where informed, motivated and prepared CNPs or any of the nursing staff are given the opportunity to use their creative talents in educating various people about the principles of HIV/AIDS. All students from the health disciplines may be utilized in these areas, as most CHCs have students present at any given time throughout the year. Each discipline has specific aspects about HIV/AIDS that they emphasize such as the importance of diet given by dietitians. Additionally, an opportunity for job creation can be made where community workers are trained about HIV/AIDS and can then be employed on a part-time basis to run educational presentations and programmes within the CHC.

During the time patients and companions sit in the waiting room, visual material will provide the perfect means of passive learning. Posters and pamphlets can be displayed and made available for all to read and look at within this area of the CHC including television and digital videos. This will increase visual learning for patients and therefore learning will not be restricted to the time limits that restrain nurses in their consultation rooms. Mansoor and Dowse (2007:37) substantiate the advantages of visual learning who found that patients gained more knowledge through simple pamphlets with many pictograms and minimal text, as opposed to pamphlets with text only as not all patients can read.

Small initiatives such as simple, colourful and eye-catching medicine labels or stickers can be designed and added into or pasted onto medicine containers to promote awareness of aspects such as danger signs or what to do in the case of a missed dose. These stickers can be made available in all presenting languages, which give different hints or 'did you know' information for patients to be aware of. Numerous stickers with various information can be made so that patients can get a different sticker every month. Wolf, Davis, Bass, Curtis, Lindquist, Webb, Bocchini, Bailey and Parker (2010:54), found in their studies that simple messages on tablet containers significantly improved patients adherence to treatment regime and improved their understanding.

5.5.3 Continuous professional development

As HIV/AIDS is an ever changing epidemic, nurses need to have regular updating regarding the changes and developments of HIV/AIDS and ART care, as most (n=167/83.5%) participants in this study received their HIV/AIDS and ART knowledge from the registered nurse. Regular opportunities need to be presented to staff for additional training and updating in order for them to be well informed and motivated to convey relevant and important information to patients as per the ICCC framework (discussed in paragraph 1.11.1). In-service training needs to be conducted within the CHC, where managers convey their knowledge to their staff. This will in turn facilitate updating and refreshing of staff knowledge on a regular basis.

5.5.4 Community development

According to the ICCC framework, key figures such as church, spiritual and family leaders play significant roles in the community members' lives (Epping-Jordan *et al.*, 2004:301), and therefore an effort should be made to educate these leaders on HIV/AIDS and ART, and to inform them of misconceptions and challenges that nurses are facing with their patients in the CHC. These leaders will then be motivated, informed and equipped with the necessary skills to provide education outside the CHC to patients and community members with whom they have a relationship and have great influence.

5.5.5 Patient acknowledgment

Public acknowledgment and honour should be given to those patients who are adherent to all aspects of their treatment. They could possibly be provided with a certificate of good adherence or a prize, which will motivate others to achieve the same. Regular opportunities should then be created for these individuals to tell their stories and explain how they overcame their challenges to patients in the clinic. In doing so, this may provide a platform

for patients to identify with someone who is in the same situation as them, how to cope in their own situation and how to overcome their individual and unique challenges.

5.5.6 Health promotion

Health promotion provides a platform for wide-spread learning. In the researcher's experience, a well-advertised health promotion day is a way of reaching and educating many people at the same time from all areas of the community. Health promotion days can be advertised by means of visual posters outside the clinic prior to and on the day of the health promotion or marches through the streets to attract people. Announcements can be made on local radio stations, where all information regarding the activities is given and community members are invited to the day. Health promotion days can be made attractive to the patients, by making use of various resources. Sponsorships for food and entertainment can be arranged, and various non-governmental organizations can be approached in educating patients about safe sex options. Various members of the multidisciplinary team such as the pharmacist and occupational therapist can be approached to give their input for the day, by educating on drug side-effects and providing information to patients on where they can attend support groups. Students in the clinic or HIV/AIDS infected patients can be approached to conduct role plays or short 'skits' to educate participants. Guest speakers, such as doctors, academics and AIDS activists from various organizations can be approached to educate on different aspects of HIV/AIDS and treatment.

Such days can be planned in line with the health calendar, for example the World AIDS day on 1 December every year.

According to Zweigenthal, Puoane, Reynolds, London, Coetzee, Alperstein, Duncan, Atkins, Loveday, Hutchings, Geiger, Petersen, Ferguson, Hewett and Batley (2009:157), one of the main features of health promotion is that it equips people and communities to practice self-control and it empowers them.

5.6 FURTHER RESEARCH

More research is needed in evaluating knowledge of HIV/AIDS and its treatment. This study needs to be implemented in other low socio-economic communities, as well as more affluent communities, to see which variables influence knowledge, and how they compare.

It is also suggested that further research needs to be done into evaluating the knowledge of people who have not been diagnosed with HIV/AIDS. Preventing the spread of HIV is heavily influenced by understanding safe-sex practices and understanding the modes of

transmission of the virus. This knowledge is therefore crucial for non-HIV suffering individuals to know and understand.

Additionally, more research needs to be conducted in order to establish and evaluate the HIV/AIDS and ART knowledge of registered nurses and CNP's working in the ART clinic, as they play the biggest role in the education of HIV positive patients.

5.7 LIMITATIONS

According to Burns and Grove (2007:545), limitations are the 'theoretical and methodological restrictions in a study that may decrease the generalizability of the findings.'

This study focused on the patients at Delft Community Health Centre only, and did not include any other community. It was limited to the Cape Metropole area, and therefore cannot be generalized.

The research was delayed, as the application to do research in a government facility took three (3) months to obtain. The data collection was a slow process due to the fact that each participant needed to be interviewed individually.

5.8 CONCLUSION

In this chapter, the findings were discussed in relation to the objectives set out in the study. The purpose of the study was to explore and evaluate the knowledge of HIV/AIDS infected patients on ART of HIV/AIDS and its treatment. This chapter showed that the aim was achieved. The findings show that the overall knowledge (n=160/80%) is poor. Basic terms and principles of HIV/AIDS and ART are not understood and serious misconceptions regarding the disease were revealed.

Patient education is vital as patients are enabled to take the information, carry the knowledge with them and render self-care based on what they know and have learnt. However, in this study, it is clear that knowledge and understanding are poor. Nurses need to take up the role as a supportive-educative medium for the patient, by educating the patient and equipping them to make informed decisions based on what they know and understand and promote self-care rather than making decisions on behalf of the patient. Nurses however, as per the ICCC framework (as discussed in paragraph 1.11.1), need to be informed, motivated and prepared to convey information and to educate patients. By identifying the patient's self-care shortcomings as discussed in paragraph 4.8.1, nurses can decide which support modality is needed to promote self-care and compliance, and they can then give education and support as the patient requires. Additionally, in line with the ICCC

framework leaders in the community also need to be equipped with the skills to support, motivate and knowledge to educate members of the community about HIV/AIDS.

Education and health promotion empower people to take control of their own lives and their own health and create an environment which support healthier lifestyles and informed decision making based on knowledge and understanding. Ultimately this may contribute to an improvement in the quality of life of HIV/AIDS infected patients and a decrease in the rapid spread of this disease.

Recommendations are based on the findings which indicate that increased patient education is needed in the clinical setting. As South Africa constitutes 17% of the global HIV/AIDS and the number of people living with HIV/AIDS has shown a constant increase every year since the first diagnosis of HIV/AIDS in the 1980's (South Africa, 2007:11), measures to improve patient education need to be developed and implemented as soon as possible, especially since the research shows that patient knowledge is poor. Education is essential in facilitating the patient in helping to become a mature individual who is able to make informed decisions regarding his/her own health and wellbeing.

Further research is recommended as explained in paragraph 5.6 to overcome the limitations which were identified in this study.

LIST OF REFERENCES

- Africa, M., Budlender, D. & Mpetsheni, Y. 2001. *Education in South Africa: Findings from Census 1996* [Online]. Available:
<http://www.info.gov.za/view/DownloadFileAction?id=70237> [2011, September 12].
- Almeida, R.F.C., & Vieira, A.P.G.F. 2009. Evaluation of HIV/AIDS Patients' Knowledge on Antiretroviral Drugs. *The Brazilian Journal of Infectious Diseases*, 13(3):183-190.
- Anderson, D.M., Keith, J., Novak, P.D. & Elliot, M.A. 2002. *Mosby's Medical, Nursing & Allied Health Dictionary*. 6th Edition. St. Louis: Mosby.
- Attia, A. 2005. Why Should Researchers Report the Confidence Interval in Modern Research? *Middle East Fertility Society Journal* 10(1): 78-81. [Online]. Available:
<http://www.bioline.org.br/pdf?mf05015> [2011, November 23].
- Bangsberg, D.R. 2006. Less than 95% Adherence to Non-nucleoside Reverse-Transcriptase Inhibitor Therapy Can Lead to Viral Suppression. *Journal of Clinical Infectious Diseases* 43(7): 939-941. [Online]. Available:
<http://www.ncbi.nlm.nih.gov/pubmed/16941380?dopt=Abstract> [2010, April 13].
- Bhat, V.G., Ramburuth, M., Singh, M., Titi, O., Antony, A.P., Chiya, L., Irusen, E.M., Mtyapi, P.P, Mofoka, M.E., Zibeke, A., Chere-Sao, L.A., Gwadiso, N., Sethathi, N.C., Mbondwana, S.R. & Msengana, M. 2010. Factors Associated with Poor Adherence to Anti-retroviral Therapy in Patients Attending a Rural Health Centre in South Africa. *European Journal of Clinical Microbiological Infectious Diseases*, 29:947-953.
- Bhengu, B.R., Ncama, B.P., McInerney, P.A., Wantland, D.J., Nicholas, P.K., Corless, I.P., McGibbon, C.A., Davis, S.M., Nicholas, T.P. & Ros, A.V. 2011. Symptoms Experienced by HIV-Infected Individuals on Antiretroviral Therapy in KwaZulu-Natal, South Africa. *Journal of Applied Nursing Research*, 24:1–9.
- Brink, P.J. & Wood, M.J. 2006. *Basic Steps in Planning Nursing Research: From Question to Proposal*. 5th Edition. Sudbury, USA: Jones and Bartlett.
- Burns, N. & Grove, S.K. 2007. *Understanding Nursing Research: Building an Evidence-Based Practice*. 4th Edition. Missouri: Saunders Elsevier.

- Burns, N & Grove, S.K. 2009. *The Practice of Nursing Research: Appraisal, Synthesis & Generation of Evidence*. 6th Edition. Missouri: Saunders Elsevier.
- Cefrey, H. 2001. *Epidemics: Deadly Diseases Throughout History*. New York: Rosen Publishing Group, Inc.
- Cook, L., Castrogiovanni, A., David, D., Stephenson, D.W., Dickson, M., Smith & D. & Bonney, A. 2008. Patient Education Documentation: Is it Being Done? *Medsurg Nursing Journal*, 17:306-310.
- Cutilli, C.C. 2007. Health Literacy in Geriatric Patients: An Integrative Review of the Literature. *Orthopaedic Nursing Journal*, 26:43-48.
- De Vos, A.S., Strydom, H., Fouche, C.B. & Delport, C.S.L. 2007. *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 3rd Edition. Pretoria: Van Schaik Publishers.
- Dewalt, D.A., Berkman, N.D., Sheridan, S., Lohr, K.N. & Pignone, M.P. 2004. Literacy and Health Outcomes: A Systematic Review of the Literature. *Journal of General Internal Medicine: Official Journal of the Society for Research and Education in Primary Care Internal Medicine*, 19:1228-1239.
- Epping-Jordan, J.E., Pruitt, S.D., Bengoa, R. & Wagner, E.H. 2004. Improving the Quality of Health Care for Chronic Conditions. *Quality and Safety in Health Care Journal*, 13:299-305.
- Evian, C. 2008. *Primary HIV/AIDS Care*. Melville: Jacana Media.
- Ewings, F.M., Bhaskaran, K., McLean, K., Hawkins, D., Fisher, M., Gilson, R., Nock, D., Brettle, R., Johnson, M., Phillips, A. & Porter, K. 2008. Survival Following HIV Infection of a Cohort Followed up from Seroconversion in the UK. *AIDS Journal*, 22:89-95.
- Griffin, J., McKenna, K. & Tooth, L. 2003. Written Health Education Materials: Making Them More Effective. *Australian Occupational Therapy Journal*, 50:170-177.
- Guimarães, M.D.C., Rocha, G.M., Campos, N., de Freitas, F.M.T., Gualberto, F.A.S., Teixeira, R.A.R. & de Castilho, F.M. 2008. Difficulties Reported by HIV-Infected Patients Using Antiretroviral Therapy in Brazil. *Clinics Journal*, 64:165-172.

- Hammer, S.M., Saag, M.S., Schechter, M., Montaner, J.S., Schooley, R.T., Jacobsen, D.M., Thompson, M.A., Carpenter, C.C., Fischl, M.A., Gazzard, B.G., Gatell, J.M., Hirsch, M.S., Katzenstein, D.A., Richman, D.D., Vella, S., Yeni, P.G. & Volberding, P.A. 2006. Treatment for Adult HIV Infection: 2006 Recommendations of the International AIDS Society-USA panel. *Journal of the American Medical Association* 296(7):827-843. [Online], Available: <http://www.ncbi.nlm.nih.gov/pubmed/16905788>. [2011, September 2].
- Harries, A., Maher, D. & Graham, S. 2004. *TB/HIV A Clinical Manual*. 2nd Edition. Geneva: World Health Organisation.
- Jackson, H. 2002. *AIDS Africa: Continent in Crisis*. Harare: Southern Africa AIDS Information Dissemination Services.
- Jehuda- Cohen T. 2011. The HIV Seronegative Window Period: Diagnostic Challenges and Solutions. *InTech Online Open Publisher*. [Online]. Available: <http://www.intechopen.com/articles/show/title/the-hiv-seronegative-window-period-diagnostic-challenges-and-solutions> [2011, October 11].
- Kerridge, I., Lowe, M. & McPhee, J. 2007. *Ethics and Law for the Health Professions*. 2nd Edition. The Federation Press: Sydney.
- King, J. & Taylor, M.C. 2010. Adults Living with Limited Literacy and Chronic Illness: Patient Education Experiences. *Adult Basic Education and Literacy Journal*, 4:24-33.
- Kip, E., Ehlers, V.J. & Van der Wal, D.M. 2008. Patients' Adherence to Anti- Retroviral Therapy in Botswana. *Journal of Nursing Scholarship* 41(2): 149-157. [Online]. Available: <http://www.zimbio.com/HIV/articles/C2CC6DfUEel/Patients+Adherence+Anti+Retroviral+Therapy> [2010 August 25].
- Kozier, B., Erb, G., Berman, A.J. & Burke, K. 2000. *Fundamentals of Nursing: Concepts, Process and Practice*. California: Prentice- Hall.
- Loiselle, C.G., Profetto-McGrath, J., Polit, D.F. & Beck C.T. 2010. *Canadian Essentials of Nursing Research*. 3rd Edition. Philadelphia: Lippincott Williams & Wilkins.
- Mansoor, L. & Dowse, R. 2007. Written Medicines Information for South African HIV/AIDS Patients: Does it Enhance Understanding of Co-trimoxazole Therapy?. *Health*

- Education Research Journal* 22(1): 37-48. [Online]. Available: <http://her.oxfordjournals.org/content/22/1/37.full.pdf+html>. [2011, November 3].
- Mash, B., Blitz, J., Kitshoff, D. & Naudé, S. 2010. *South African Clinical Nurse Practitioners Manual*. Pretoria: Van Schaik.
- Miles, M. & Huberman, A.M. 2003. *Qualitative Data Analysis*. London: Sage Publications.
- Mills, E., Nachega, J.B., Bangsberg, D.R., Singh, S., Rachlis, B., Wu, P., Wilson, K., Buchan, I., Gill, C.J. & Cooper, C., 2006. Adherence to HAART: A Systematic Review of Developed and Developing Nation Patient-Reported Barriers and Facilitators. *Global Health Sciences Literature Digest*, 3(11):438.
- Molassiotis, A., Nahas-Lopez, V., Chung, W.Y.R., Lam, S.W.C., Li, C.K.P. & Lau, T.F.J. 2002. Factors Associated with Adherence to Antiretroviral Medication in HIV-infected Patients. *International Journal of STD & AIDS*, 13:301-310.
- Mouton, J. 2002. *Understanding Social Research*. Pretoria: Van Schaik.
- Mouton, J. 2005. *How to Succeed in Your Master's and Doctoral Studies: A South African Guide and Resource Book*. Pretoria: Van Schaik
- Mukona, D., Charumbira, A.P.G., Nyamakura, R., Zvinavashe, M. & Manwere, A. 2011. HIV Knowledge and Adherence. *HIV Nursing Matters: A Magazine of the Southern African HIV Clinicians Society*, 2:16-19.
- Nachega, J.B., Lehman, D.A., Hlatshwayo, D., Mothopeng, R., Chaisson, R.E. & Kardtaedt, A.S. 2005. HIV/AIDS and Antiretroviral Treatment Knowledge, Attitudes, Beliefs, and Practices in HIV-Infected Adults in Soweto, South Africa. *Journal of Acquired Immune Deficiency Syndrome*, 38:196-201.
- Nath, C. 2007. Literacy and Diabetes Self-Management. *American Journal of Nursing*, 107:43-49.
- National Department of Health. 2010. *Clinical Guidelines for the Management of HIV & AIDS in Adults and Adolescents*. Pretoria: National Department of Health.
- Neuman, W.L. 2006. *Social Research Methods: Qualitative and Quantitative Approaches*. 6th Edition. Boston: Pearson International.

- Neyhart, C.D. 2008. Education of Patients Pre and Post-Transplant: Improving Outcomes by Overcoming Barriers. *Nephrology Nursing Journal*, 35:409-410.
- Odu, B.K. & Akanle, F.F. 2008. Knowledge of HIV/AIDS and Sexual Behaviour Among the Youths in South West Nigeria. *Humanity & Social Sciences Journal* 3:81-88. [Online]. Available: <http://idosi.org/hssj/hssj3%281%2908/10.pdf>. [2011, September 20].
- Orem, D. E. 1985. *Nursing: Concepts of Practice*. 3rd Edition. New York: McGraw-Hill.
- Orem, D. E. 1971. *Nursing: Concepts of Practice*. New York: McGraw-Hill.
- Orem, D.E. 1991. *Nursing: Concepts of Practice* 4th Edition. St Louis: Mosby.
- Pendukeni, M. 2004. The Impact of HIV/AIDS on Health Care Provision: Perceptions of Nurses Currently Working in One Regional Hospital in Namibia. Unpublished Masters in Public Health. Cape Town: University of the Western Cape.
- Polit, D.F. & Beck, C.T. 2008. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 8th Edition. Philadelphia: Lippincott Williams & Wilkins.
- Racey, C.S., Zhang, W., Brandson, E.K., Fernandes, K.A., Tzemis, D., Harrigan, P.R., Montaner, J.S.G., Barrios, R., Toy, J. & Hogg, R.S. 2010. HIV Antiviral Drug Resistance: Patient Comprehension. *AIDS Care Journal*, 22:816-826.
- Rougemont, M., Stoll, B.E., Elia, N. & Ngang, P. 2009. Antiretroviral Treatment Adherence and its determinants in Sub-Saharan Africa: A prospective study at Yaounde Central Hospital, Cameroon. *AIDS Research and Therapy Journal*, 6:1-12.
- Rubin, A. & Babbie, E.R. 2011. *Research Methods for Social Work*. 7th Edition. California: Brooks/Cole.
- Salmon, P. & Young, B. 2005. Core Assumptions and Research Opportunities in Clinical Communication. *Patient Education and Counselling Journal*, 58:225-234.
- Second National HIV Communication Survey 2009 - findings from the Western Cape. 2009. [Online]. Available: <http://www.jhhesa.org/docs/Western%20Cape.pdf> [2011, June 23].
- Smeltzer, S.C. & Bare, B.G. 2004. *Brunner and Suddarths Textbook of Medical- Surgical Nursing*. Philadelphia: Lippincott Williams & Wilkins.

- Smith Fawzi, M.C., Jagannathan, P., Cabral, J., Banares, R., Salazar, J., Farmer, P. & Behforouz, H. 2006. Limitations in Knowledge of HIV Transmission among HIV-positive Patients Accessing Case Management Services in a Resource- poor Setting. *AIDS Care Journal*, 18:764-771.
- South Africa. Department of Health: Provincial Government of the Western Cape. 2010. *Clinical Guidelines of the Western Cape: Primary Care Management of Adults HIV/AIDS, TB, Asthma/COPD & STI's*. Palsa Plus.
- South Africa. Department of Health 2007. *HIV and AIDS and STI Strategic Plan for South Africa, 2007-2011*. [Online], Available: <http://www.doh.gov.za/docs/misc/stratplan-f.html>. [2010, September 12].
- South Africa. Western Cape Provincial Languages Act. 1998. [Online]. Available: <http://www.capegateway.gov.za/Text/2004/8/act13-98.pdf>. [2011, July 23].
- Statistics South Africa, *2001 Socio-Economic Status Index by Suburb 2001*. [Online]. Available: http://www.capetown.gov.za/en/stats/Documents/SES_Indicators_by_2001_Suburbs_%28Map%29_3010200614540_359.pdf [2011, November 20].
- Stellenberg, E.L. 1995. An Evaluation of the Effect of a Patient Education Programme on the Eventual Quality of Life of the Laryngectomy Patient. Unpublished Masters Thesis. Cape Town: Stellenbosch University.
- Taylor, S.G. 2002. Self-Care Deficit Theory of Nursing, in Tomey, A.M. & Alligood, M.R. 2002. *Nursing Theorists and Their Work*. 5th Edition. Missouri: Mosby.
- Terre Blanche, M. & Durrheim, K. 2004. *Research in Practice*. Cape Town: University of Cape Town Press.
- UNAIDS. *2007 AIDS Epidemic Update*. 2007. [Online]. Available: http://data.unaids.org/pub/epislides/2007/2007_epiupdate_en.pdf [2011, May 3].
- UNAIDS. *2009 AIDS Epidemic Update*. 2009 [Online]. Available: http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf [2010, August 25].
- Van Dyk, A., 2008. *HIV/AIDS Care and Counselling: A Multidisciplinary Approach*. 4th Edition. Cape Town: Maskew Miller Longman.

- Watson, R., McKenna, H., Cowman, S. & Keady, J. 2008. *Nursing Research Designs and Methods*. Toronto: Elsevier.
- Wehrwein, E.A., Lujan, H.L. & DiCarlo, S.E. 2006. Gender Differences in Learning Style Preferences Among Undergraduate Physiology Students. *Advances in Physiology Education Journal* 31(2):153-157. [Online]. Available: <http://advan.physiology.org/content/31/2/153.full.pdf+html> [2011, 4 November].
- Weiner, E.J. 2005. *Private Learning, Public Needs: The Neoliberal Assault on Democratic Education*. New York: Peter Lang Publishing.
- Weiser, S., Wolfe, W., Bangsberg, D., Thior, I., Gilbert, P., Makhema, J., Kebaabetswe, P., Dickenson, D., Mompati, K., Essex, M. & Marlink, R. 2003. Barriers to Antiretroviral Adherence for Patients Living with HIV Infection and AIDS in Botswana. *Journal of Acquired Immune Deficiency Syndrome* 34:281-288. [Online]. Available: http://journals.lww.com/jaids/Fulltext/2003/11010/Barriers_to_Antiretroviral_Adherence_for_Patients.4.aspx?WT.mc_id=HPxADx20100319xMP# [2011, July 2].
- Weisstein, E. W. 2011. Fisher's Exact Test. [Online]. Available: <http://mathworld.wolfram.com/FishersExactTest.html> [2011, November 20].
- Wolf, M.S., Davis, T.C., Arozullah, A., Penn, R., Arnold, C., Sugar, M. & Bennett, C.L. 2005. Relation Between Literacy and HIV Treatment Knowledge Among Patients on HAART Regimens. *AIDS Care Journal*, 17:863-872.
- Wolf, M.S., Davis, T.C., Bass, P.F., Curtis, L.M., Lindquist, L.A., Webb, J.A., Bocchini, M.V., Bailey, S.C. & Parker, R.M. 2010. Improving Prescription Drug Warnings to Promote Patient Comprehension. *Archives of Internal Medicine* 170(1):50-56. [Online]. Available: <http://archinte.ama-assn.org/cgi/reprint/170/1/50>. [2011, 3 November].
- World Health Organisation. 2004. [Online]. Available: <http://www.who.int/tb/hiv/faq/en/>.
- Zuniga, I., van Cutsem, G. & Saranchuk, P., 2010. *Management of HIV- related Conditions and Antiretroviral Therapy in Adults and Children: HIV Guide for Primary Health Care in South Africa*. 7th Edition. Cape Town: Médecins Sans Frontières.

Zweigenthal, V., Puoane, T., Reynolds, L., London, L., Coetzee, D., Alperstein, M., Duncan, M., Atkins, S., Loveday, M., Hutchings, C., Geiger, M., Petersen, L., Ferguson, G., Hewett, G. & Batley, K. 2009. *Primary Health Care: Fresh Perspectives*. Cape Town: Pearson/Prentice Hall.

APPENDICES

APPENDIX A: DATA COLLECTION TOOL

The knowledge about HIV/AIDS and Antiretroviral treatment of patients receiving antiretroviral therapy

Study Aim

The purpose of this study is to determine the knowledge of infected HIV/AIDS patients who are receiving antiretroviral medication about HIV/AIDS and ART.

Dear Participant

Thank you for agreeing to voluntarily participate in this study. The information that you provide is very valuable, and in providing the information, you are helping to make this study a success. Therefore it is important that you answer honestly and accurately. Your contribution is valued.

All information will be treated confidentially and the researcher undertakes not to reveal any information in this questionnaire at any time.

This structured interview will take approximately 20 minutes to complete.

Yours Sincerely,

Lauren Terblanche

Cell: 0845511588

SECTION A: DEMOGRAPHIC DATA

Please complete the entire questionnaire by marking the appropriate answer with an x

*Correct answers typed in **bold**. Critical Questions marked with an asterisk (*).*

1. Age:

2. Gender

Male (M)	
Female (F)	

3. Language

1. English	
2. Afrikaans	
3. Xhosa	
4. Zulu	
5. Other (please specify)	

4. What is your highest level of education achieved?

.....

5. Are you able to read and write?

1. No	
2. Write only	
3. Read only	
4. Read and write	

6. How long have you been living with HIV?

1. Less than a year	
2. > one and ≤ three years	
3. > three and ≤ five years	
4. > five years	

7. How long have you been on treatment for HIV/AIDS (ART)?

1. Less than a year	
2. ≥ one and < three years	
3. > three and ≤ five years	
4. > More than five years	

SECTION B: KNOWLEDGE OF HIV AND ART

8. What does the HIV virus do in the body? *

1. Kills your immune system	
2. Destroys your organs	
3. Causes TB	
4. Makes you stronger	

9. Is HIV spread through any of the following? *

a. Kissing	Yes	No
b. Hugging	Yes	No
c. Sexual intercourse	Yes	No
d. Mosquitoes	Yes	No
e. Coughing	Yes	No
f. Blood transfusion	Yes	No
g. Contact with HIV positive blood or body fluids	Yes	No

10. What is the window period? *

1. When you get HIV through the air	
2. When HIV cannot be seen in the blood	
3. The time when you are safe to have sex without a condom	
4. Do not know	

11. How long does the window period last? *

1. 3 months	
2. 6 months	
3. 9 months	
4. 1 year	
5. 2 years	
6. Do not	

12. What is a CD4 count? *

1. The number of HIV cells in your blood	
2. The number of fighter cells in your blood which HIV likes	
3. The test done to determine whether you are HIV positive	
4. Do not know	

13. When last was your CD4 count done?

1. Less than 6 months ago	
2. ≥ 6 months < 12 months ago	
3. ≥ 12 months to < 24 months	
4. > 24 months ago	
5. Do not know	

14. How often should you have your blood drawn for a CD4 count? *

1. Every 6 months	
2. Every 12 months	
3. Every 24 months	
4. Every 60 months	
5. Do not know	

15. Why is it important to monitor your CD4 count?

1. To monitor how many HIV cells you have in your blood	
2. To see if you have been cured of HIV	
3. To see if the HIV treatment is working	

4. Do not know	
----------------	--

16. What is a viral load?

1. Is the amount of HIV cells in your blood	
2. The transfer of HIV to your partner	
3. The number of immune cells in your blood	
4. Do not know	

17. When last was your blood drawn for viral load?

1. Less than 6 months ago	
2. ≥6 months to <12 months	
3. ≥12months to ≤24 months	
4. > 24 months ago	
5. Do not know	

18. Do you know what stage of HIV you are currently in? If yes, state which stage you are currently in

No (n)	
Yes, I am in stage...	

19. If you are HIV positive, will your children also definitely be HIV positive?*

Yes (y)	
No (n)	

20. Why did the staff at the clinic say that you must start treatment?

.....

21. Can ART cure HIV? *

Yes (y)	
No (n)	

22. What does ART do to the HIV virus in the body? *

1. Kills the virus	
2. Makes the HIV viral load less in the blood	
3. Makes it safe to have unsafe sex	

23. Did the clinic staff say that you can expect side-effects with the medication you are using?

Yes (y)	
No (n)	

24. Can ART cause side effects that can be very dangerous? *

Yes (y)	
No (n)	

25. Can you name two danger signs? * (Must know at least 2.)*

1. Skin rash	
2. Jaundice (yellow skin colour)	
3. Vomiting	
4. Do not know	

26 What should you do if you experience any of the danger signs? *

1. Skip one day of medication and continue the next day	
2. Carry on taking your medication until the symptoms go away	
3. Stop medication and go to the clinic as soon as you can	

27 If you forget to take your medication, what should you do? *

1. Drink it immediately when you remember	
2. Throw away tablet that was skipped and carry on	
3. Stop medication completely	
4. Take missed tablet/s together with your next dose	

28. What will happen if you stop taking your medication? *

1. Nothing will happen	
2. Your medication may become less effective and HIV will increase in you	
3. You will be cured of HIV	
4. Do not know	

29. From where did you learn most of the knowledge about HIV and its treatment from?

1. The HIV sister at the clinic	
2. Posters in the clinic	
3. TV and Radio	
4. The internet	
5. Books in the clinic	
6. A family member or	
7. The doctor	
8. Other	

Thank you!

APPENDIX B: ETHICAL COMMITTEE APPROVAL LETTER



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

08 April 2011

MAILED

Mrs L Terblanche
Department of Nursing
2nd Floor
Teaching Block

Dear Mrs Terblanche

"Infected patient's knowledge regarding HIV/AIDS and anti-retroviral therapy."

ETHICS REFERENCE NO: N11/02/056

RE : APPROVED WITH STIPULATIONS

It is a pleasure to inform you that a review panel of the Health Research Ethics Committee has approved the above-mentioned project with STIPULATIONS on 07 April 2011, including the ethical aspects involved, for a period of one year from this date.

1. Please check the spelling in the Afrikaans questionnaire.

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in ALL future correspondence. You may start with the project. Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary.

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

08 April 2011 14:26

Page 1 of 2



Fakulteit Gesondheidswetenskappe • Faculty of Health Sciences



Verbind tot Optimale Gesondheid • Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun • Division of Research Development and Support
Posbus/PO Box 19063 • Tygerberg 7505 • Suid-Afrika/South Africa
Tel.: +27 21 938 9075 • Faks/Fax: +27 21 931 3352

APPENDIX C: ETHICAL COMMITTEE APPROVAL LETTER



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvennoot • your knowledge partner

Approval Date: 07 April 2011

Expiry Date: 07 April 2012

Yours faithfully

MS CARLI SAGER

RESEARCH DEVELOPMENT AND SUPPORT

Tel: +27 21 938 9140 / E-mail: carlis@sun.ac.za

Fax: +27 21 931 3352

08 April 2011 14:26

Page 2 of 2



Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences



Verbind tot Optimale Gesondheid · Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352

APPENDIX D: PGWC APPROVAL LETTER



DEPARTMENT
of HEALTH

Provincial Government of the Western Cape

Directorate: Tygerberg/Northern Substructure

Cnr Frans Conradie & Mike Pienaar

Bellville, 7530

Tel: +27 21 918 1679

Fax: +27 21 918 1768

www.capegateway.gov.za

REFERENCE: LSB/ELS/08/11

ENQUIRIES: Dr. LS Bitalo

Dr Stellenberg
Head of research
Division of Nursing
Faculty of Health Sciences
Stellenbosch University
Tygerberg Campus
Cape Town

Dear Dr Stellenberg

Your e-mail dated 26/07/2011 hereby formally acknowledged.

We formally give permission for student L Terblanche to do research at the Delft Community Health Centre as required for her studies. Our office did inform the appropriate people and we do apologise for any inconvenience caused by the delay.

The Delft Community Health Centre Manager is Mr J Van Heerden and he can be contacted at 021 9542237. Please note that during the month of August Mr M Horn will be standing in as facility Manager and he can be contacted on the same number.

Yours sincerely

Dr L Bitalo
Director: Northern/Tygerberg Sub-structure
Date: 8 August 2011

APPENDIX E: LETTER OF INFORMED CONSENT

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

The Knowledge About HIV/AIDS and Antiretroviral Treatment of Patients Receiving Antiretroviral Therapy.

REFERENCE NUMBER: N11/02/056

PRINCIPAL INVESTIGATOR: Lauren Terblanche

ADDRESS: 21 Nice Street, Durbanville, 7550

CONTACT NUMBER: 0845511588

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The study will take place at Delft community health centre where 200 patients who are HIV positive and on ART will be asked to participate in the study.
- The study aims to find out what knowledge HIV patients on ART have of HIV and ART. By finding this out, the researcher will be able to see how much patients understand, and if they don't, what the reasons are for not understanding. By knowing this, I will be able to work out strategies to improve patient education in the

clinics. By having more knowledge and understanding, patients will exercise safer sex practices, adhere to their medication and prevent the transmission of HIV.

- You will be required to answer a questionnaire anonymously by means of an interview with the researcher or trained fieldworker which will last a maximum of 20 minutes.
- Two hundred participants will be chosen randomly. If you are at the clinic on the day the researcher is there and you are willing and available to participate, then an interview will be held with you.

Why have you been invited to participate?

- You have been invited as you are above 18 years of age, are HIV positive and on ART in this specific Delft community. By answering this questionnaire, you are helping this study to be successful as your knowledge and understanding of HIV and ART is important to this study, and will help others in your community in the future.

What will your responsibilities be?

- You will be responsible to answer the questionnaire honestly, knowing that the information you provide will be very valuable only if it is honest.

Will you benefit from taking part in this research?

- Depending on what the study shows, if there is not enough understanding and knowledge about HIV and ART, strategies to improve knowledge and understanding will be made for educating patients in the future. This will lead more people to practice safe sex, drink their medication as they should and eventually help prevent the transmission of HIV/AIDS in the future. This study will therefore benefit the people in your community and also yourself.

Are there any risks involved in your taking part in this research?

- There is no risk for you as a participant.

If you do not agree to take part, what alternatives do you have?

- You may stop your participation at any time, you are not forced to take part. It is your own free will whether to take part or not.

Who will have access to your medical records?

- The information you provide in the questionnaire will be treated as confidential and protected and only the researcher or trained fieldworker will have access to your personal details. The study will be presented in a printed thesis, but all participants' identities will remain anonymous at all times. A statistician will have access to your anonymous questionnaire, as well as the researcher or fieldworker and supervisor. All consent forms will remain with the researcher or fieldworker, and no one else will have access to these documents.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

- Not applicable

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- You can contact Sr. Lauren Terblanche at tel. 0845511588 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study registered nurse.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled '***The Knowledge About HIV/AIDS and Antiretroviral Treatment of Patients Receiving Antiretroviral Therapy***'.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2011.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2011.

.....
Signature of investigator

.....
Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)

.....
Signature of interpreter

APPENDIX F: AFRIKAANS DECLARATION

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek,

....., om deel te neem aan 'n navorsingsprojek getiteld

'Die kennis oor MIV/VIGS en Antiretrovirale Terapie van Pasiente Wat Antiretrovirale Terapie Ontvang'.

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (*plek*) op (*datum*) 2011.

.....

Handtekening van deelnemer

.....

Handtekening van getuie

Verklaring deur navorser

Ek (*naam*) verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

- Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie. (*Indien 'n tolk gebruik is, moet die tolk die onderstaande verklaring teken.*)

Geteken te (*plek*) op (*datum*) 2011.

.....
Handtekening van navorser

.....
Handtekening van getuie

Verklaring deur tolk

Ek (*naam*) verklaar dat:

- Ek die navorser (*naam*) bygestaan het om die inligting in hierdie dokument in Afrikaans/Xhosa aan (*naam van deelnemer*) te verduidelik.
- Ons hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek 'n feitelik korrekte weergawe oorgedra het van wat aan my vertel is.
- Ek tevrede is dat die deelnemer die inhoud van hierdie dokument ten volle verstaan en dat al sy/haar vrae bevredigend beantwoord is.

Geteken te (*plek*) op (*datum*) 2011.

.....
Handtekening van tolk

.....
Handtekening van getuie

APPENDIX G: XHOSA DECLARATION

Isifungo somthathi-nxaxheba

Ngokuyityikitya ngezantsi, Mna ndiyavuma ukuthatha inxaxheba kwisifundo sophando semfuzo esibizwa ngokuba ***'The Knowledge About HIV/AIDS and Antiretroviral Treatment of Patients Receiving Antiretroviral Therapy'***.

Ndazisa ukuba:

- Ndilufundile okanye ndalufunda olu lwazi kunye nefomu yemvumelwano kwaye ibhalwe ngolwimi endiliciko nendikhululekileyo kulo
- Bendinalo ithuba lokuba ndibuze imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyakuqonda ukuba ukuthatha inxaxheba kolu phando kube **kukuzithandela kwam** kwaye andikhange ndinyanzelwe ukuba ndithathe inxaxheba.
- Ndingakhetha ukusishiya isifundo naninina kwaye andisayi kohlwaywa okanye uqal' ugwetywe nangayiphi indlela.
- Usenokucelwa ukuba usishiye isifundo phambi kokuba siphela, ukuba ugqirha wesifundo okanye umphandi ukubona kuyinzuzo kuwe, okanye ukuba andisilandeli isicwangciso sesifundo, ekuvunyelenwe ngaso.

Kutyikitywe e-(indawo) ngo-(usuku) 2011.

.....

Umtyikityo womthathi-nxaxheba

Umtyikityo wengqina

Isifungo somphandi

Mna (*igama*) ndiyafunga ukuba:

- Ndilucacisile ulwazi olu kweli xwebhu ku-.....
- Ndimkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.
- Ndiyaneliseka kukuba uyakuqonda ngokwanelisayo konke okumalunga nophando okuxoxwe ngasentla.
- Ndisebenzise/andisebenzisanga toliki. (*Ukuba itoliki isetyenzisiwe kumele ityikitye isaziso ngezantsi.*)

Kutyikitywe e-(indawo) ngo-(usuku) 2011.

.....
Umtyikityo womphandi

.....
Umtyikityo wengqina

Isifungo setoliki

Mna (*igama*) ndazisa ukuba:

- Ndicende umphandi (*igama*) Ekucaciseni ulwazi olu lapha kweli xwebhu ku-(*igama lomthathi-nxaxheba*) ndisebenzisa ulwimi lwesiAfrikaans/lwesiXhosa.
- Simkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.
- Ndimxelele eyona nto iyiyo malunga nokunxulumene nam.
- Ndiyaneliseka kukuba umthathinkxaxheba ukuqonda ngokupheleleyo okuqulathwe loluxwebhu lwemvumelwano eyazisiweyo kwaye nemibuzo yakhe yonke iphendulwe ngokwanelisayo.

Kutyikitywe e-(indawo) ngo-(usuku) 2011.

.....
Umtyikityo wetoliki

.....
Umtyikityo wengqina



SERVICES

English/Afrikaans
* Translations
* Editing
* Proof-Reading
* Academic Manuscript Preparation
* Archival Research
* Transcriptions from Archived Documents



Member: South African Translators' Institute (SATI)

3 Beroma Crescent
Beroma
Bellville 7530

13 November 2011

TO WHOM IT MAY CONCERN

This letter serves to confirm that the undersigned

ILLONA ALTHAEA MEYER

has proof-read and edited the document contained herein for language correctness.

(Ms IA Meyer)

SIGNED