



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

**THE BIOPSYCHOSOCIAL FACTORS INFLUENCING HIV/AIDS PATIENT
ADHERENCE TO ANTIRETROVIRAL THERAPY (ART): A SOCIAL WORK
STUDY**

by

**MARGARETHA SPIES
STUDENT NUMBER: 77132158**

**A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR THE DEGREE
DOCTOR PHILOSOPHIAE IN SOCIAL WORK (D.PHIL)**

in the

**THE DEPARTMENT OF SOCIAL WORK AND CRIMINOLOGY
FACULTY OF HUMANITIES
UNIVERSITY OF PRETORIA**

APRIL 2007

PROMOTER: Dr. CL Carbonatto



DEDICATION

I walked through your lives...

robbers

murderers

grandmothers

children

old men

policemen

refugees

young women

doctors

counsellors

priests

wives

teachers

students

happy people, sad people,

the rich and the poor

innocent or guilty

colleagues, family and friends

the creation of society

ordinary human beings

...by sharing your experiences and dreams

I could meet my own.

I will be forever grateful to thee!

THE RESEARCHER



ACKNOWLEDGEMENTS

The contributions of the following persons are herewith acknowledged with gratitude:

- My employer, The Department of Health, HAST Directorate, Gauteng Province.
- My colleagues at the Department of Social Work, Pretoria Academic Hospital, specifically Magda-Marié Hertzog, for professional consultation, friendship and motivation. Adriana Weber for continuous support.
- My colleagues at the antiretroviral clinic, Tshwane District Hospital, specifically, Dr. Theresa Rossouw, for expert advice and editing of medical chapters.
- The Department of Social Work and Criminology, at the University of Pretoria, specifically Dr. C.L. Carbonatto, my promoter.
- The Department of statistics at the University of Pretoria, specifically Dr. Mike van der Linde, for assistance with the statistical processing of data.
- Mrs. Elize Nagel, ITS training Manager, the University of Pretoria, for technical assistance in word processing.
- Mr. David Levey, for professional editing of the text.
- Family and friends for support.
- My husband, Hennie Coetzee, for continuous support, motivation and care.
- My children, Esté and Mia, for unconditional love.
- God Almighty for the clarity of thought, means and abilities to complete this study.



ABSTRACT

THE BIOPSYCHOSOCIAL FACTORS INFLUENCING HIV/AIDS PATIENT ADHERENCE TO ANTIRETROVIRAL THERAPY (ART): A SOCIAL WORK STUDY

The study emanates from the need to identify the biopsychosocial factors that influence patients' adherence to antiretroviral therapy (ART) within the South African context. The specific goal of the study was to explore these in order to make recommendations to enhance service delivery.

Applied research was conducted, with its primary task being to stimulate thought and action concerning the challenges faced by patients who are on ART. In order to gather comprehensive data, the researcher engaged in a combination of the qualitative and quantitative approaches. For the qualitative case study the researcher made use of semi-structured interviews, utilizing the non-probability sampling method, aiming to understand and interpret the meaning that the multidisciplinary team accorded to matters of antiretroviral treatment. For the quantitative part of the study the probability random sampling method was made use of for the quantitative descriptive survey. Questionnaires were employed to collect data from 201 patients already on antiretroviral medication.

The conclusions, which were drawn from the research findings, identified challenges to adherence to ART: the study confirmed that since the advent of combination antiretroviral therapy (HAART), HIV/AIDS has been transformed into a manageable and chronic condition, and has undoubtedly extended and improved the quality of life for people living with HIV/AIDS. However, it also confirmed that ART is a complex intervention, which is accompanied by severe biopsychosocial implications, requiring near-perfect adherence in order to prevent the development of resistance. The impact that the various psychosocial needs of millions of HIV/AIDS people living on ART will have on current social structures and services, will tax the available professional social



services, particularly the social work profession. The social correlation of HIV/AIDS and poverty is endorsed by the findings, confirming that the high level of unemployment, coupled with families who are headed by women and who receive little support, lead to almost total dependency on social security. The findings further indicate a specific relationship between socio-economic circumstances and the ability to adhere to ART.

Empowering HIV/AIDS patients, to be able to adhere to ART, is therefore indicated, as is the further need for a regulator of HIV/AIDS support services, in order to protect and promote high standards of service delivery, especially counselling.

Keywords: Acquired immune deficiency syndrome (AIDS), antiretroviral therapy (ART), assessing, biopsychosocial, adherence, compliance, concordance, counselling, counsellors, human immunodeficiency syndrome (HIV), psychosocial, resistance, social work.



**UNIVERSITY OF PRETORIA
FACULTY OF HUMANITIES
RESEARCH PROPOSAL & ETHICS COMMITTEE**

DECLARATION

Full Name:

Student Number:

Degree/Qualification:

Title of thesis/dissertation:

.....

I declare that this thesis / dissertation is my own original work. Where secondary material is used, this has been carefully acknowledged and referenced in accordance with university requirements.

I understand what plagiarism is and am aware of university policy and implications in this regard.

.....

Signature

.....

Date



**UNIVERSITEIT VAN PRETORIA
FAKULTEIT GEESTESWETENSKAPPE
NAVORSINGSVOORSTEL- EN ETIEKKOMITEE**

VERKLARING

Volle Naam:

Studentenommer:

Graad/Kwalifikasie:

Titel van tesis/verhandeling:

.....

Ek verklaar dat hierdie tesis / verhandeling my eie oorspronklike werk is. Waar sekondêre materiaal gebruik is, is dit noukeurig erken en aangedui in ooreenstemming met universiteitsvereistes.

Ek verstaan wat plagiaat beteken en is bewus van die universiteit se beleid en implikasies in hierdie verband.

.....

Handtekening

.....

Datum



SAMEVATTING

DIE BIOPSIGOSOSIALE FAKTORE WAT MIV/VIGS PASIËNTE SE VOLDOENING AAN DIE VEREISTES VAN ANTIRETROVIRALE TERAPIE (ART) BEÏNVLOED: 'N MAATSKAPLIKE WERK ONDERSOEK

Die doel van hierdie studie was die identifisering en beskrywing van die biopsigososiale faktore wat moontlik MIV/VIGS pasiënte se voldoening aan die eise van teenretrovirale terapie (ART) kan beïnvloed. Om aanbevelings te maak rakende relevante faktore wat in ag geneem moet word in die assessering van HIV/VIGS pasiënte, vir die gebruik van teenretrovirale medikasie, om derhalwe die ontwikkeling van weerstandigheid teenoor teenretrovirale middels te minimaliseer. Die navorser huldig die opinie dat beter kennis en begrip aangaande die biopsigososiale faktore wat teenretrovirale terapie (ART) beïnvloed, tot meer effektiewe dienslewering aan MIV/VIGS pasiënte kan lei, deur maatskaplike werkers en ander multidissiplinêre spanlede betrokke by sodanige dienslewering.

Ten einde navorsingsdata te versamel, is die volgende navorsingsmetodes deur die navorser gebruik: Binne die kwalitatiewe navorsingsparadigma het die navorser van die nie-waarskynlike steekproefmetodes gebruik gemaak om respondente te identifiseer uit die multidissiplinêre spanlede tans betrokke by Teenretrovirale dienslewering. Data is versamel deur onderhoude aan die hand van semi-gestruktureerde onderhoudskedules te voer. Hoofemas is geselekteer en veskeie subtemas het uit die navorsingstudie na vore gekom.

Tydens die kwantitatiewe fase van die navorsingsprojek is 'n ewekansige monster geselekteer wat bestaan het uit 201 respondente om beskrywende data te verkry. 'n Vraelys is gebruik om data te verkry van pasiënte wat reeds teenretrovirale terapie ontvang.

Die navorsingsprojek kan as toegepaste navorsing geklassifiseer word omdat dit ten doel het om groter begrip van die uitdagings wat die teenretrovirale



terapie aan die pasiënt stel, by die lede van die multidissiplinêre span te ontwikkel. Die navorsingsresultate sal gebruik word om die beradingspraktyk vir MIV/VIGS pasiënte sodanig aan te pas, dat dit sal lei tot beter voldoening aan die vereistes van teenretrovirale terapie. Ook om probleme wat tans deur multidissiplinêre spanlede betrokke by antiretrovirale dienslewering te verlig.

Aan die hand van die navorsingsbevindings het die navorser die volgende gevolgtrekkings en aanbevelings vir die praktyk geformuleer: Die navorsing het bevestig dat sedert die beskikbaarstelling van teenretrovirale terapie (ART), die lewens van HIV/ VIGS pasiente verleng en kwaliteits lewe besorg, dit is van 'kroniese siekte toestand. Die navorsing het bevestig dat teenretrovirale terapie (ART) 'n komplekse intervensie is, wat perfekte voldoening aan die vereistes van teenretrovirale terapie (ART) vereis om die ontwikkeling van weerstandigheid te voorkom. Die gepaardgaande ernstige biopsigososiale implikasie en die impak van die vele psigososiale behoeftes van MIV/VIGS pasiente, op teenretroviral medikasie, sal huidige ondersteunings strukture en dienste uitdaag tot verantwoordelikheid roep en onder druk plaas. Spesifiek die maatskaplike werk profesie word

Die verwantskap tussen MIV/VIGS en armoede word verder deur die studie bevestig. Hoe werkloosheid syfer, vrouens en kinders met weinig ondersteuning en die afhanklikheid van staatspensioene. Verbeterde staatspensioen kriteria vir HIV/VIGS pasiënte word voorgestel ten einde pasiënte en families in staat te stel om vinniger toegang tot staatshulp te verkry. Die uitbreiding van pleegouer kapasiteit word ook voorgestel. Die verhouding tussen swak sosio-ekonomiese omstandighede en die moontlikheid om te voldoen aan die vereistes van ARV is ook aangedui. Die bemagtiging van MIV/VIGS pasiente, om faktore aan te spreek wat die voldoening aan die vereistes van ART te ondersteun voldoen is aanbeveel met spesifieke verwysing na Ondersteunings groepe en NRO's moet onderwerp word aan sekere standaarde. Aandag moet gegee word aan die werksomstandighede, werksbeskrywing en standaarde van beraders. Die navorsing was uitvoerbaar en binne die finansiële en praktiese raamwerk van die navorser al die navorsings doelwitte is bereik.



Sleuteltermes: assessering, teenretrovirale middels (ARM), biospsigososiale berader, menslike immuniteitsgebreksindroom (MIV), maatskaplike werker, psigososiale, samewerking, voldoening, verworwe immuniteitsgebrek sindroom (VIGS), weerstandigheid.



TABLE OF CONTENTS

Title	Page
DEDICATION	ii
ACKNOWLEDGEMENTS	iii
ABSTRACT	iv
SAMEVATTING	viii
TABLE OF CONTENTS	xi
LIST OF TABLES	xix
LIST OF FIGURES	xxi
CHAPTER 1: GENERAL INTRODUCTION TO RESEARCH	1
1.1 Introduction	1
1.2 Problem Formulation	9
1.3 Purpose, Goal, and Objectives	12
1.3.1 Purpose	12
1.3.2 Goal	12
1.3.3 Objectives	13
1.4 Research Questions and hypothesis	14
1.5 Research Approach (Qualitative and Quantitative)	14
1.6 Type of Research	16
1.7 Research Design and Methodology	17
1.7.1 Research Design	18
1.7.1.1 Quantitative research design	18
1.7.1.2 Qualitative Research Design	19
1.7.2 Data Collection Methods	20
1.7.2.1 Quantitative Data Collection Methods	20
1.7.2.2 Qualitative Data Collection Methods	20
1.7.3 Methods of Data Analysis	22
1.7.3.1 Quantitative Data Analysis	22
1.7.3.2 Qualitative data analysis	22
1.8 Pilot Study	24
1.8.1 Feasibility of the Study	24
1.8.2 Testing the Data Collection Instruments	25
1.9 Research Populations, Sample and Sampling Methods	26
1.9.1 Research Population	26
1.9.2 Delimitation of Sample	27
1.9.3 Research Sample, Sampling Method and Procedures	27
1.9.3.1 Quantitative Sampling	28



1.9.3.2	Qualitative Sampling.....	28
1.10	Ethical Aspects.....	30
1.10.1	Consequences for Human Beings. Harm to Experimental Subjects and/or Respondents	31
1.10.2	Informed Consent Voluntary Participation	32
1.10.3	Deception of Subjects and/or Respondents	33
1.10.4	Confidentiality and Violation of Privacy	33
1.10.5	Action and Competence of Researcher	34
1.10.6	Cooperation with contribution credit for endeavors	34
1.10.7	Release or Publication of the Findings. Reporting and Analysis of Data	34
1.10.8	Debriefing of Subjects or Respondents.....	35
1.11	Limitations of the Study	35
1.12	Definition of Key Concepts	36
1.12.1	Adherence	36
1.12.2	Anti Retroviral Therapy (ART)/Highly Affective Antiretroviral Therapy (HAART).....	37
1.12.3	Antiretroviral (ARV).....	37
1.12.4	Biopsychosocial	37
1.12.4	Compliance.....	38
1.12.5	Concordance	38
1.12.6	Counselling.....	38
1.12.7	Counsellors.....	39
1.12.7.1	Registered professional or trained counsellors.....	39
1.12.7.2	Lay counsellors	39
1.12.8	HIV/AIDS	39
1.12.9	Multidisciplinary Team	40
1.12.10	Screening	40
1.13.	Contents of the Research Report following this Chapter	41
CHAPTER 2: CLINICAL ASPECTS OF HIV/AIDS		42
2.1	Introduction	42
2.2	The Human Immunodeficiency Virus.....	43
2.2.1	Aetiology of Aids.....	44
2.2.2	Diagnosing HIV by means of Voluntary Counselling and Testing.....	45
2.2.3	Morphology of HIV	47
2.2.4	Pathophysiology of HIV.....	48
2.2.5	Viral Load	50
2.3	Modes of Transmission.....	51
2.3.1	Sexual	51



2.3.2	Blood	52
2.3.3	Mother-to-child Transmission (MTCT).....	52
2.4	Preventing the Spread of HIV	52
2.4.1	Behaviour Intervention by means of Education	53
2.4.2	Voluntary Counselling and Testing (VCT)	53
2.4.3	Prevention Technology	54
2.4.4	Post-exposure Prophylaxis (PEP).....	55
2.4.5	Mother-to-child Transmission (PMTCT)	55
2.5	Immune System	56
2.5.1	CD4 Cell Count.....	57
2.5.2	WHO Staging.....	59
2.6	Summary.....	61
CHAPTER 3: ANTIRETROVIRAL THERAPY (ART).....		63
3.1	Introduction	63
3.2	Goals of antiretroviral therapy	64
3.3	Initiating Antiretroviral Therapy	66
3.4.	Antiretroviral drugs (ART).....	68
3.4.1	Nucleoside Reverse Transcriptase Inhibitors. (NRTIs).....	70
3.4.2	Non-nucleoside Reverse Transcriptase Inhibitors (NNRTI).....	71
3.4.3	Protease inhibitors	71
3.5	Response to antiretroviral treatment and Treatment failure	73
3.5.1	Clinical response	74
3.5.2	Virological response	76
3.5.3	Immunological response	77
3.6	Strategies in Treatment Failure.....	79
3.7	Side Effects and Drug Interactions of Art.....	81
3.7.1	Medication or drug interactions	81
3.7.2	Adverse drug reactions and side effects	83
3.8	Other Uses of Antiretroviral Therapy	85
3.8.1	Post- exposure prophylaxis.....	85
3.8.2	Sexual exposure or raped victims	85
3.8.3	Prevention of Maternal-To-Child Transmission (PMTCT).....	86
3.9	Summary.....	86
CHAPTER 4: RESISTANCE AND THE ROLE OF ADHERENCE IN ANTIRETROVIRAL THERAPY (ART).....		88
4.1	Introduction	88
4.2	Adherence	89
4.3	Resistance.....	92



4.4	Predicting Adherence.....	95
4.5	Strategies for Measuring Adherence.....	97
4.6	Medication Alert Strategies to Enhance Adherence.....	100
4.7	Adherence Support during the Different Phases.....	103
4.7.1	Phase 1: Patient pre-treatment (preparation).....	103
4.7.2	Phase 2: ART Commencement.....	105
4.7.3	Phase 3: Monitoring adherence.....	106
4.7.4	Phase 4: Managing of low adherence.....	107
4.7.5	Step-up adherence package for people with reduced adherence or virological failure.....	109
4.8	Special groups with regards to adherence.....	111
4.9	Factors Influencing Adherence to Art.....	113
4.9.1	Patient Factors.....	114
4.9.1.1	<i>Physiological / biological factors influencing ART.....</i>	<i>115</i>
4.9.1.2	<i>Socio, cultural and socio-economic/interactional issues and characteristics.....</i>	<i>115</i>
4.9.1.3	<i>Psychological matters influencing adherence to ART.....</i>	<i>116</i>
4.9.2	Provider Factors Influencing Art.....	116
4.9.2.1	<i>Multidisciplinary Team Members Involved in Rendering Services to the HIV/Aids Patient on ARV.....</i>	<i>117</i>
4.9.2.2	<i>Administration staff.....</i>	<i>121</i>
4.9.2.3	<i>Counsellors.....</i>	<i>121</i>
4.9.2.4	<i>Dietician.....</i>	<i>123</i>
4.9.2.5	<i>Physician.....</i>	<i>124</i>
4.9.2.6	<i>Pharmacist.....</i>	<i>125</i>
4.9.2.7	<i>Professional nurse.....</i>	<i>126</i>
4.9.2.8	<i>Social worker.....</i>	<i>127</i>
4.9.3	Other community support.....	129
4.9.4	Regimen Factors Influencing Adherence to ART.....	131
4.10	Summary.....	132
CHAPTER 5: THE SOCIAL WORKERS ROLE IN ASSISSING THE HIV/AIDS PATIENT FOR ANTIRETROVIRAL THERAPY UTILISING THE BIOPSYCHOSOCIAL MODEL.....		134
5.1	Introduction.....	134
5.2	The Social Work Profession.....	136
5.2.1	Background.....	138
5.2.2	The goals of social work.....	139
5.2.3	The characteristics and role of the social worker.....	140
5.3	The Roles and Skills of the Social Worker in ARV Matters.....	143
5.3.1	Caring for and protecting vulnerable populations, social justice and equity.....	145



5.3.2	Healing and caring	146
5.3.3	<i>Serve as a broker of community services, providing linkages of patient needs with appropriate resources</i>	147
5.3.4	Policy and programme development	148
5.3.5	Professional education and practice development	148
5.3.6	Heightened awareness of ethical and legal issues	149
5.3.7	Engage in research, to assure a broadening of the knowledge base	150
5.3.8	Collaboration with the multi-disciplinary team in the delivery of services, to assure maximum utilization of skills and knowledge.....	151
5.3.9	Counselling	152
5.4	Assessing the HIV/Aids Patient for Adherence to ART - Utilizing the Biopsychosocial Model	155
5.4.1	Assessment	155
5.4.2	The Biopsychosocial Model	157
5.4.2.1	<i>Assessing the biological/ physiological dimension</i>	161
5.4.2.2	<i>Assessing the psychological dimension</i>	163
5.4.2.3	<i>Social dimension</i>	166
5.5	Summary.....	170
CHAPTER 6: EMPIRICAL FINDINGS FROM THE QUANTITATIVE AND QUALITATIVE PHASES OF THE STUDY: THE BIOPSYCHOSOCIAL FACTORS INFLUENCING HIV/AIDS PATIENT ADHERENCE TO ANTIRETROVIRAL THERAPY (ART): A SOCIAL WORK STUDY .		
	171
6.1	Introduction	171
6.2	Research Methodology	171
6.2.1	Type of research, and research approach and design	171
6.2.2	Research questions and hypothesis	172
6.2.3	Goal and objectives	173
6.2.4	Methods of data collection	173
6.2.5	Sampling method and sample.....	174
6.2.6	Methods of data analysis	176
6.2.7	Collecting and recording data	177
6.2.7.1	<i>Managing the data</i>	178
6.2.7.2	<i>Reading, writing memos</i>	178
6.2.7.3	<i>Describing, classifying and interpreting</i>	178
6.2.7.4	<i>Representing, visualizing</i>	179
6.3	Research Findings	186
6.3.1	Biographical Data	187
6.3.1.1	<i>Gender of Respondents</i>	187
6.3.1.2	<i>Age Group</i>	190



6.3.1.3	<i>Marital Status of Respondents</i>	194
6.3.1.4	<i>Home Language</i>	196
6.3.1.5	<i>Educational level of respondents</i>	200
6.3.1.6	<i>Areas where respondents were staying</i>	203
6.3.1.7	<i>Living conditions of respondents (Type of accommodation)</i>	205
6.3.2	<i>Clinical factors and adherence detail</i>	207
6.3.2.1	<i>CD4 counts of respondents</i>	208
6.3.2.2	<i>Period on ART</i>	211
6.3.2.3	<i>Current performance status of respondents according to the Karnofsky Scale</i>	214
6.3.2.4	<i>The WHO staging before initiation of treatment</i>	215
6.3.2.5	<i>Factors that enhance adherence to ART</i>	217
6.3.2.6	<i>Difficulties that respondents experience as a result of ART</i>	222
6.3.2.7	<i>Respondents' motivation for ART</i>	225
6.3.2.8	<i>Assisting Respondents with adherence to ART</i>	229
6.3.2.9	<i>Alternative healing methods</i>	232
6.3.3	<i>Psychosocial needs of respondents</i>	235
6.3.3.1	<i>Psychosocial needs/problems that respondents experienced since receiving ART: psychological dimension</i>	236
6.3.3.2	<i>Alcohol Consumption</i>	239
6.3.3.3	<i>Drug Abuse</i>	241
6.3.3.4	<i>Criminal Record</i>	242
6.3.3.5	<i>Need for Counselling</i>	243
6.3.3.6	<i>Issues relating to accommodation</i>	245
6.3.3.7	<i>Financially-Related Problems</i>	247
6.3.3.8	<i>Financial Support</i>	250
6.3.3.9	<i>Emotions</i>	252
6.3.3.10	<i>Treatment for depression</i>	255
6.3.3.11	<i>Religions</i>	256
6.3.3.12	<i>Sexual activity of the respondent</i>	258
6.3.3.13	<i>Other sexual matters</i>	262
6.3.3.14	<i>Disclosure</i>	265
6.3.3.15	<i>Disclosure</i>	265
6.3.3.16	<i>Disclosure to whom</i>	266
6.3.3.17	<i>Experience regarding quality of life</i>	268
6.4.	<i>Summary</i>	270
6.4.1	<i>Biographical</i>	271
6.4.2	<i>Medical</i>	271
6.4.3	<i>Social matters</i>	272
6.4.4	<i>Psychological matters</i>	273



6.5	Final remark.....	274
CHAPTER 7: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS.....		275
7.1.	Introduction.....	275
7.2	Summary of Research Methodology.....	276
7.2.1	Illustrated Research.....	277
7.2.2	Phase 1: The selection of a researchable topic.....	277
7.2.3	Phase 2: Formulation of Formal Model.....	277
7.2.3.1	<i>Goal of the research</i>	278
7.2.3.2	<i>Objectives of the Research</i>	278
7.2.3.3	<i>Research Questions</i>	280
7.2.4	Phase 3: Planning.....	281
7.2.5	Phase 4: Implementation.....	283
7.2.6	Phase 5: Interpretation and presentation.....	283
7.3	Summary of Literature Study.....	284
7.3.1	Chapter 2: Clinical Aspects of HIV/AIDS.....	285
7.3.2	Chapter 3: Antiretroviral therapy.....	285
7.3.3.	Chapter 4: Adherence and resistance and the role of adherence to anti-retroviral therapy.....	285
7.3.4	Chapter 5: The social worker's role in assessing the HIV/AIDS patient for anti-retroviral therapy utilizing the biopsychosocial model.....	286
7.4	Summary of Empirical Study (Findings).....	287
7.5	Conclusions.....	291
7.5.1	Biographical.....	291
7.5.2	Biomedical.....	292
7.5.3	Social.....	293
7.5.4	Psychological.....	296
7.6	Recommendations.....	297
7.6.1	Recommendations focused on the provider.....	297
7.6.1.1	<i>Recommendations regarding Government guidelines</i>	297
7.6.1.2	<i>Recommendation regarding closer co-operation between service providers</i>	298
7.6.1.3	<i>Recommendation regarding equal standards of care for HIV/AIDS patients on antiretroviral therapy</i>	299
7.6.1.4	<i>Recommendations regarding education</i>	299
7.6.1.5	<i>Recommendation regarding social grants</i>	299
7.6.1.6	<i>Recommendation regarding social structures</i>	301
7.6.1.7	<i>Recommendations regarding the multidisciplinary team members involved in antiretroviral adherence issues</i>	302
7.6.1.8	<i>Recommendations re adjustment of salaries in the public sector</i>	304
7.6.1.9	<i>Recommendations regarding the faces of AIDS in South Africa</i>	305



7.6.2	Recommendations regarding patient factors.....	305
7.6.3	Recommendations regarding regime factors.....	306
7.6.4.	Recommendations regarding future research	306
7.7	Closing Remarks.....	308
REFERENCES	310
APPENDIXES	327



LIST OF TABLES

Table		Page
Table 1:	Illustrated research process.....	18
Table 2:	Multidisciplinary team members purposively selected for interview	30
Table 3:	Contents of research report.....	41
Table 4:	The CD4 count, CD4% and immune suppression in adults	58
Table 5:	WHO (2006) staging.....	60
Table 6:	Karnofsky Score, HIV/AIDS and antiretroviral therapy).....	75
Table 7:	Correlation between Adherence and Virological Response to ART	76
Table 8:	Roles of the social worker	142
Table 10:	Theme: Gender plays a role in adherence to ART	188
Table 11:	Theme: Age plays a role in adherence to ART.	192
Table 12:	Theme: Marital status influence adherence to ART.....	195
Table 13:	Theme: Language, culture and traditions influence adherence to ART.....	198
Table 14:	Education influences adherence to ART	201
Table 15:	Distribution regarding urban and rural area.....	203
Table 16:	Theme: The influence of living area on adherence.....	205
Table 17:	Living conditions of respondents	205
Table 18:	Theme: Living conditions influence adherence to ART.	206
Table 19:	Knowledge of the CD 4 count could influence adherence to ART.....	210
Table 20:	Theme: The period a patient has been on ART influences adherence	213
Table 21:	Performance status (Karnofsky) of patients influences adherence to ART indirectly	215
Table 22:	Theme: WHO staging does not influence adherence to ART directly	217
Table 23:	Adherence enhancement to ART by respondents as indicated across the nine individual aspects measured	218
Table 24:	Theme: Various forms of support and aids are necessary to enhance, adherence to ART.	219
Table 25:	Difficulties experienced with ART as reported by respondents across the ten individual aspects measured	223
Table 26:	Patients experience various difficulties regarding adherence to ART	224
Table 27:	Motivation for adherence to ART as indicated by Respondents across the eight individual aspects measured	226
Table 28:	The need of patients to stay alive (survival) are featuring features as their strongest motivation to adhere to ART	227
Table 29:	Assistance and support regarding adherence of patients on ART is very important for adherence.....	231
Table 30:	Traditional healing influences adherence to ART in SA	233



Table 31:	Psychosocial needs of Respondents as indicated across the eight individual aspects measured	236
Table 32:	Psychosocial needs of patients featured strongly	238
Table 33:	Alcohol dependency not reported often at ART clinics	240
Table 34:	Theme: Drug abuse and adherence	241
Table 35:	Theme: Criminal record and adherence	243
Table 36:	Theme: Counselling needs	244
Table 37:	Accommodation needs is not prominent in adherence matters	246
Table 38:	Financially-related problems reported by respondents.....	247
Table 39:	Economic factors influence adherence to ART	249
Table 40:	Financial support of respondents as indicated across seven individual aspects measured	250
Table 41:	Financial difficulties are reported by respondents as to influence adherence to ART.....	251
Table 42:	Emotions as indicated by Respondents across the five individual aspects measured	253
Table 43:	Patients reported in general positive feelings and feelings of optimism, hope and to be grateful gratitude.....	254
Table 44:	Theme: Depression is often contraindicated for adherence to ART	255
Table 45:	Theme: Religion and adherence	257
Table 46:	Sexual activities do influence adherence to ART.....	260
Table 47:	Theme: Sexual problems and adherence.....	263
Table 48:	Disclosure as indicated by respondents across seven individual aspects measured	266
Table 49:	Theme: Disclosure influence adherence to ART.....	267
Table 50:	Theme: The quality of life of most patients had improved on ART.....	269
Table 51:	Illustrated Research	277



LIST OF FIGURES

Figure		Page
Figure 1:	Human Immunodeficiency Virus.....	47
Figure 2:	The life-cycle of the HIV-1 virus and the role of therapy in its control. Spencer (2005:6, 7).....	72
Figure 3:	Adherence team members	120
Figure 4:	The different dimensions of the bio-psychosocial model can be illustrated as follows:	161
Figure 5:	Gender Distribution	187
Figure 6:	Age Distribution	190
Figure 7:	Age to gender distribution	190
Figure 8:	Marital status.....	194
Figure 9:	Home language	197
Figure 10:	Educational level of respondents	200
Figure 11:	CD4 Counts	209
Figure 12:	Period on ART	212
Figure 13:	Assisting with adherence to ART	229
Figure 14:	Alternative healers consulted	233
Figure 15:	Sexually Active	258
Figure 16:	Practising safe sex	258
Figure 17:	Safe Sex/Contraception Methods.....	259
Figure 18:	Disclosure of Status	265



CHAPTER 1: GENERAL INTRODUCTION TO RESEARCH

1.1 Introduction

The Human Immuno-deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) have emerged as the most challenging health matters in modern times. The pandemic has created not only medical, but also ethical, legal, social, and political issues, together with economic and human rights implications. Although HIV/AIDS is incurable at present, with the introduction of antiretroviral therapy (ART), it is now considered a manageable life-threatening disease.

Epidemics are not new in the history of humankind, nor are the reactions such as fear, ignorance, panic and isolation that often accompany such diseases. History has not forgotten the devastation caused by epidemics such as the bubonic plague (Black Death) during the fourteenth century in Europe. For modern people, however, epidemics have lost their sting. Van Dyk (1993:10) alleged that our present generation believed that the time of devastating epidemics is long past. The last major epidemic to plague the world was polio during the 1930s and 1940s, which was soon conquered by medical science. HIV/AIDS, however, has shattered this false sense of security.

The Joint United Nations Programme Report on the HIV/AIDS Epidemic for 2006 (UNAIDS, 2006) found that the number of people living with HIV/AIDS worldwide was estimated to be about 39.5 million during 2006 of which 37.2 million are adults, 17.7 million women, and 2.3 million children. The above estimates the AIDS deaths in 2006 to be a total of 2.9 million. An estimated 24.7 million people in Sub-Saharan Africa live with HIV. Since the discovery of AIDS during 1981, more than 60 million people worldwide have been infected with HIV and it is estimated that about 21.8 million people have died of the disease.



According to the *Department of Health's National HIV and Syphilis Antenatal Sero-Prevalence survey in the Republic of South Africa* (South Africa, 2005) South Africa has recorded one of the highest HIV prevalence rates in the world. This country, with a population of 47 million, contains an estimated 5.54 million South Africans who are HIV-positive. The findings of above survey estimated prevalence rate of 27.9% amongst South Africans.

Of these 5.54 million HIV-positive people, 500 000 are estimated to suffer from Acquired Immunodeficiency Syndrome (AIDS) and are thus in need of ART's. The researcher is of the opinion that these statistics are an indication that everything possible should be done to treat as many people as possible and promote adherence to ART.

The presence of HIV infections is currently concentrated in the developing world, and over two-thirds of all people living with HIV are situated in Sub-Saharan Africa. This region is bearing the brunt of the global HIV/AIDS epidemic. The circumstances with which immuno-suppressed individuals living in resource-poor communities have to contend are different from those who live in affluent communities. In South Africa, HIV/AIDS is as much a political as a social issue. This is apparent from the *Government's Operational Plan for Comprehensive HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment*, which was accepted during November 2003 (South Africa, 2003).

The researcher is of the opinion that the above statistics imply that the AIDS epidemic continues to increase, despite the dramatic advances made in understanding the natural history of the HIV disease and the development of antiretroviral therapies. The aforementioned growth has displayed some disturbing trends. HIV/AIDS morbidity and mortality increasingly impact on the poor, the disenfranchised, and the young. The statistics, in themselves, are an indication for further study regarding the present research topic. Research in the field of HIV/AIDS is exceptionally relevant at present, since we are not only reaching the peak of the risk, but we are also facing new challenges with the availability of ART. The emphasis on adherence to ART further contributes to



the need for research, especially due to the possibility of resistance developing in non-adherent patients.

Over the last few years there has been a rapid change in the treatment strategies used for HIV infection. Numerous new therapies have been introduced since 1996 and the indications for antiretroviral therapy have undergone dramatic changes in recent years. Antiretroviral treatment has moved from mono-therapy to triple drug or combination therapy - highly active antiretroviral therapy (HAART), since it has been found that these drugs are more effective when three or more are taken at the same time (Kasper, Braunwald, Hauser, Longo, Fauci, & Jameson, 2005:1071; Van Dyk, 2004:69).

One of the foremost concerns of ART programmes is the ability of people living with HIV/AIDS to maintain near-perfect adherence in the long term. Both patients and healthcare providers face significant challenges with respect to adherence to ART. In order to achieve the goal of antiretroviral therapy (ART), i.e. undetectable levels of the virus in the blood, patients are required to maintain more than a 90-95% adherence. Once initiated, ART is a lifelong treatment that consists of multiple medications. Inadequate adherence to treatment is associated with detectable viral loads, declining CD4 counts, disease progression, episodes of opportunistic infections and poorer health outcomes (Botes & Levay, 2004:13-20; Friedland, 2003:35-40; WHO, 2003; Van Dyk, 2004: 69; South Africa, 2003a; Ross & Deverell, 2004:10).

Antiretroviral medication only controls HIV virus replication or multiplication. Even when the virus is undetectable in the blood as a result of successful ART, there are some sites in the body where drugs are unable to reach the virus. Therefore, it cannot be completely eradicated from the body and it continues to remain hidden in these sanctuary sites. The virus emerges when ART fails or is discontinued. Since the virus cannot be eradicated, antiretroviral medication has to be taken regularly for the rest of the patient's life.

HIV infection still cannot be cured, but it can be managed. The goal of ART is to achieve the maximum, longest-lasting suppression of virus replication (Botes



& Levay, 2004:13-20; Friedland, 2003:35-40; WHO, 2003; Van Dyk, 2004:65; South Africa, 2003; Horizons, 2004).

One of the multitude of problems the multidisciplinary health team encounters regarding antiretroviral treatment, is the burden of responsibility to ensure that patient adhere to therapy. The researcher has experienced that most of the patients are not aware of the protocol, are symptomatic, often terminal, and they have to use their last degree of strength to obtain ART.

The potential of a patient developing resistance to antiretroviral medication should always be remembered. Resistance is an important reason why many antiretroviral drugs have limited or short-term effects. Whenever HIV is still able to reproduce in someone taking antiretroviral drugs, it is extremely likely that resistant strain will eventually emerge and that the viral load will increase. When patients take their medication irregularly, or when providers prescribe inappropriate doses of combinations of medication, the virus is exposed to inadequate concentrations of antiretroviral medication. This, in turn, leads to ongoing viral replication and to the development of resistance to antiretroviral medication. Such resistance, accounts for a large portion of treatment failures (Friedland, 2003:35-40; WHO, 2003; Van Dyk, 2004:65; Horizons, 2004).

An additional critical problem is the issue of cross-resistance. Once the virus becomes resistant to a particular antiretroviral medication, the virus may also exhibit resistance to other medications of the same class. The second issue stemming from viral resistance is that resistant strains of the virus can be transmitted. This is a major public health problem in resource-limited situations where the choice of medication is already restricted due to high costs and limited availability (Kasper *et al.*, 2005:1071; Horizons, 2004).

The worldwide increase in the prevalence of antiretroviral resistance is of particular concern to researchers and practitioners. Resistance remains one of the most significant threats to the long-term success of any HAART regimen. The multidisciplinary team involved with ART is therefore anxious to learn from past mistakes, translate new knowledge into appropriate treatment strategies,



and develop new drugs that remain useful in the face of established resistance. Further to this, the development of resistance due to poor adherence to the therapy can accelerate, rather than retard, disease progression (Chesney, 1997:2; Friedland, 2003:35).

Many terms have been used during the past century to describe how well patients follow – or do not follow – the advice of doctors, for example defaulters, faithless, untrustworthy, unreliable, non-compliant, concordance etc. The more recent term, “adherence”, is a better alternative because it captures the increasing complexity of medical care by characterising patients as independent, intelligent and autonomous people who take a more active and voluntary role in defining and pursuing goals for their medical treatment. It can be defined as the act or quality of “sticking” with something or “adhering” to something (South Africa, 2003a:4).

The researcher is of the opinion that whatever term emerges as the most popular, the most important issue in ART is ensuring that patients take the drugs as prescribed, at the right time, in the right way, and in the right quantity, because missing a dose, taking the wrong dose, or taking a drug in such a manner that one absorbs too little, may lead to the more rapid development of resistance to the drug. Strict adherence to these multi-drug regimens is essential to obtain the full benefits of the therapy, maintaining suppression of the viral load, and preventing the development of drug resistance (Chesney, 1997:1).

Regarding the issue of compliance, Friedland (2003:39) notes that, “Added to the challenge of more widespread and equitable access to antiretroviral therapy in South Africa and elsewhere, is the issue of adherence to these therapies when they are made available. Clinicians need to develop and employ strategies to support antiretroviral adherence that are practical, relevant and appropriate to the African context.” As suggested above, research has found that adherence greater than 95% is needed to achieve virological suppression (South Africa, 2003a).



The researcher believes that patients need to be educated and screened with regards to the potential development of resistance to antiretroviral drugs, its consequences, and the implications of non-adherence. However, more information regarding the biopsychosocial factors influencing adherence to ART needs to be established by research. This knowledge may be utilised during assessment in order to establish a patient's risk for non-adherence. The service rendered to patients should be adjusted in order to assist the team and the patient in an attempt to achieve maximum adherence. The knowledge obtained from such research could therefore also serve a preventative purpose.

The researcher argues that adherence should be assessed by means of the biopsychosocial model, which recognises the interaction between the medical, behavioural, psychological and emotional dimensions of the patient. The researcher firmly believes that the biopsychosocial model, with its focus on the promotion and maintenance of health by means of socio-environmental and behavioural changes, is an appropriate model that could successfully be used in researching the HIV/AIDS pandemic.

Barker (1991:23) defines the biopsychosocial model as "...a phenomena that consists of biological, psychological and social elements". Kaplan *et al.* (1994:1) assert that the biopsychosocial model of disease, stresses an integrated systems approach to human behaviour and disease. Shannon (1989:35) also notes the importance of social, cultural and economic conditions in health. Furthermore Sherr (1995:69), stresses that the psychosocial functioning of the individual impacts on adherence to antiretroviral therapy. Practitioners are now experiencing the fact that medical treatment is often incomplete, and occasionally, impossible to render, without the accompanying social support and counselling services.

Skidmore, Thackeray & Farley (1994:146), define social work in health care as the application of social work knowledge, skills, attitudes and values in healthcare, where the social worker addresses him/herself to illness, brought about by, or related to, social and environmental stresses that result in failures in social functioning and social relationships. The researcher is of the opinion



that this is applicable to HIV/AIDS, since the disease is closely related to social circumstances and can result in social malfunction. This challenges all social workers in healthcare to establish themselves as essential members of the HIV/AIDS multidisciplinary health team.

The researcher believes that without taking all the dimensions into consideration, it would not be possible to support and treat the HIV/AIDS patient effectively. It is therefore essential to provide all patients with a comprehensive plan to support adherence. It is not possible for health care providers to reliably predict which individuals will ultimately adhere to their treatment plan, since adherence does not correlate with gender, cultural background, language, socio-economic or educational level (South Africa, 2003).

However, Friedland (2003:35-40) states the following: "With regard to patient related characteristics, the literature in the developed world indicates that age and race consistently predict adherence. Older adults are likely to be more adherent, and in the USA, studies have found that the African Americans race and low literacy levels are associated with poorer adherence." Whether this finding will hold in South Africa remains undetermined.

The researcher believes that the issue of adherence to ART is accompanied by various biopsychosocial factors that patients face, and which need to be attended to by the relevant professions. These aspects require a comprehensive service rendered by the multidisciplinary team to enable patients to successfully adhere to treatment (Botes & Levay, 2004:13-20; Friedland, 2003:35-40; WHO, 2003; Van Dyk, 2004:65; South Africa, 2003a).

Factors that have been studied regarding patients' adherence to ART include socio-demographic factors such as gender, ethnicity, age, employment, income, education and literacy; as well as psychosocial factors such as active drug or alcohol use, degree of social support, social stability, depression and other psychiatric illnesses. Patients' knowledge of their medication regimen and their understanding of the relationship between non-adherence and the building-up of resistance to medication, also predict better adherence. A patient's belief



and confidence in the therapy and his/her self-efficacy (confidence in the ability of oneself to adhere), also influences adherence to medication regimens.

Adding to this complex issue, research has also shown that monitoring and support of adherence is essential, because adherence tends to wane as time progresses, and new symptoms and diagnoses also influence compliance. Assessing the patients' biopsychosocial circumstances for adherence to ART treatment is essential to maintain long-term health and to avoid the development of drug resistance (Friedland, 2003:35; Gray, Morris & McIntyre, 2002:5; Roux, 2002:34; South Africa, 2003).

The paradigm employed by the researcher focuses on her belief that all individuals have the right to comprehensive health care and quality of health. She believes that all people must enjoy access to the best service, regardless of their financial status. Reality has shown that it is usually the poor who have no access to treatment, feel worthless and cannot help themselves. This is specifically true in a developing country like South Africa.

Regarding this matter, Cockerham (2001:28) states: "What makes AIDS a disease of society is that it is clearly grounded in the conduct of social life, and its potential for changing norms, values, sex habits and lifestyles worldwide is enormous. Thus AIDS is no ordinary epidemic; it is a lethal illness with far-reaching implications for individuals, families, communities, health care providers, delivery systems and societies around the globe".

The researcher's employer, the *Department of Health confirms, with its Comprehensive Care and Treatment of HIV/AIDS and TB rollout plan for Antiretroviral Treatment* (South Africa, 2003a) confirms that research regarding adherence would be welcomed since it could break new ground in South Africa with regards to the issue of adherence.

Several experts and multidisciplinary team members, Rossouw (2005), clinical Manager, ART clinic, Tshwane District Hospital; Ghood (2005), Medical doctor, Dept of Family Medicine, University of Pretoria; Nkhwashu (2005), Dept. of



Health, HAST unit; Stoltz (2005), Specialist Physician; Brouard (2005), Assistant Director, Centre for the Study of AIDS, University of Pretoria, were all consulted to determine the extent of the problem and thus, the need for this study. These experts all confirmed the researcher's view and are of the opinion that research in the field of adherence to ART in HIV/AIDS patients is needed, specifically with regard to the factors influencing adherence (Strydom, 1998:181).

This particular research will, in the opinion of the researcher, contribute to the *Government's Comprehensive HIV and AIDS Care, Management and Treatment plan*, (South Africa, 2003) especially since Cabinet has instructed the Department of Health to develop a detailed plan on antiretroviral treatment. *The National Government's Comprehensive HIV and AIDS Care, Management and Treatment plan*, which was approved during November 2003 (South Africa, 2003), proposed that not everyone who is HIV-positive needs ART; and the decision as to whether or not to put a patient onto ART should be based on clinical staging (WHO, 2006), CD4 counts, and psychosocial considerations.

In conclusion, the researcher holds the view that adherence to antiretroviral therapy has emerged as one of the most challenging issues in services rendered to HIV/AIDS patients, especially in South Africa. She, in exploring the biopsychosocial circumstances of HIV/AIDS patients on ART, will make recommendations for improved service delivery by means of socio-environmental and behavioural changes in order to address the HIV/AIDS pandemic.

1.2 Problem Formulation

A research problem is defined as a difficulty of which we are aware, and about which something ought to be done (Grinnell, 1993:22; Grinnell & Williams, 1990:58). Fouche (2002a:102) also emphasises that the problem must be researchable and its meaning should have a clear significance and utility for practice. Fouche (2002a:96) states further, there are various sources for the



identification of research problems such as “observation of reality, theory, previous research, curiosity and supervisor”.

The researcher is of the opinion that adherence to antiretroviral therapy has emerged as one of the most important issues regarding the rendering of services to HIV/AIDS patients. “Strict adherence to ARV multi-drug regimens is essential to obtaining the full benefits of therapy, maintaining suppression of viral replication, and preventing the development of drug resistance” (Chesney 1997:1). In South Africa, in particular, screening procedures are fairly new and rely mostly on assumptions. Friedland (2003:37) adds that: “Adherence is a complex clinical behaviour with a wide array of determinants. A useful framework is to consider characteristics of the patient, the provider or clinician, the regimen, the clinical setting and the disease itself”.

Further to this, the development of resistance in patients with poor adherence to treatment can accelerate, rather than retard, the progression of disease. The biopsychosocial circumstances of people inevitably influence adherence and cannot be over-emphasised.

The researcher, within her working environment at the ART clinic at Tshwane District Hospital, is confronted with patients referred for assessment and screening for ART. She has observed the need for more information on and knowledge about the factors and circumstances that may influence patients’ adherence to ART.

With the introduction of ART and the possibility of patients developing resistance and infecting other individuals with the resistant virus, it is necessary to explore the factors and/or circumstances affecting adherence to ART. The burden of education, training and research increasingly falls on the health professionals involved with service delivery to HIV/AIDS patients referred for ART.

Adherence counselling has emerged as an approach in HIV/AIDS counselling. However, little knowledge and information is available regarding this topic,



which, therefore, results in non-effective and conflicting screening methods of patients for ART. More knowledge with regards to the factors influencing HIV/AIDS patients' adherence to ART will clarify circumstances or specific factors that should be considered in assessing patients for ART. This new knowledge could enhance service delivery by means of relevant assessment and screening procedures that are responsive to the needs of patients in order to enhance adherence, and subsequently limit the development of resistance, to ART.

This research problem has been formulated by the researcher as follows: The biopsychosocial factors influencing the HIV/AIDS patient's adherence to ART are unknown. There are insufficient guidelines for assessing and screening the biopsychosocial circumstances of HIV/AIDS patients, as regards antiretroviral therapy, that are practical, relevant and appropriate in the African context. Sufficient guidelines for assessment and screening could lead to enhanced adherence and thus minimise the development of resistance to antiretroviral drugs.

- There is consequently a need to explore the biopsychosocial factors that should be assessed when screening patients for ART.
- There is also a need for universal screening criteria and guidelines, to be employed by the multidisciplinary team specifically related to adherence in receiving ART, from the biopsychosocial perspective.

The proposed study focuses on investigating the biopsychosocial factors related to HIV/AIDS, specifically those that influence adherence to antiretroviral therapy, as experienced and perceived by both the multidisciplinary team involved with the service rendering of ART to HIV/AIDS patients, and the patients themselves. In this respect, "The complexity of factors involved in the disease process calls for comprehensive care, which integrates the patient's physical, psychological and social well-being. Since this kind of care cannot be provided by a single health profession, it brings with it the need for a multidisciplinary approach based on teamwork" (Ross & Deverell, 2004:6).



1.3 Purpose, Goal, and Objectives

1.3.1 Purpose

The *Concise Oxford Dictionary* (1995:1113) defines “purpose” as: “An object to be attained, a thing intended, the intention to act, resolution, determination”.

According to Neuman (2003:28) the purpose of the research can either be descriptive, exploratory, explanatory or a combination thereof. Grinnell & Williams (1990:105) assert that the idea of an exploratory research study is to explore; nothing more and nothing less. Bless & Higson-Smith (1995:20), also state that exploratory research is conducted in order to gain insight into a situation, phenomenon, community or individual. Rubin & Babbie (2001:123), see the purpose of exploratory study as examining a new interest, even if the subject of study is relatively new and unstudied.

The researcher has formulated this study to be exploratory in nature, making use of descriptive measures (Grinnell, 1993:136; Fouche, 2002a:108 and Neuman, 2003:29). The general purpose of this research was to explore and gain insight into the biopsychosocial factors related to adherence to antiretroviral therapy for HIV/AIDS patients, within the South African context, since little is known about this field of study. The said researcher has made recommendations regarding the factors to be considered during the assessment of these patients.

The researcher has thus explored and described the biopsychosocial predicting factors of HIV/AIDS patients that influence adherence to antiretroviral therapy, in order to formulate recommendations for this purpose.

1.3.2 Goal

A "goal" is defined by The Concise Oxford Dictionary (1995:580) as: “The object of a person’s ambition or effort, a destination, an aim.” Fouche (2002b:108), cites Neuman’s view that the goals of research are “...exploratory, descriptive and explanatory”. The specific goal of the present study is to explore the



biopsychosocial factors that influence patient adherence to ART, in order to make recommendations for practical and relevant factors which should be considered in assessing patients for ART.

1.3.3 Objectives

Fouche (2002b:107,109) asserts that being “exploratory, descriptive and explanatory” can be regarded as objectives of professional research and also goes further, explaining that the “goal, purpose or aim” is the dream, while “objectives” are the steps one has to take one by one, realistically at grass-roots level, within a certain time span, in order to attain the dream. “Objective” is defined by the *Concise Oxford Dictionary* (1995:938) as “aimed at, something sought or aimed at”.

The researcher has therefore identified the following objectives for the current study:

- To explore the importance of adherence and the implications of non-adherence, and subsequently, the development of resistance to antiretroviral therapy;
- To explore, and describe the biopsychosocial factors that influence adherence to antiretroviral therapy in patients, as perceived by the multidisciplinary team members actually involved in service delivery to HIV/AIDS patients on anti-retroviral therapy;
- To explore the biopsychosocial factors that influence adherence (negative and positive) to antiretroviral therapy as experienced by HIV/AIDS patients on anti-retroviral therapy; and
- To explore and analyse circumstances to determine whether the predictive generalisation of the theory holds true, and to make recommendations regarding the biopsychosocial factors that are practical, relevant and appropriate in the South African context and that should be considered when screening HIV/AIDS patients for ART.



1.4 Research Questions and hypothesis

The researcher examined a subject (the biopsychosocial factors influencing a patient's adherence to ART) and determined the questions that the study is designed to answer. The said research seeks to answer the basic questions, as identified by Grinnell (1993:25, 45) i.e. what is the researcher trying to determine (the factors), and for what purpose (the recommendations) will the findings be used?

In the current study, the researcher aims to answer the following questions:

- What are the biopsychosocial factors that influence adherence to antiretroviral therapy, as perceived by multidisciplinary team members involved in service delivery to HIV/AIDS patients on antiretroviral therapy?
- What are the existing biopsychosocial circumstances influencing adherence of HIV/AIDS patients already on antiretroviral therapy?
- What influence do the biopsychosocial circumstances of HIV/AIDS patients on antiretroviral therapy have on their adherence and the subsequent development of resistance to antiretroviral therapy?
- How can these identified biopsychosocial factors be utilised in the rendering of services to enhance the adherence of HIV/AIDS patients to antiretroviral therapy in order to minimise the development of resistance?

Kerlinger (1986:17), defines the formulation of the hypothesis as a conjectural statement of the relationship between two variables. The researcher has formulated the following hypothesis for this research :

- The biopsychosocial circumstances of HIV/AIDS will influence adherence to ART.

1.5 Research Approach (Qualitative and Quantitative)

At present there are two well-known and recognised approaches to research, viz. the qualitative and the quantitative paradigms (Fouche & Delpont, 2002:79). In this study, a combination of qualitative and quantitative approaches,



according to Creswell's dominant-less-dominant model will be utilised (De Vos, 2002a:365). According to Fouche (2002c:365), the two approaches are often both employed in one study with one approach being used more than the other, according to the demands of the topic.

The researcher sought various types of sources that could provide insight with regards to the same events or relationships. A combination of the two approaches has led to a greater confidence in the results, because comprehensive and rich data could be gathered. According to this type of triangulation, the researcher presented the study within a single, dominant paradigm (quantitative), with one small component being drawn from the alternative paradigm (qualitative).

One might engage in qualitative observations with a limited number of informants, followed by a quantitative survey of a sample from a population. The advantage of this approach is that it presents a consistent paradigm picture in the study and still gathers limited information to probe, in detail, one aspect of the study (De Vos, 1998:118; Strydom & Delpont, 2002:334; De Vos, 2002b: 366; Grinnell, 1993:159,162; Grinnell & Williams, 1990:22,128; Neuman, 2003:213, 223; Strydom & Venter, 2002:2005).

The researcher utilized a combination of research designs for the current research. A randomised cross-sectional survey; i.e. a quantitative-descriptive one, requiring the selection of respondents by random sampling methods, utilising questionnaires for data collection, was conducted. She added to this the collective case study strategy as a qualitative research strategy, which aims to understand and interpret the meaning that the subjects give to their everyday lives (Fouche, 2002c:273 & Neuman, 2003:142,148).

Data collection methods from both paradigms were employed; i.e. semi-structured interviews with an interview schedule for the qualitative data collection methods, and the questionnaire and documents for quantitative data collection (Bless & Higson-Smith, 1995:113; Delpont, 2002a:172; Greeff, 2000:302, 306-317; Rubin & Rubin, in Mouton, 2003:196; Strydom, 2002b:292).



Various sampling methods were employed. Probability (random) sampling methods were used in the quantitative research, as well as the non-probability sampling (non-random) method, in the qualitative part of the study (Neuman, 2003:211, 223). Sampling techniques of the various sampling methods were utilized; i.e. purposive sampling techniques for the qualitative research and a simple random technique for the quantitative approach. Qualitative (less standardised) and quantitative (standardised) data analysis techniques were employed (De Vos, 2002:341; Neuman, 2003:430).

1.6 Type of Research

The type of study can either be basic or applied. Basic or pure research seeks an understanding of social reality or increases the knowledge base, whereas applied researchers wish to apply and tailor knowledge to address the specific practical issues (Grinnell, 1993:14; Fouche, 2002c:108; Neuman, 2003:21). Fouche (2002c:108), further states: “We see basic and applied research as broad goals of research and exploration, description and explanation as objectives, mainly of basic or knowledge-generating research”.

De Vos, Schurink & Strydom (2001:8) define applied research as follows: “It addresses immediate problems facing the professional in practice. The goal of applied research most often is the scientific planning of induced change in a troublesome situation. Baily (1982:21), concurs with the above definition where the findings can be applied to solve social problems of immediate concern. Applied research covers a wide range of social science areas, including education.

The research questions of the present study fit the description of empirical questions, according to Mouton (2001:153) because they address real life problems. The research is intended to be applied since the aim was to provide improved service delivery. “Applied research, however, is aimed at solving specific policy problems or at helping practitioners accomplish tasks. It is focused on solving problems in practice” (Fouche, 2002c:109; Rubin & Babbie, 1993:79).



The above clearly indicates to the researcher that applied research is found to be relevant because the aim of the current study was to explore the biopsychosocial factors related to ART for AIDS patients and to make recommendations for intervention. This will benefit the comprehensive service delivery to HIV/AIDS patients on ART and promote adherence thereto.

The present study, therefore, is applied in nature, since its primary task was to stimulate thought and action about the challenges faced by patients on ART. The knowledge generated from the findings was aimed at changing adherence counselling in South Africa, since it was aimed at improving adherence and sets out to solve practical problems in social welfare (Grinnell, 1993:15; Fouche, 2002c:108; Neuman, 2003:21).

The findings of the said study realise the goal, since it was geared towards the improvement of adherence in HIV/AIDS patients to ART. By unearthing the biopsychosocial factors influencing adherence and addressing the screening criteria for ART, the research could possibly lead to enhanced adherence.

1.7 Research Design and Methodology

Whereas a research design is a plan or a blueprint of how the research is to be conducted (Grinnell, 1993:45 & Mouton, 2003:45), research methodology refers to the systematic methodological and accurate execution of the design (Fouche & Delport, 2002:79). In the present study, both quantitative and qualitative research designs were used.

In line with the literature, the researcher believes that a research design is a form of planning required before a research project is undertaken. This implies that this planning will guide the process from the beginning to the end. Rubin & Babbie, as cited by Fouche & De Vos (2002:138), define design as a set of logical arrangements to be selected, and they take the stand that research design should only refer to those groups of small, worked-out formulas from which prospective (quantitatively orientated) researchers can select. In qualitative research literature the preferred term is strategy.

The researcher would like to illustrate this research process, according to Fouche & Delpont's (2002:85) proposed steps:

Table 1: Illustrated research process

Type of research: Applied		
	Qualitative	Quantitative
Approach	Creswell's: dominant-less-dominant design/Triangulation Qualitative – (Less-dominant)	Quantitative (Dominant)
Design/strategy	Case study Collective case study	Quantitative-descriptive (survey) design Randomised cross-sectional survey
Respondents	Multidisciplinary team (20)	Patients on ART (200)
Data collection	Semi-structured interview Interview Schedule Documents	Questionnaires Personal questionnaires
Sampling Type/method/	Non probability sampling	Probability random sampling
Sampling technique	Purposive	Simple random
Data analysis technique	Themes, Sub themes Meanings	Figures, tables

1.7.1 Research Design

1.7.1.1 Quantitative research design

Fouche & De Vos (2002:138), describe quantitative research designs as falling into two broad categories, viz. experiments and surveys, and provide the following examples:

- Pre-experimental/hypothesis-developing/exploratory design;
- Quantitative-descriptive (survey) designs;
- Quasi-experimental/associative designs; and
- True experimental/cause-effect/explanatory design.



The researcher found the quantitative-descriptive (survey) design relevant to the current study, because, by means of this type of research design, and by utilising a questionnaire, she was able to unearth the knowledge, perceptions, feelings and attitudes of the research participants regarding factors influencing adherence. Fouche & De Vos (2002:148) point out that the purpose of this design is typical when a researcher examines a new interest and the subject of study is relatively new and unstudied.

1.7.1.2 Qualitative Research Design

Denzin & Lincoln (1994:202-208) prefer to term methodologies such as ethnography, phenomenology and the biographical method, “strategies of enquiry or tools that can be used to design qualitative research”. A research design in a qualitative study is tentative and open to change (Fouche, 2002c:122).

Fouche (2002c:272) further identifies the strategies of inquiry that could be employed to design qualitative research as biography, phenomenology, grounded theory, ethnography and case study.

The qualitative research strategy employed in the current study is the case study. A case study, as a qualitative research strategy, aims to attain an in-depth description of a case, or cases, within its larger context, with the focus remaining on the issue being illustrated (Fouche, 2002a:275).

The researcher employed collective case studies, where multiple cases were explored and analysed. Where multiple cases are involved, the research is referred to as a collective case study (Fouche, 2002a:275). The researcher wishes to understand a certain issue (i.e. factors influencing adherence) and according to Fourie (2002a:277), “The collective case study furthers the understanding of the researcher about a social issue or population being studied. The interest in the individual case is secondary to the researcher’s interest in a group of cases”. Fouche (2002a:275), describes the case study further: “The exploration and description of the case take place through



detailed, in-depth data collection methods, involving multiple sources of information that are rich in context. These can include interviews, documents, observations or archival records. Cases are selected so that comparisons can be made between cases and concepts, and theories can be extended and validated.”

1.7.2 Data Collection Methods

The researcher collected data from respondents or research subjects selected from the ART Clinics of the Tshwane/Metsweding Region of the Gauteng Department of Health.

Both quantitative and qualitative data collection methods and techniques were employed. The instruments utilised for data collection were tested for validity and reliability (De Vos, Fouche & Venter, 2002:242,361; Delpont, 2002a:166).

1.7.2.1 Quantitative Data Collection Methods

The selection of data collection methods for a quantitative approach, as categorised by Delpont (2002a:171), can include questionnaires, checklists, indexes and scales. In the current study, questionnaires were utilised as the method for the collection of the quantitative data. According to Fouche & De Vos (2002:142), a survey design requires utilisation of questionnaires as a data collection method, and respondents are selected by means of the simple random sampling method.

In the present study, the questionnaires, delivered by hand in order to gather information, and administered by the present researcher, were given to 201 respondents already on ART.

1.7.2.2 Qualitative Data Collection Methods

Fouche (2002b:275) defines data collection for the case study as a method used in qualitative studies as “...detailed in-depth data collection methods, involving multiple sources of information that are rich in context. These can



include interviews, documents, observations or archival records. As such the researcher needs access to, and the confidence of, the participants.”

The researcher used the semi-structured, one-on-one interview with an interview schedule in this research as a method of data collection. She interviewed a total of 20 members from the multidisciplinary team who were actively involved in service-rendering to ART patients. The participants were perceived to be experts in the field of ART and therefore, afforded maximum opportunity to provide input. The interviews were recorded and transcribed. As has been pointed out, “Semi-structured interviews are especially suitable where one is particularly interested in complexity or process, or where an issue is controversial or personal.” (Bless & Higson-Smith, 1995:113; Delpont, 2002:172; Greeff, 2002:302, 306-317; Rubin & Rubin in Mouton, 2003:196; Strydom, 2002b:292)

The interview schedule is defined by Greeff (2002:302) as: “A questionnaire written to guide interviews.” Such a schedule provided the researcher with a set of predetermined questions.

The researcher also utilised document study as a method of data collection. According to Strydom & Delpont (2002:321), document study is often neglected in research. Official documents imply that documents are compiled and maintained on a continuous basis by large organisations such as government institutions.

The said researcher reviewed documents, which indicate bio-chemical results of the patients, such as CD 4 counts and viral loads, on the initiation of ART. The records could then be compared to the CD 4 count and viral loads at follow-up visits, since this is usually a good indication of adherence, and may also indicate the effects of alcohol or drug abuse.



1.7.3 Methods of Data Analysis

Data analysis refers to the manner in which data will be analysed and the statistical procedures employed (Grinnell & Williams, 1990:275). The analysis of data is intended to reduce the collection of data to simple and more understandable terms without distorting or losing too much of the valuable information collected (De Vos, 2002c:340-346; Mouton, 2001:108,110; and Neuman, 2003:430).

In this regard De Vos, Fouche & Venter (2002:222) state: “One reason is that, in a well-designed research study, the question of what to do with the data was anticipated and the analysis planned well before the data were collected.” The present researcher has adhered to this method.

1.7.3.1 Quantitative Data Analysis

Basically, data analysis (in the quantitative paradigm) requires that the analyst breaks the data down into constituent parts in order to obtain answers to research questions and test research hypotheses (De Vos, Fouche & Venter, 2002:223).

Quantitative data analysis involves the data collection process, complemented by the use of computer software, after it has been collected. Processing, with a view to quantification, is an important procedure in the data analysis (De Vos, Fouche & Venter, 2002:224). The researcher constructed the questionnaire so that it could be processed by computer in numerical form, with the help of the Department of Statistics at the University of Pretoria.

1.7.3.2 Qualitative data analysis

Data analysis is the process of bringing order, structure and meaning to the mass of collected data. Qualitative data analysis and interpretation was carried out by means of the identification of themes, recurring ideas and patterns or beliefs, and was interpreted to demonstrate credibility (De Vos, 2002c:354).



The steps in qualitative data analysis are not as linear as they appear, but are outlined as such for the purpose of the current study. The present researcher employed reasoning in order to reach conclusions based on evidence collected (De Vos, 2002c:341; Neuman, 2003:430). She followed the process of analysing data qualitatively as described by Creswell and presented by De Vos (2002c:340), which comprises the following aspects:

Collecting and recording Data

In conducting data analysis during data collection, the researcher utilised triangulation, and sought different sources that could provide insight regarding the data. The triangulation method means mingling qualitative and quantitative styles of research in data collection and the recording of data in order to keep it intact, complete, organised and accessible. She kept records of interview notes and recordings of interviews according to themes, e.g. bio-themes, psycho-themes and social-themes.

Managing the data

The researcher managed the data obtained from the interview schedule by organising files and notes and also making use of computer programmes so that it was easily retrievable. She evaluated the merits of the transcribed interviews and determined whether the data was authentic, valid, true, worthy, manageable, and of value for the research currently being undertaken.

Reading, writing memos

After the collection of the transcribed data, the data were studied to enable the researcher to become familiar with the content as a whole, prior to categorising it in order to identify similarities that may exist in the various categories. She kept memos of the different themes uncovered.

Describing, classifying and interpreting

De Vos (2002c:344) states that, in this regard, classifying means taking the text or qualitative information apart and searching for categories, themes or dimensions of information. The researcher sought explanations and identified similarities from the views of the various multidisciplinary team members and



compared them before describing the data. She also interpreted the data in order to accord meaning to it before they were analysed and conclusions were drawn.

The said researcher employed descriptive statistical analyses for the purposes of summarising, describing and analysing major characteristics of the collected data.

Representing, visualizing

The researcher presented data in text, tabular and figure form, thus creating a visual image of the information, making use of the Department of Statistics, University of Pretoria.

1.8 Pilot Study

The author holds to the usual definition of a pilot study as a study conducted on a small scale prior to a large piece of research, with the intention of determining whether the methodology, sampling instruments and analyses are adequate and appropriate. Such a study is performed in order to determine the feasibility of conducting the main study (Strydom, 2002c:202, 11). A pilot study is defined by the *New Dictionary of Social Work* (1995:45) as the “process whereby the research design for a prospective survey is tested”.

The pilot study commences with a literature study, which places the experiences of various experts on the table, together with an overview of the actual, practical situation where the prospective investigation will be executed, as well as an intensive study of strategic units, which will allow for feedback from the respondents. Strydom (2002c:210-214) adds that the pilot study is one way in which the prospective researcher can orientate him/herself to the project in mind.

1.8.1 Feasibility of the Study

One of the major reasons for sampling is to sustain feasibility, as stated by Strydom & Venter (2002:199). The researcher is of the opinion that the current



research is feasible, taking into account that she has conducted previous research in this field and thus knows the nature and extent of the problem. Since the said researcher is employed by The Department of Health, ART clinic at Tshwane District Hospital, the current study is within the scope of her work.

Furthermore, the said researcher holds the view that the following contributed to the feasibility of the study:

- Consultation with experts and the pilot project provided her with an indication as to whether or not the study was feasible.
- She obtained support from the following key role players: South African Council for Social Services Professions (SACSSP), National Health, Gauteng Province (HIV/AIDS STD & TB Program), the Centre for the study of AIDS, University of Pretoria and the CEO's of the various hospitals involved in the research.

The said author conducted an in-depth literature review regarding this topic, and has consulted good introductory textbooks, studied journals and research reports, conducted literature searches, consulted various resources on the internet, and attended the 2005 AIDS Conference in Durban.

1.8.2 Testing the Data Collection Instruments

Bless & Higson-Smith (1995:50) maintain that pilot testing of the data collection instrument enables the researcher "to identify any difficulty with the method or materials and to investigate the accuracy and appropriateness of any instruments that has been developed". Strydom & Delpont (2002:216) support this, by asserting that thoroughly pilot-tested questionnaires ensure that errors are rectified immediately at little cost and that necessary modifications are made before the questionnaire is presented to the full sample.

- For the purpose of the present quantitative study, questionnaires were administered to the respondents. In the pilot phase, these were administered



to two respondents who were not part of the main study. Modifications were made for the main investigation.

- Since the researcher conducted semi-structured interviews guided by an interview schedule as a data gathering method for the qualitative part of the current study, the interview schedule was also administered during the semi-structured interview to two respondents of the multidisciplinary team at the comprehensive ART clinic of the Pretoria Academic Hospital prior to the actual study. This was performed in order to test whether the constructed interview schedule yielded the expected information.
- This was executed very carefully exactly according to the plan for the main investigation in order to identify possible deficiencies. Feedback was requested from the respondents and they were asked to evaluate the interview schedule so that the author could effect the required changes prior to the full-scale study (Bless & Higson-Smith, 1995:43).

None of the participants who participated in the pilot project were included in the main study. Their views and opinions on the methods used were obtained and changes were made (Strydom, 2002c:215). The present researcher acknowledges that the testing of the interview schedule and questionnaire is important.

1.9 Research Populations, Sample and Sampling Methods

1.9.1 Research Population

Seaberg in Strydom & Venter (2002:199) describes a population as the total set from which the individuals or units of the study are selected. The population sets boundaries on the study units. The population in the present study comprises the multidisciplinary team, who are viewed as experts regarding ART, are practising and have experience regarding adherence and/or non-adherence to ART. These are the specific characteristics on which the researcher focused for the qualitative part of the current study. Further to this, the population consisted of HIV/AIDS patients older than 18 years, referred to Tshwane District Hospital for ART. All the HIV/AIDS patients in South Africa on



ART constitute the universe of the current study. In this context, "universe" refers to all potential subjects who possess the attributes in which the researcher is interested (Strydom & De Vos, 2002:198).

1.9.2 Delimitation of Sample

This study was conducted in Pretoria, in the Tshwane/Metsweding regional ART sites of the Gauteng Provincial Government, during October and November 2005. The focus of the research fell on the ART clinic of the Tshwane District Hospital, which forms part of the Comprehensive HIV/AIDS Treatment Clinic of the Gauteng Provincial Government.

The respondents had all been referred to the Clinic for antiretroviral therapy and were therefore already in the AIDS phase, mostly with a CD 4 count of <200 and in Stage 3 or 4 (WHO, 2004) of the disease. Most patients were already severely immuno-suppressed. The researcher also interviewed respondents from the multidisciplinary team, who are viewed as experts in ART, and purposively selected according to their involvement in ART.

1.9.3 Research Sample, Sampling Method and Procedures

The researcher believes that a complete coverage of the total population is seldom possible since all the members of a population of interest cannot possibly be reached. Sampling may, therefore, result in more accurate information than might have been obtained if one had studied the entire population. It is usually not possible to study the entire population, or the universe, for that matter (Arkava & Lane, 1983:157 in Strydom & Venter, 2002:199). This fact, therefore, compels the researcher to consider the use of a sample as a means of studying only units (a portion of the population) that represent the entire set from which a sample is drawn, and also, to understand that particular set (Grinnell, 1993:154; Strydom & Venter, 2002:199).

Various authors describe probability and non-probability as the two major groups of the sampling procedures. The researcher was aware that the concept of sampling is one of the most important considerations in the total



research endeavour; since it possesses elements of the actual population considered for inclusion in the study. A combination of both sampling procedures was followed in the current study. The researcher divided the population into two main sectors, i.e. patients on ART and the multidisciplinary team members.

1.9.3.1 Quantitative Sampling

Selection of participants (patients refer for ART) to complete the questionnaire. The present researcher employed probability sampling to select a total of 201 participants to complete the questionnaire, and particularly, the simple random sampling technique. Random sampling refers to drawing a sample of a population so that each member of the population has an equal chance of being selected. (Strydom & Venter, 2002:197).

The list of the file numbers of patients attending the ARV clinic represented approximately 2000 patients. The present researcher decided on a sample size of 201. Strydom, (2002c:197) maintains the following regarding drawing of a random sample: "As mentioned above some methodologists suggest that drawing a 10% sample of a known population has become convention which serves as a handy rule of some". The researcher decided on 201 (10%) of the total population of 2 000 registered ART patients at the time of the research.

She selected participants at the ART clinic where she is employed. Each participant was numbered. She then selected every tenth person on the list to participate in the study, until the desired sample size was reached; these participants completed the questionnaire.

1.9.3.2 Qualitative Sampling

For inclusion of respondents in the qualitative part of the current study, the present researcher utilised the non-probability sampling technique (Strydom & Venter, 2002:201).



A sample of 20 multidisciplinary team members was drawn from the population using the purposive sampling technique. This technique is defined by Strydom & Venter (2002:207) as “a sample composed of elements that contain the most characteristic, representative or typical attributes of the population”.

The criteria for the selection of this sample were:

- Multidisciplinary team members, male or female, any race;
- Professional as well as non-professional individuals (medical doctors, professional nurses, social workers, dieticians, pharmacists, lay counsellors); and
- Individuals actively involved in rendering services to HIV/AIDS patients, particularly for ART, for at least one year or are perceived as experts due to their contribution to this field of study (i.e. published authors, academics, policy writers). The team members could include individuals from the private sector, as well as the public sector.

According to Creswell in Strydom & Delpont (2002:334); Grinnell (1993:162); Grinnell & Williams (1990:128), as well as Neuman (2003:213), the above refers to the purposive selection of participants where the researcher determines a clear rationale for her decision and seeks to obtain rich information from the participants. This approach will ensure that in-depth information on the subject is obtained, since the multidisciplinary team members are knowledgeable and have experience in the area of study.

The selection of experts is illustrated in table 2.

Table 2: Multidisciplinary team members purposively selected for interview

National Department of Health- HAST Directorate	1
Gauteng Health- HAST program	1
Gauteng Health- HAST programme ART sites:	
Social Worker:	
Kalafong Hospital	1
Laudium Clinic	1
Soshanguve Clinic	1
George Mukari Hospital (SW)	1
Mamelodi Hospital	1
Pharmacist	2
Dietician Pretoria Academic Hospital	1
Professional nurse	1
Medical doctors	2
Adherence lay counselors	4
NGO's	1
Academic Institution: University of Pretoria	1
Foundation for Professional Development	1
Total	20

1.10 Ethical Aspects

The ethical guidelines for research have been designed in order to help protect the interests of participants. Extensive literature reviews discuss ethical considerations in research (Grinnell, 1993:304; Grinnell & Williams, 1990:304; Mouton, 2003:245-246; Neuman, 2003:120-127; Strydom, 2002a:63-64).

The researcher is aware of her responsibility to ensure that this study meets all the ethical requirements, and is of the opinion that ethical issues are of the utmost importance in research. She is further aware of the fact that, in researching HIV/AIDS issues, where human behaviour, stigmatisation and disclosure of certain behaviours play a role (specifically sexual behaviour), the respondents can easily feel threatened.



The screening of patients for antiretroviral treatment is itself an ethical issue because, if a patient is denied ART, this person will inevitably die of AIDS. On the other hand, prescribing ART irresponsibly can contribute to the development of a resistant virus (a threat to the community at large), and this is also an ethical aspect to be taken into consideration.

The researcher found the following ethical issues to be relevant to this study:

1.10.1 Consequences for Human Beings. Harm to Experimental Subjects and/or Respondents

The researcher is aware of the fact that she has an ethical obligation to protect respondents against any form of discomfort in extracting sensitive and personal information from subjects, unless such information is crucial for the purposes of the present research. The researcher was further aware of the fact that circumstances linked to their possible HIV transmission may be recalled to memory by respondents during the investigation and that it could be the beginning of renewed emotional harm. Bailey (1994:472) assert: "in some cases negative effects of a more negative nature than the anticipated harm of the research project exist in respondents' everyday, natural situation. In these cases it is surely justified that respondents suffer a certain degree of discomfort in order to eventually better circumstances" (Grinnell, 1993:304; Mouton, 2003:245-246; Neuman, 2003:120-123; Strydom, 2002a:63-64).

The researcher concurs with Strydom (2002a:63-64), who states the following regarding this matter: "We take the firm stance in this book that a researcher is ethically obliged to change the nature of his research rather than expose his respondents to the faintest possibility of physical and/or emotional harm of which he may be aware". The writer was aware of the fact that negative behaviour in the past, e.g. stigmatisation, promiscuity, rape, abuse and infidelity, might be recalled during this specific investigation and could initiate renewed personal trauma or embarrassment in the respondents. The researcher did not include sensitive matters, such as probing into who and how respondents contracted HIV. Only questions crucial to answer the research



questions were included in the questionnaires. Potential respondents, who were vulnerable, such as terminally ill patients, were eliminated from the study beforehand.

The researcher explained the anticipated consequences of her research to the participants by means of the letter of informed consent. Possible risks or harm that could emanate from participation in the research were disclosed by her; for example, renewed emotions. This was handled with great sensitivity. If counselling was needed, the participants were referred to an appropriate team member to address his/her needs.

1.10.2 Informed Consent Voluntary Participation

The researcher obtained written, informed consent from each respondent. The content was also discussed personally with each respondent, particularly, illiterate respondents. At every ART site, lay counsellors, specifically trained in ART matters and who are members of the multidisciplinary adherence team were called upon by the researcher, to interpret when necessary. This implied that the respondents had adequate information with regards to the goal of the investigation and the subsequent procedures. The possible advantages and disadvantages of the current study were discussed with the respondents.

The respondents were thoroughly informed regarding the potential impact of the investigation, beforehand. Each respondent received an information leaflet together with an informed consent form. A signed copy was handed to the patient and a copy was kept by the researcher. The researcher was aware of all the above ethical issues. In particular, the fact that respondents might have felt obliged to participate in this research, since they need antiretroviral therapy, was discussed and handled with the necessary honesty and sensitivity. Participants were likewise informed of their right to refuse to participate in this research study and also that they could withdraw at any time, as their participation was entirely voluntary (Grinnell, 1993:82-84; Mouton, 2003:245-243; Neuman, 2003:124; Strydom, 2002a:65-66).



1.10.3 Deception of Subjects and/or Respondents

The researcher was aware of the danger of deliberately misrepresenting facts such as withholding information, or offering incorrect information in order to ensure participation of subjects, when they would otherwise, possibly, have refused participation. Strydom's (2002a:67) view regarding deception of subjects is that: "...no form of deception should ever be inflicted on respondents. If this happens inadvertently, it must be rectified immediately after or during the debriefing interview". The said researcher is the social worker at the clinic and is thus part of a multidisciplinary team that monitors the patients. No deception of any form was inflicted on any respondents.

1.10.4 Confidentiality and Violation of Privacy

The researcher has not disclosed any information concerning the respondents, since she was aware of the importance of safeguarding their privacy and identity. Furthermore, she firmly believes in the individual's right to self-determination, regardless of age, cultural or economic status. According to Strydom (2002a:67), privacy implies the element of personal privacy, while confidentiality indicates the handling of information in a confidential manner. Singleton, as quoted by Strydom (2002a:67), argues that sexual behaviour and illegal activities are two areas, which almost everyone will consider private.

Stigmatisation and the issues of confidentiality have always characterised HIV/AIDS issues, and this was taken into account with regards to the family life, relationships, and employment situations of the respondents. Doing research in the field of HIV/AIDS almost always implies questions concerning the sexual behaviour of patients. Questionnaires were therefore anonymously completed by respondents and were personally distributed by the said researcher. A copy of the signed consent forms were given to each respondent and the original was kept by researcher in a file, with the other confidential information of the patients. The completed questionnaires were numbered and stored in sealed boxes at the residence of the researcher for analysing purpose. The data will be stored for 10 years as prescribed by the University of Pretoria. (Grinnell, 1993:82-87; Mouton, 2003:245-243; Neuman, 2003:127; Strydom, 2002a:68).



1.10.5 Action and Competence of Researcher

The researcher is of the opinion that she is competent and adequately skilled to undertake this sensitive research. She has 20 years of experience dealing with confidentiality issues regarding HIV/AIDS, is knowledgeable regarding the subject of research and has completed a similar research study for her Master's degree.

1.10.6 Cooperation with contribution credit for endeavors

The said researcher has not involved any sponsors for the current research. She has received a bursary from the University of Pretoria and is only bound by the standards of the University of Pretoria's Ethical Committee, as well as the standards of Tshwane District Hospital and the Department of Health, her employer, with regards to the current research.

The necessary protocols were followed and acknowledgement has been given for the contribution of each participant (Strydom, 2002:71; Grinnell, 1993:88).

1.10.7 Release or Publication of the Findings. Reporting and Analysis of Data

A further ethical issue, as discussed by Strydom (2002a:69), and one that the researcher took into account, concerns the correct reporting of the analysis of data and the results of the present study. "Apart from the normal situation in qualitative research, the onus is also on the researcher to deal ethically not only with the research results, but also with the therapy" (Strydom, 2002a:69).

Since the current research was also conducted across cultural boundaries, the researcher respected the cultural values, norms and customs of the respondents. Regarding the above, Strydom (2002a:70) also contributes the following: "No value judgments are to be made, under any circumstances whatsoever, on the cultural aspects of communities".

The said researcher has, as far as possible, formulated the information accurately and objectively in the present research report, which includes the



shortcomings of this research. She is aware of the necessity of avoiding plagiarism and acknowledgement is given to all sources consulted as well as to the people with whom she had collaborated. Regarding this ethical issue, Strydom quotes Babbie (1988:73), who states that "...closely related to altering the results are the incorporation of someone else's work into your own without proper acknowledgement".

The present researcher has also been granted ethical clearance by the Ethical Committees of the Faculty of Health Sciences and the Faculty of Humanities, University of Pretoria.

1.10.8 Debriefing of Subjects or Respondents

The respondents continue to be supported and monitored following the study. The respondents will be debriefed by the researcher if needed. If further counselling is indicated the researcher will refer the respondents for counselling.

1.11 Limitations of the Study

The elaborate bureaucracy, with which the present researcher had to deal prior to commencing the current research, was very time consuming. This included obtaining permission from the Department of Health, clearance from two different ethics committees, one from the University of Pretoria, Faculty of Health Sciences and the other, from the Faculty of Humanities, regarding ethical matters; they each had different expectations.

Various expectations stemming from the Department of Social Work and Criminology prior to even beginning the research, such as: oral exams regarding the research methodology, a research forum and a doctoral seminar, made the period of study very lengthy.

The submission of a lengthy research report, when the submission of the research findings, by means of an article published in a scientific journal, seems to be more appropriate.



The fact that the Department of Statistics, University of Pretoria, which processed and analysed data, had different expectations to those of the Department of Social Work and Criminology, was also time-consuming and thus, required discussions between the role players.

All electronic devices, a personal computer and a dictaphone were lost during a theft at Tshwane District hospital. The researcher lost almost all the literature study data gathered and had to start from scratch again with the literature study. No confidential data were stored on the computer that was stolen only literatures study. Thus patient confidentiality and privacy was not compromised.

Further limitations that the said researcher experienced were related to the fact that HIV/AIDS issues, and particularly, antiretroviral matters, are so dynamic and controversial, with daily changes and constant reports of new research, that data needed to be updated regularly.

Conducting the present research, specifically the qualitative part, was very time-consuming. In retrospect, the said researcher should have utilized focus groups in order to gather information for this part of the study.

1.12 Definition of Key Concepts

The following key concepts are defined for better understanding of the text:

1.12.1 Adherence

“Adherence, the quality of yielding to pressure or force without disruption. An expression of the ability to yield to pressure without disruption” (*Dorland’s Illustrated Medical Dictionary*, 1994:388).

Adherence is also defined as the act or quality of sticking to something, or to adhere to something. Adhere - to behave according to, follow in detail, faithfully observing a rule (*The Concise Oxford Dictionary*, 1995:272).



The researcher is of the opinion that both compliance and adherence refer to the act of “sticking to” a treatment regimen since it captures the increasing complexity of medical care by characterising patients as independent, intelligent, and autonomous people who take more active and voluntary roles in the decisions regarding their treatment.

1.12.2 Anti Retroviral Therapy (ART)/Highly Affective Antiretroviral Therapy (HAART)

Combination antiretroviral therapy (Kasper, *et.al.*, 2005:1124) is defined as “or HAART, is the cornerstone of management of patients with HIV infections” (Kasper, *et.al.*, 2001:1899). The present researcher defines antiretroviral therapy and HAART as the use of several antiretroviral drugs (combination of drugs) for the treatment of HIV/AIDS.

1.12.3 Antiretroviral (ARV)

“An agent with the quality of being effective against retroviruses” (Mosby Pocket Dictionary of Medicine, Nursing & Health Professions, 2006, 97).

1.12.4 Biopsychosocial

“A phenomenon that consists of biological, psychological and social elements, a term applied to phenomena that consist of biological, psychological and social elements”. (Barker, 1991:23) “The bio-psychosocial model of disease stresses an integrated systems approach to human behaviour and disease”. (Kaplan, *et al.*, 1994:1)

The current researcher believes in a holistic approach to healthcare management, which the term “biopsychosocial” encompasses, that is the patient’s medical-, psychological- emotional-, and social (behaviour, relationships, support systems and environment) functioning, in order to provide a comprehensive service.



1.12.4 Compliance

“Compliance is the act of conforming. Compliance, the act or an instance of complying, obedience to a request, command” (*Dorland’s Illustrated Medical Dictionary*, 1994:388).

The term "adherence" is preferable to "compliance", since compliance implies that some prompting is necessary to ensure that the medication is taken, whereas adherence is voluntarily driven by the individual.

1.12.5 Concordance

Concordance is based on the notion that the work of prescriber and patient in the consultation is a negotiation between equals and that therefore the aim is a therapeutic alliance between them. Its strength lies in a new assumption of respect for the patient’s agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust or concealment. It is promoting power sharing between provider and patient and in respecting the patients’ perspective (Rier & Indyk, 2006:137).

1.12.6 Counselling

Counselling is defined in the *New Dictionary of Social Work* (1995:15) as comprising “interviewing procedures aimed at guiding the client towards insight, with a view of promoting his social functioning”.

In the *Dictionary of Counselling* (1994:63), counselling is similarly defined as a “helping process in which one person, a helper, facilitates exploration, understanding and actions about developmental opportunities and problem conditions presented by a helper or client”.



1.12.7 Counsellors

1.12.7.1 Registered professional or trained counsellors

Registered counsellors are psychological workers who perform psychological screening and basic assessment and technically limited psychological interventions with a range of people, aiming at enhancing personal functioning in a variety of contexts including school, work sport and community. Registration as a Registered Counsellor is contingent on completion of: An accredited 4 year B Psych or Honours degree in Psychology accredited by the Board as equivalent to the B Psych degree and an approved 6 month's practicum in the designated practice area. The required practicum included in the B Psych must be done under supervision of a registered Psychologist according to criteria set by the Professional Board. (*Health Professions Council of South Africa (HPCSA): Professional Board for Psychology: Framework for Education, Training and Registration as a Registered Counsellor*)

1.12.7.2 Lay counsellors

Lay counsellors in ARV are defined as voluntary workers who do basic assessments and limited interventions with a range of people aiming at enhancing their bio-psychosocial functioning in a variety of contexts including the realm of HIV/AIDS: VCT, PMTCT, HIV pre-test, HIV post-test and adherence to ARV counselling. Such counsellors receive in-service training to conduct such services (Dept of Health, South Africa: 2003).

1.12.8 HIV/AIDS

"Human immunodeficiency virus". (*Dorland's Illustrated Medical Dictionary*, 1994:826) AIDS: any HIV-infected individual with a CD4+T cell count of <200/ μ L has AIDS by definition, regardless of the presence of symptoms or opportunistic disease" (Kaplan, *et al.*, 2001:1852).



1.12.9 Multidisciplinary Team

“A multidisciplinary health team can be defined as a team whose members represent the widest possible spectrum of individuals and organisations concerned with, or involved in, any aspect that has a bearing on the health and welfare of the community, in an attempt to provide effective, comprehensive health care that will assist in the achievement of optimal health for all people” (Dennill et al., 1995:111).

The WHO (2005) defines the multidisciplinary health team as: “A group of people who share a common health goal and common objectives, determined by community needs, to the achievement of which each member of the team contributes, in accordance with his or her competence and skills, and in coordination with the functions of others.”

The researcher is of the opinion that multidisciplinary teamwork in healthcare is the delivery of critical, comprehensive interventions, to the individuals, families, groups and/or communities, who are related or affected by illness. The aim of the team intervention is to provide a holistic approach that could ultimately improve social functioning and quality-of-life in general, including prevention of illness and promotion of health by means of education. By acknowledging the physical, mental, emotional, social, economical, cultural and spiritual dimensions of human life, the members of the multidisciplinary team in healthcare are all role players, who, according to their knowledge, contribute to a patient’s holistic medical care.

1.12.10 Screening

“A system of checking for the presence or absence of a disease, ability, attribute; check on (a person) for the presence or absence of a quality, esp. reliability or loyalty” (*The Concise Oxford Dictionary*, 9th Edition.1995, 1995:1241)
Social Work profession.



1.13. Contents of the Research Report following this Chapter

Table 3: Contents of research report

Chapter	Contents
Chapter 2	Medical aspects of HIV/AIDS
Chapter 3	Antiretroviral therapy
Chapter 4	Resistance and the role of adherence to antiretroviral therapy
Chapter 5	The social workers role in assessing the HIV/AIDS patient for anti-retroviral therapy utilising the biopsychosocial model
Chapter 6	Empirical findings (qualitative) Empirical findings (quantitative)
Chapter 7	Summary, conclusions and recommendations



CHAPTER 2: CLINICAL ASPECTS OF HIV/AIDS

2.1 Introduction

Despite the dramatic advances made in understanding the natural history of HIV and the development of effective antiretroviral therapies, the AIDS epidemic continues to spread. This growth has displayed some disturbing trends. HIV/AIDS morbidity and mortality increasingly affect the poor, the disenfranchised, and the young.

The Joint United Nations Programme Report on the HIV/AIDS Epidemic for 2006 (UNAIDS, 2006), estimated the number of people living with HIV/AIDS worldwide at about 39.5 million during 2006; of which 25 million live in sub-Saharan Africa. It further estimated the number of AIDS deaths in 2006 at a total of 2.9 million.

As noted previously, in South Africa, with a population of 47,7 million, the *National HIV and Syphilis Antenatal Sero-Prevalence survey in South Africa* (South Africa, 2005), conducted by the Department of Health, estimated that approximately 5.54 million South Africans were HIV-positive. Women are traditionally over-represented in these groups, as portrayed by the abovementioned survey. The researcher is of the opinion that unless we empower people, and more specifically women, this destructive disease will not be conquered. Of these 5.54 million HIV positive people, 500 000 are estimated to have contracted AIDS and are thus in need of ART's. The said researcher is further of the view that these statistics are an indication of why everything feasible should be done to treat as many people as possible and promote adherence to ART.

Although infection with HIV/AIDS is incurable at present, AIDS is considered to be a manageable chronic disease. Friedland (2003:35) argues that the treatment of patients with HIV infection requires not only a comprehensive



knowledge of the possible disease processes that may occur, but also, the ability to deal with the problems of a chronic, potentially life-threatening illness. Great advances have been made in the treatment of patients with HIV Infection. The appropriate use of a potent combination of highly active antiretroviral therapy (HAART), as well as prophylactic interventions, e.g. giving antiretroviral medications to prevent mother-to-child transmission, occupational injuries, and victims of sexual assault, is of critical importance in providing each patient with the best opportunity to live a long and healthy life despite the presence of HIV infection (Isselbacher, *et al.*, 1999:1853; Van Dyk, 1993:4-16).

In addition to the above, the patients must be educated regarding the importance of adherence and the consequences of non-adherence, for instance the potential development of resistance to antiretroviral drugs and its consequences. The present researcher concurs with Miller (2004:23) that for ART to be successful, education regarding adherence should be at the core of the treatment programme.

In chapter two, the clinical aspects of HIV/AIDS and antiretroviral therapy are discussed. Matters considered in this chapter are the clinical aspects of HIV/AIDS; the aetiology of AIDS; the morphology of HIV; modes of transmission; the human immune system and the effect of the HI virus on the immune system; CD 4 count; viral load; WHO stages and VCT. The said researcher is of the opinion that unless we understand the pathogenesises of the HI virus and antiretroviral therapy, we cannot attempt to treat it.

2.2 The Human Immunodeficiency Virus

The Human Immunodeficiency Virus (HIV) is defined as the virus that causes AIDS. The acronym Acquired Immune Deficiency Syndrome (AIDS) emphasizes that the disease is acquired and not inherited (*Dorland's Illustrated Medical Dictionary*, 1994:826).

HIV is caused by a virus that invades the body, which subsequently attacks the body's immune system and makes it so weak and ineffective that it is unable to



protect the body from both serious and common infections and pathogens. Any HIV-infected individual with a CD4+T cell count of $<200/\mu\text{L}$ has AIDS by definition, regardless of the presence of symptoms or opportunistic disease (*Dorland's Illustrated Medical Dictionary*, 1994:826; Kasper *et al.*, 2005:1852).

2.2.1 Aetiology of Aids

The first recognized cases of the Acquired Immune Deficiency (AIDS) syndrome occurred in America in the summer of 1981, when certain diseases suddenly appeared simultaneously in several patients. These patients all displayed a number of characteristics in common; they were young homosexual men with compromised immune systems. Soon afterwards, a new disease, which undermined the immune system and caused diarrhoea and weight loss, was identified in central Africa in heterosexual people. It was only in 1983 that it was discovered that the disease was caused by a virus which was then named HIV (human immunodeficiency virus).

There are many theories and myths about the origin of the human immune deficiency virus. The researcher supports the theory generally accepted by scientists, that HIV crossed the species barrier from primates to humans. It is not uncommon for a virus to cross from animals to humans as has been demonstrated with HTLV (Human T-cell Lymphotropic Virus) and the influenza viruses, and, as feared, might occur with the Avian Influenza virus.

The human immunodeficiency viruses, HIV type -1 and HIV type 2, which are cytopathic viruses, were identified during 1983. The history of the discovery of the HI virus is both interesting and controversial. Dr. Luc Montagnier and Dr. Francois Barre-Sinoussi and colleagues at the Louis Pasteur Institute in Paris, France, discovered HIV-1 in 1983. A year later Dr. Robert Gallo from the National Cancer Institute in the United States, claimed that he had been the first to discover the virus. Both Montagnier and Gallo are now officially recognized as co-discoverers of the virus (Isselbacher *et al.*, 1999:1853; Abdool Karim & Abdool Karim, 2005:32 and Van Dyk, 1999:4-16).



The HI virus belongs to the family of human retroviruses (retroviridae), and the subfamily of lentiviridae. Two viruses are mainly associated with AIDS: **HIV-1**, which is associated with infections in Central, East and Southern Africa, North and South America, and Europe. The most common cause of HIV diseases throughout the world is HIV-1. In 1999 it was demonstrated that HIV-1 infection in humans was zoonotic and had originated from the pan troglodytes species of chimpanzees (Isselbacher *et. al*, 1999:1853; Van Dyk, 1999:4-16 and Page, Louw, and Pakkiri, 2006:16-27).

HIV-2 was discovered in West Africa (Cape Verde Islands, Guinea-Bissau and Senegal) in 1986, and is mostly restricted to West Africa. HIV-2 is more closely related to the simian immunodeficiency virus (SIV) found in sooty mangabeys, than it is to HIV-1 (Isselbacher, *et al*,1999:1853; Van Dyk, 1999:4-16; Van Dyk, 2004:5).

The current researcher holds the view that studies on the different types and mutations of HIV indicate that the virus has probably occurred in humans for at least a century, but has been isolated within a community, which had little contact with the outside world. As migration to the cities started to take place, HIV began to spread, which coincided with the decay of morals and values.

2.2.2 Diagnosing HIV by means of Voluntary Counselling and Testing

In the case of individual testing, it is recommended that people make use of voluntary counselling and testing (VCT) services in order to ascertain their status. Internationally, much emphasis is placed on the process of counselling a person when he/she is undergoing an HIV test and the South African Department of Health, similarly, makes special provision for counselling and counsellors, in its regulations (South Africa:2003).

HIV counselling is defined as a confidential dialogue between a client (patient) and a care-provider, aimed at enabling the client to cope with the stress of a positive diagnosis and to assist the client in taking personal decisions related to



HIV/AIDS, for instance, when and to whom to disclose the diagnosis according to the Global Programme on AIDS (WHO, 2006).

An HIV test can be indicated for a variety of reasons: screening donated blood, epidemiological surveillance and mapping of HIV prevalence, and the diagnosis of HIV-infected individuals. The diagnosis of HIV infection is based mainly on the laboratory testing of blood samples. Two broad classes of tests can be distinguished in diagnosing HIV: an HIV antibody test and an HIV antigen test.

HIV Antibody Tests

Antibodies are molecules produced by animals in response to antigens which possess the particular property of combining specifically with the antigen that induced the antibody's formation. HIV antibody tests are therefore based on the principle that the immune system manufactures antibodies against the viral infection and that these antibodies can be quantified.

The major factor limiting the antibody tests is the so-called 'window period': that period between the onset of HIV infection and the appearance of detectable antibodies to the virus. The period is about 3 to 12 weeks and any antibody test performed in this period may give false negative results. This means that although the virus is present in the person's blood, there are, as yet, no (detectable) antibodies in the blood. In such cases, the tests, therefore, erroneously indicate that the person is not infected. This false negative test is particularly dangerous since the person is already infectious and may unknowingly infect others (Foundation for Professional Development, 2006).

The best-known and most-often used antibody test is the ELISA or Enzyme-Linked ImmunoSorbent Assay.

Rapid Tests

Rapid tests - antibody tests that can be performed outside a laboratory in rural and isolated places - have become very useful in the rapid diagnosis of HIV. The advantages of this test are that the results are available immediately, it is easy to use, and is relatively inexpensive and reliable. Blood is obtained from

the patient by a finger-prick, and a drop of blood is placed on the inset with a drop of solution. After 3 to 5 minutes the results are visible. One line indicates a negative result. Two or more lines indicate that the patient is HIV-positive. A positive result must be confirmed with a second test.

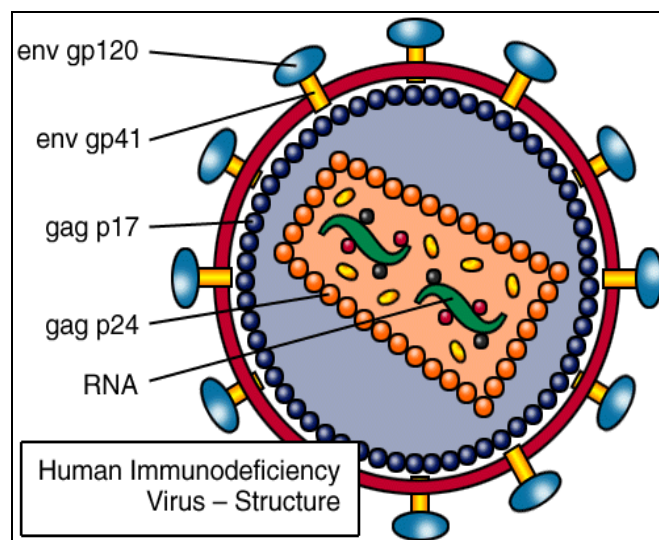
HIV p24 Antigen Test

In order to minimize the problem of the window period, blood tests that detect the actual virus (HIV) in the blood have been developed to diagnose HIV-infection. The HIV p24 antigen test detects the proteins of the virus and is directed specifically at the predominant HIV antigen (p24). This antigen is usually detectable in the blood approximately 16 days after initial HIV-infection and thus lends itself to an earlier diagnosis of HIV. Viral antigens are detected by the HIV PCR - Polymerase Chain Reaction – technique. Since this test does not rely on the development of antibodies, it is useful in the early diagnosis of HIV. For instance, this test is used in the case of HIV-exposed babies where a definitive diagnosis is required at the baby’s “6 weeks” clinic visit. This test is however very expensive and is reserved for specific cases and settings.

2.2.3 Morphology of HIV

The researcher will refer to the following illustration to explain the morphology (study of the form or shape of an organism) of the virus.

Figure 1: Human Immunodeficiency Virus



(University of Pretoria, 2006)



The above illustration can be explained as follows:

The HI virus possesses a circular shape and consists of an inner matrix of protein called the core, in which the genetic material (viral RNA) is housed.

The core is surrounded by an outer layer of protein called a nucleocapsid. Electron microscopy shows that the HIV virion is an icosahedral structure containing numerous small glycoprotein projections (external spikes) on its surface, formed by the two major envelope proteins: the external gp 120 and the transmembrane gp41.

The three enzymes that are crucial to viral replication are reverse transcriptase, integrase and protease. Two of these enzymes are currently targeted by antiretroviral drugs (Isselbacher *et. al*, 1999:1853; Van Dyk, 1999:4-16; Foundation for Professional Development, 2006 and Spencer, 2005:6, 7).

2.2.4 Pathophysiology of HIV

The researcher is of the opinion that the physiology of the HI virus is a very complex issue that can cause great difficulties in communication between social workers, counsellors, patients, and the public in general. The physiology and biochemical functioning of the virus must be understood if antiretroviral and adherence matters are to be addressed.

As illustrated in 2.2.3 above, glycoprotein projections (spikes) are situated on the outer layer of the virus that attach themselves to CD4 receptors, which are present on various types of cells such as: monocytes (a type of white blood cell or leukocyte: part of the human body's immune system that protects against blood-borne pathogens and moves quickly); and macrophages (cells within the tissues that originate from monocytes) and tissue cells in mucous membranes (e.g. the genital and rectal tracts, and certain brain cells). The main role of macrophages is to stimulate an immune response to an infectious agent. When HIV therefore invades the body, and the macrophages attempt to do their usual



job by capturing the invader, the real problem begins (Isselbacher *et. al*, 1999:1853; Spencer, 2005:10 & Van Dyk, 2004:66).

The HI virus incorporates itself in the DNA of the nucleus (a small area inside the cell where genetic material is kept) and becomes integrated in this sanctuary part of the cell, thereby effectively hiding from the body's natural immune system.

The virus, furthermore, uses the body's DNA to replicate itself. This is achieved by employing normal physiological processes, whereby cells copy DNA (the "blueprint" for building living cells) into RNA (the construction foreman), which tells enzymes (the workers) to build new proteins. Proteins are the building blocks used to create living things. This process eventually destroys the body's CD4 cells and it is this unique response that makes HIV so dangerous (and ultimately fatal) to human beings (Van Dyk, 2004:15: Foundation for Professional Development, 2006:34).

The specific events in the replication cycle of the HIV are explained by Spencer (2005:6, 7):

- Free virus (HIV);
- Fusion with CD4 receptor/co-receptor and cell membrane;
- Penetration and entry of HIV into cytoplasm of cell;
- 'Uncoating' of virus and liberation of 'free' virus and its associated viral enzymes;
- Transformation of viral RNA into viral DNA;
- Reverse Transcription;
- Penetration of the nucleus of the cell and integration of viral DNA into host (genomic) DNA to form proviral DNA;
- Activation of the CD4 cell leads to the transcription of proviral DNA into its original (genomic) viral RNA and messenger, mRNA;



- Viral RNA leaves the nucleus together with viral mRNA. mRNA is translated into appropriate viral proteins (structural, enzymic) on the ribosomes of the endoplasmic reticulum;
- Translated viral proteins and genomic viral RNA are processed, assembled, packaged and released in the form of a new infectious virus; and
- New viral assembly

In summary, HIV hijacks the most important defensive cell in the immune system (the CD4 cell) and turns it into an efficient virus factory to manufacture replicas of it. Although several antibodies are formed during this process, they are completely powerless against HIV, because HIV hides inside the CD4 cells. The body is then left defenceless because the antibodies will certainly not attack and kill their own CD4 cells.

2.2.5 Viral Load

The HIV RNA viral load quantification or HIV RNA assay is a measurement of the number of viral particles in the blood. The viral load is expressed as “copies per millilitre” of blood. The test measures the viral RNA, since this is the form in which HIV particles carry their genetic material.

A rising viral load is indicative of very active HIV disease. The higher the viral load, the more rapidly a person’s immune system will be damaged by CD4 cell destruction. It is important to know the estimated number of HI viruses in the blood in order to manage HIV infection effectively, since this indicates the degree of viral activity and the subsequent pace of development of immune deficiency. A high viral load is furthermore associated with an increased risk of developing mutations that might afford resistance to anti-viral medication (University of Pretoria, 2006 & Bartlett, Gallant, & Joel, 2005:40).

The ultimate purpose of antiretroviral therapy is to achieve an undetectable viral load (less than 50 viral copies per millilitre of blood) and sustain it as such. Measurement of the viral load is thus very useful in monitoring the response to antiretroviral therapy. This is, however, a very expensive test and is unavailable



in many developing countries, and, therefore, is not an absolute requirement for the management of patients on anti-retroviral treatment.

The viral load changes logarithmically. Only a change of more than 0.5 log₁₀ is regarded as clinically significant and an ideal response would be a decrease in the viral load of 1 log after 8 weeks of antiretroviral treatment. The following example illustrates the point: a change in viral load from 100 000 to 10 000 copies/ml represents a 1 log₁₀ change and is regarded as clinically significant, whereas a change in viral load from 100 000 to 30 000 copies/ml represents a 0.48 log₁₀ change and is not clinically significant. The final aim of treatment is to reduce the viral load to fewer than 50 copies per millilitre after 24 weeks of ARVs and to maintain that level (Isselbacher *et. al*, 1999:1853; Spencer, 2005:10 & Van Dyk, 2004:66).

2.3 Modes of Transmission

For infection with HIV to occur, the virus must find a way to enter the bloodstream. This is more likely to happen if there are sufficient quantities of the virus in the fluid (i.e. semen, vaginal fluid, and blood or breast milk), and one is exposed to the virus for a long time.

2.3.1 Sexual

HIV infection is primarily sexually transmitted when the virus enters a person's bloodstream via the body fluids of an infected individual. HIV is spread most commonly by unprotected vaginal or anal penetrative, sexual contact with an infected partner and possibly by oral sexual contact under certain conditions, e.g. in the presence of ulcerations of the buccal mucosa.

The membrane linings of body cavities, especially in the ano-rectal area and the vagina, are very delicate and can be torn as a result of friction generated during sexual intercourse. The virus can enter the body through the lining of the vagina, vulva, penis and rectum during sex. This makes it easy for the virus to enter the sex partner's bloodstream – either through the tears or by mixing with blood from larger injuries. There are other body fluids, including saliva, sweat,



tears and urine that do not contain sufficient quantities of the virus to be transmitted.

2.3.2 Blood

HIV can also be spread by means of contact with infected blood. For instance, drug- users frequently spread HIV by sharing needles or syringes contaminated by the blood of someone infected with the virus.

Healthcare workers can also become infected with HIV when injured with needles, syringes, razor blades or other sharp instruments contaminated with HIV-infected blood. Similarly, a person can be infected when s/he receives HIV-contaminated blood via a blood transfusion (Evian, 2000:20 & Van Dyk, 2004:19).

2.3.3 Mother-to-child Transmission (MTCT)

Mother-to-child transmission (MTCT) of HIV is the major causes of HIV infection in children. HIV can be transmitted from an infected mother to her baby either via the placenta during pregnancy, by blood contamination during childbirth or by breastfeeding (Evian, 2000:32 & van Dyk, 2004:19).

2.4 Preventing the Spread of HIV

HIV/AIDS is a life-threatening disease. In the absence of a cure, or vaccine to prevent transmission of the virus, the only strategy would be prevention.

Prevention strategies include:

- Behaviour intervention by means of public education campaigns and outreach, testing and counselling;
- prevention technology by using condoms, or sterile needles;
- post-exposure prevention with antiretrovirals and
- mother-to-child transmission (PMTCT) by administering antiretrovirals.



2.4.1 Behaviour Intervention by means of Education

Behaviour interventions, where the focus specifically falls on preventing and spreading the HI-virus, have the biggest chance of limiting the epidemic. Public health education campaigns to raise awareness of high-risk activities have proven to be effective if successfully implemented as part of an integrated education prevention programme.

Abdool Karim & Abdool Karim (2005:268) corroborate this perspective on HIV/AIDS and education as follows: “Widespread education and associated high levels of knowledge have done little so far to contribute to a decline in HIV prevalence. There is increasing recognition that public health approaches that promote abstinence, fidelity and condom use, in the absence of wider societal changes, are not effective”. There is a distinct gap between cognitive knowledge of safe sex and risky sexual behaviour and behavioural outcome (actual refraining from risky behaviour) (Kasiram, Dano & Partab, 2006:54-55). The researcher is of the opinion that little correlation exists between knowledge and refraining from unprotected sexual encounters, since knowledge is cognitive and sexual behaviour is usually an emotional act and a basic human need.

- Ross and Deverell (2004:16) opine that cultural considerations definitely influence whether members of a population choose to participate in prevention campaigns and whether they choose to believe, internalise and accept the messages propagated by such campaigns, such as adhering to antiretroviral treatment.

2.4.2 Voluntary Counselling and Testing (VCT)

Voluntary counselling and testing (VCT) is a process whereby people in a community, industry or business receive counselling which enables them to understand the advantages of knowing their HIV status and more about the process of HIV antibody testing. Using this knowledge they can make an informed decision about being tested for HIV.



The results of an HIV test can have enormous psychological and social implications for the person being tested. As daunting as the barriers to HIV testing can be, it is important for everyone to confront these. When people learn their HIV status early, important benefits result, both in terms of prevention and care (Page, Louw, & Pakkiri, 2006:60).

2.4.3 Prevention Technology

Condoms

Studies have shown an increased acceptance of condom use, especially among young people. It is important, however, that consistent messages are provided which promote and support the proper and continued use of condoms. The male condom, when used consistently and correctly, is an effective means of preventing HIV infection.

The first record of condom use comes from Egypt, where hieroglyphics from before 1000BC show men wearing sheaths over their erect penises. Condoms were used during the Roman Empire and the word condom is probably derived from the Latin word "condon", meaning receptacle. In Europe, during the seventeenth and eighteenth century condoms made from linen or animal intestines were available for the prevention of pregnancy as well as prophylaxis against sexually transmitted infections. The rubber condom, as we know it today, was first widely produced after the vulcanization of rubber was patented in 1844 (Abdool Karim & Abdool Karim, 2005:172).

Microbicides

A new experimental method that might expand our current armamentarium to prevent HIV infection is the development of microbicides. The term "microbicide" refers to a range of different products that share one common characteristic: the ability to prevent the sexual transmission of HIV and other sexually transmitted infections (STI's), when applied topically in the vagina before sexual intercourse. These come in many forms including gels, creams, suppositories, films, sponges or rings that release the active ingredient over time. Phase 2 and 3 clinical trials of microbicides, are currently underway in the



developing world; yet no safe and effective microbicide is yet available to the public (Rossouw, 2007).

Vaccines

It is widely believed that a vaccine will be the only effective way to control the pandemic globally. The different subtypes and variants characteristic of the virus, however, pose a major scientific challenge in the development of single or multiple vaccines effective against all major subtypes of HIV. The HIV vaccine undergoing phase III, trials currently in the USA and Thailand (AIDSVAX), was designed to reduce susceptibility only to HIV subtype B, and hence its efficacy in sub-Saharan Africa, where subtype C predominates, is questionable.

2.4.4 Post-exposure Prophylaxis (PEP)

Post-exposure prophylaxis (PEP) is a method of attempting to prevent HIV infection in a person who has been exposed to infected blood or other body fluids, as in the case of occupational exposure or rape. With PEP, anti-HIV drugs should preferably be started within an hour of the injury and then be continued for a month thereafter (Evian, 2000:30; Van Dyk, 2004:19).

2.4.5 Mother-to-child Transmission (PMTCT)

Great advances have been made in the prevention of mother-to-child transmission of HIV. Antiretroviral therapy is administered to women during pregnancy, labour and delivery in order to reduce their viral load and lessen the risk of transmission to the baby (Evian, 2000:31; Van Dyk, 2004:19).

Since there is no cure or vaccine for HIV infection, the only way to prevent infection is by prevention itself. The social worker's role in prevention is pivotal, especially in facilitating education regarding sexual behavioural change. Behavioural change is a complex task requiring integrated inter-sectoral approaches, implemented at all levels of society, and sustained over years.



2.5 Immune System

The researcher is aware that, in order to understand HIV/AIDS and ARV's, it is also important to understand the working of the human immune system. The immune system is defined by Van Dyk (2004:8) as being the defence force that defends the body from external threats and invasions.

Disease can be caused by a variety of factors, including genetic defects, hormone imbalances, nutritional deficiencies, and infection. Transmission of disease via infection involves the invasion of the body by pathogenic microbes and their subsequent growth in various parts of the body. In HIV infection, the profound immune suppression caused by the virus renders patients vulnerable to opportunistic infections and malignancies.

Opportunistic infections are caused by organisms that would, under normal circumstances, and in the presence of a normally functioning immune system, not cause disease; but, in the presence of the HIV-depleted immune system, do cause significant disease processes.

The median time from HIV infection to AIDS is approximately 8-10 years in developed countries. Different people, however, respond differently to HIV infection. Some people remain healthy and active for as long as 10 to 20 years, with little or no sign of immune suppression, while other people deteriorate rapidly and develop full-blown Aids within 5-7 years, or even sooner.

Botes (2005:119-124) postulates that the reasons why people respond differently to HIV infection are:

- Differences in the strains of HIV;
- Differences in the infective dose – people are infected by different 'dosages' of the virus;
- Differences in the human immune response – people respond differently to the virus; and



- Differences in the general health status of the person concerned, affect the course of the disease.

HIV causes a viral infection but elicits an immunological disease. The most important cell involved in the immune attrition is the CD4 T-lymphocyte since it plays a central coordinating role in the immune response (Isselbacher *et al.*, 1999:1853 and Van Dyk, 1999:4-16).

The immune system, which protects the body against viral, bacterial and parasitic infections, is directly attacked and destroyed by the HIV; this makes the virus so unique and fatal. No other virus known in the history of humankind has been manifested in this manner. In order to understand the danger of AIDS fully, the functioning of the immune system must also be understood by patients and counsellors.

2.5.1 CD4 Cell Count

CD4 lymphocytes are a subset of the white blood cells and play an important role in keeping the immune system healthy. The CD4 lymphocyte count is the single, most important test for determining an individual's immune status.

The CD4 count is used as a reflection of the damage incurred by the immune system as well as immune system restoration in patients on antiretroviral therapy. It is the best predictor of the risk of opportunistic infections in HIV-infected people. The CD4 cell count has been shown to be an independent risk factor for progression to AIDS and death (Van Dyk, 2004:423).

The CD4 count of a patient is highly variable and dependent on the individual's immune system, his/her general state of health and the presence of concurrent diseases (South Africa, 2004:2). The normal CD4 count in adults ranges from 600 to 2000 cells/mm³. In children, the absolute CD4 count is variable and age dependent, and CD4% should rather be used. A CD4 value below 500 cells/mm³, is usually an indication of immune suppression and vulnerability to opportunistic infections. People generally tend to become symptomatic when the CD4 is below 400 cells/mm³. According to the World Health Organization



(WHO: 2005), patients with a CD4 count of less than 200 cells/mm³ are classified as having AIDS.

Table 4: The CD4 count, CD4% and immune suppression in adults

CD4 Count	CD4 %	The Immune System
>500	>29	Normal immune function
200-499	14-28	Moderate immune suppression
<200	<14	Advanced immune suppression
<50		Severe immune suppression

(South Africa, 2004)

The above Table reflects the relationship between CD4 count, CD4% and immune suppression in adults. The CD4 count is expressed as an absolute number or a percentage of T-lymphocytes.

Thus, the level of CD4 cells in the peripheral blood is the key parameter to use in monitoring any changes within the immune response. It possesses the following well-defined roles:

- Indicates the degree of immune suppression;
- Establishes the risk of specific HIV-associated complications;
- Determines the need for prophylaxis against opportunistic infections; and
- Assesses response to antiretroviral therapy (WHO: 2006).

The researcher argues that in practice, the CD 4 count can fulfil a very important role in motivating patients to adhere to ART. Patients tend to be motivated when the repeat CD 4 count, taken four to six months after initiation of ART, indicates an increase; this signifies a good response to therapy. The CD4 count can be presented to patients as a practical proof of their response to ART. This value should, however, never be seen in isolation. The precondition, therefore, demonstrates that counsellors, as well as patients, should command an in-depth knowledge and understanding of the effect the HI virus has on the immune system, as well as of the interpretation of both the CD4 count, and the viral load.



It should, therefore, be clear that one of the key tasks of the social worker lies in educating counsellors and patients alike regarding the importance of a proper understanding of the function of the immune system, in general, and the CD4 count, in particular.

2.5.2 WHO Staging

The immunodeficiency that develops during HIV infection forms a continuum, but several discrete clinical phases can be identified. According to the *CDC Staging AIDS Surveillance Case Definition for Adolescents and Adults* (Centres for Disease Control and Prevention, 1993) as well as the *Comprehensive Care and Treatment of HIV/AIDS Antiretroviral Treatment guidelines* (South Africa, 2004), all HIV-infected individuals with either a CD4 count $<200\text{cell/mm}^3$ or an AIDS-defining condition (WHO stage 4), qualify for the initiation of antiretroviral therapy.

The Adult HIV and AIDS Staging System of The World Health Organization (WHO, 2005) uses standardized criteria to clinically stage HIV infection and allows stratification of individuals in terms of clinical criteria and performance status. This staging accommodates facilities where CD4 testing is not freely available, and thus only takes into account clinical determinates and symptoms of the patient. Once a patient has been staged, he/she remains in that stage, unless his/her condition deteriorates, in which case he/she will move to a more advanced stage according to the *HIV/AIDS management for Professional Nurses Manual*, (Foundation for profession Development, 2004:90 and Botes and Levay 2004:13).

The researcher contends that WHO staging could be linked to quality-of-life issues. For example, a person with WHO stage 4 would suffer from severe AIDS-related symptoms, which will impair his/her, quality of life severely. Similarly, a person's WHO stage might improve to stage 1 or 2 after the initiation of ARVs, with concurrent improvement in his/her quality of life. According to the researcher, this improvement is the most important goal of ARV therapy.



The stages can be employed to motivate patients not only to commence ART but, also, to continue with the treatment, long-term according to *the Comprehensive Care and Treatment of HIV/AIDS Antiretroviral Treatment Guidelines* (South Africa, 2003:4). Staging, however, is generally more often used by the medical profession and the terminology is often, not well understood by counsellors.

Table 5: WHO (2006) staging

<p>The WHO (2005) proposed staging system for HIV infection and disease in adults and adolescents is:</p> <p>Clinical Stage I: Performance scale 1: Asymptomatic, normal activity</p> <ol style="list-style-type: none">1. Asymptomatic2. Persistent generalized lymphadenopathy (PGL) <p>Clinical Stage II: And/or Performance scale 2: symptomatic, normal activity</p> <ol style="list-style-type: none">3. Weight loss, < 10% of body weight4. Minor mucocutaneous manifestation (seborrheic dermatitis prurigo, fungal nail infection, recurrent oral ulcerations, angular cheilitis)5. Herpes Zoster, within the last 5 years6. Recurrent upper respiratory tract infection (i.e., bacterial sinusitis) <p>Clinical stage III: And/or performance scale 3: bed-ridden < 50% of the day during the last month</p> <ol style="list-style-type: none">7. Weight loss > 10% of body weight8. Unexplained chronic diarrhoea >1 month9. Unexplained prolonged fever (intermittent or constant) > 1 month10. Oral candidiasis (thrush)11. Oral hairy leukoplakia12. Pulmonary tuberculosis, within the past year13. Severe bacterial infections (i.e./ pneumonia, pyomyositis) <p>Clinical Stage IV: And/or Performance scale 4: bed-ridden > 50% of the day during the last month</p> <ol style="list-style-type: none">14. HIV wasting syndrome, as defined by CDC15. Pneumocystis carinii pneumonia16. Toxoplasmosis of the brain17. Cryptosporidiosis with diarrhoea > 1 month18. Cryptococcus, extra pulmonary19. Cytomegalovirus (CMV) disease of an organ other than liver, spleen or lymph nodes20. Herpes simplex virus (HSV) infection, mucocutaneous > 1 month, or visceral any



	duration
21.	Progressive multifocal leukoencephalopathy (PML)
22.	Any disseminated endemic mycosis (i.e. histoplasmosis, coccidioidomycosis)
23.	Candidiasis of the oesophagus, trachea, bronchi or lungs
24.	Atypical mycobacteriosis, disseminated
25.	Non-typhoid Salmonella septicaemia
26.	Extra pulmonary tuberculosis
27.	Lymphoma
28.	Kaposi's sarcoma (KS)
29.	HIV encephalopathy, defined by CDC

(WHO: 2006)

An explanation of the above table, illustrating the clinical staging (WHO: 2006) of HIV and AIDS and its link to the viral load, CD 4 count as well as quality-of-life, follows:

A patient in Clinical Stage 1 (Asymptomatic), will possibly have a low viral load and a high CD 4 count (>200) and function according to the Karnofsky score (WHO, 2005) at 90% to 100%: which is independent, with minimal symptoms. While, on the other hand, a patient in Clinical Stage 4 (AIDS-related complex or full-blown AIDS), would possibly show a high viral load and a low CD 4 count (<200) and function according to the Karnofsky score, possibly at 20% to 50%, is dependent or needs hospitalisation.

2.6 Summary

In the present chapter, the researcher discussed the clinical aspects of HIV/AIDS: the aetiology of AIDS, modes of transmission, the human immune system, the morphology of HIV, the pathophysiology of HIV, the CD4 cell count, WHO staging, viral load, and diagnosing HIV by means of VCT.

HIV/AIDS and specifically, its effects on the immune system are complex issues that should be understood by the team members who deal with HIV/AIDS patients. In order to render effective counselling and treatment services, aspects such as the CD 4 count, viral load and WHO staging, should be linked



to quality-of-life issues in order to motivate patients to commence, and continue, ART.

In the following chapter, the author discusses the goals of antiretroviral therapy (ART), different antiretroviral drugs, response to, and prognosis of antiretroviral treatment, treatment failure, side-effects, and drug interactions.



CHAPTER 3: ANTIRETROVIRAL THERAPY (ART)

3.1 Introduction

Since antiretroviral treatment was introduced in 1986, mortality and accompanying opportunistic infections in patients with advanced HIV infections have declined. Likewise, according to the guidelines of the World Health Organization (WHO:2002), on the use of antiretroviral therapy, mortality has dropped significantly in Europe and North America, due to access to HAART. The main obstacles with regard to the administration of antiretroviral drugs in developing countries have been the high cost and the lack of a healthcare infrastructure necessary to access these. There were also concerns that the difficulties with adherence to complicated medication regimens would lead to treatment failure and the accumulation of resistant viral strains that could promote the spread of drug resistance.

The researcher believes that great advances have been made in the treatment of patients with HIV infection. The use of appropriate potent combination antiretroviral therapy consisting of three different drug classes, as well as prophylactic interventions to prevent opportunistic infections, are of critical importance in providing each patient with the best opportunity to live a long and healthy life, despite the presence of HIV infection. In South Africa, a significant number of people also use alternative, complementary and traditional medicines. The use of such a myriad of potentially conflicting drugs calls for some education regarding drug use, as well as the prevention and management of their adverse effects, drug interactions and medication errors. (South Africa, 2006:16).

The management of HIV disease is supported by many pillars: lifestyle changes and support, treatment and prevention of opportunistic infections and antiretroviral therapy. Because of the complicated nature of HIV disease and the chronic nature of the treatment of HIV/AIDS and opportunistic infections, it is



imperative to make use of multidisciplinary teamwork and collaboration between various disciplines, more than ever before.

Kasper *et al.* (1999:1901) confirm that the treatment of patients with HIV infection requires not only a comprehensive knowledge of the possible disease process that may occur, but also the ability to deal with the problems of a chronic, potentially life-threatening illness. Furthermore, the said researcher asserts that the patients must also be educated concerning the potential development of resistance to antiretroviral drugs, and thus, the importance of constant and continued adherence. The researcher concurs that “The cornerstone of HIV prevention strategy is education, counselling and behaviour modification” (Isselbacher *et. al*, 1999:1910).

The researcher believes that ART regimens have resulted in the reduction of mortality, retarded the progression of the HIV to AIDS and, also, reduced the incidence of opportunistic infections and hospitalisations, these results offer proof that ART contributes to the enhancement of the quality of life of HIV/AIDS positive individuals. These effects also contribute to increased productivity and therefore, to the economy, in general.

The matters that will be considered in this chapter are the goals of ART, different antiretroviral drugs, response to, and the prognosis of antiretroviral treatment, treatment failure, side effects, and drug interactions.

3.2 Goals of antiretroviral therapy

According to the *National Department of Health’s guideline for Antiretroviral Treatment*, (South Africa, 2003:2) the primary goal of ART is to decrease HIV-related morbidity and mortality. It further aims to provide maximal viral suppression, restore the immune function and improve the quality of life of HIV-positive patients.

The aforementioned guideline further stipulates the following goals for ART:



- The patient should experience fewer HIV-related illnesses;
- The patient's CD4 count should rise and remain above the baseline count;
- The patient's viral load should become undetectable (<400 copies/ml) and remain undetectable on ARV therapy.
- The secondary goal is to decrease the incidence of HIV by:
 - An increased uptake in voluntary testing and counselling with more people knowing their status and practising safer sex;
 - The reduction of transmission in discordant couples;
 - Reducing the risk of transmission from mother-to-child.

The primary goals of ART, according to the (Southern African HIV Clinicians Society, 2004) are the:

- Improvement of quality of life;
- Reduction of HIV-related morbidity and mortality;
- Maximal and durable suppression of viral load; and
- Restoration and/or preservation of immunological function.

Botes (2005:119-124) also differentiates between primary and secondary goals of ART:

Primary goals:

- Decrease in the viral load to undetectable levels for as long as possible in order to halt disease progression and prevent/reduce resistant mutations;
- Increase and maintain a high CD4 T cell count;
- Improve duration and quality of life;
- Reduce HIV-related illnesses and death; and
- Reduce HIV transmission.

Secondary goals:

- Increase voluntary counselling and testing;
- Decrease HIV transmission rates in discordant couples;
- Reduce the risk of mother-to-child HIV transmission.



The researcher argues that the primary goal and indication for ART should be to improve the biopsychosocial functioning of patients in general, since HIV/AIDS, like many chronic diseases, affects all aspects of a patient's life. In this respect Ross and Deverell (2004:211) assert the following regarding quality of life: "The pendulum of the pandemic has swung from dying from AIDS to living with HIV infection; a primary focus of therapeutic intervention is to enhance quality of life." Such quality and the psychosocial consequences of illness and treatment have not always been considered a psychological issue of importance. By measuring the impact of treatment on the individual's quality of life, one can assess whether the treatment is more harmful than the disease itself (Taylor, 2003:356). Patients should experience increased physical strength, gain independence, reclaim lost roles and take control of their lives.

The researcher is further of the view that the role of the social worker is to assess patients for ART, motivate them to adhere to it and to support them in adapting to the psychological and physical effects of living with a chronic illness. People living with HIV/AIDS need to make intermittent or permanent changes to their physical and social activities in order to undertake such an adaptation. The social worker can facilitate this process.

3.3 Initiating Antiretroviral Therapy

Recent studies indicate that there is no benefit in starting ART in asymptomatic patients with CD 4 cell counts > 350 cells/cu mm. (Spencer, 2005:10); However, there is a general consensus that patients who suffer from an AIDS-defining disease, and who are severely symptomatic (even though they do not suffer from an AIDS-defining disease), and those whose CD4 cell counts are below 200 cells/mm, should be offered ART.

The medical criteria that the Gauteng Provincial Government's Comprehensive Care and Treatment of HIV/AIDS and TB rollout plan for Antiretroviral Treatment (South Africa, 2004:4) stipulate are:

- Cd4 < 200 cells/mm³ irrespective of WHO stage; and



- WHO stage 4 irrespective of CD4+ cell count

Further to the above, the psychosocial considerations:

- Reliability of patients (i.e. the patient has attended three or more scheduled visits to an HIV clinic);
- No active alcohol or other substance abuse;
- No untreated active depression, emotional distress or any diagnosable mental illness;
- Social support. Patients should have disclosed their HIV status to a family member, a friend or joined a support group;
- Insight. Patients must have accepted their HIV status, understand HIV infection and the role of ART before starting treatment;
- Access to the clinic: Follow-up visits must be made regularly, so access to transport is essential;
- Regular place to stay, storage for medication and food; and
- Patients ready to commit themselves to treatment.

Research indicates that strict adherence to the ARV treatment regimen is essential in order to obtain the desired benefit, avoid the emergence of drug resistance, and clinical failure. The worldwide increase in the prevalence of ART resistance is of particular concern to researchers and practitioners.

Resistance can develop whenever the HIV continues to reproduce whilst ARV drugs are being taken. Since resistance remains one of the most significant threats to the long-term success of any HAART regimen, practitioners should be anxious to learn from past mistakes, translate new knowledge into appropriate treatment strategies, and develop new drugs that retain useful activity in the face of established resistance.

The researcher believes that the biopsychosocial model will provide insight into imposing factors with regards to adherence. Bearing this in mind, it is imperative that patients understand the need to strictly adhere to their ART medication



regimen and to take the drugs as directed. Good adherence to medication is the basis of effective viral control (Spencer, 2005:4). In order to render the services, indicated above, the social worker plays an essential role in the assessment of the patient's biopsychosocial circumstances, and/or referral to the appropriate resources, prior to the initiation of ART.

3.4. Antiretroviral drugs (ART)

Antiretroviral treatment has moved from mono-therapy to triple drug, or, HAART, since the discovery that these drugs are more effective when three or more are taken at the same time. HAART is also known as combination therapy. (Kasper, *et al.*, 2005:1071; Van Dyk, 2004: 69.)

Anti-HIV therapy consists of treatment by the administration of drugs that attack the virus itself. These drugs interfere with the manner in which the virus tries to reproduce itself inside a human cell, although anti-HIV drugs cannot destroy the virus completely. The ultimate purpose of ART is to reduce the HIV viral load (viral RNA levels) to below the level of detection (or at least as low as possible) as much as feasible – preferably to undetectable levels (<25 cells/ml) – for as long as possible (Spencer, 2005:4-13 and 14-26; Van Dyk, 2004:67).

Numerous new therapies have been introduced since 1996. The indications for ART have undergone dramatic changes in recent years, and recommendations for their use remain in flux (Spencer 2005:4-13 and 14-26; WHO, 2006; Van Dyk, 2004:67-73; The Foundation for Professional Development, 2004:175-221).

Combination therapy – HAART (Highly Active Antiretroviral Therapy) is recommended in order to obtain maximal antiviral treatment effects and to reduce the emergence of drug-resistant HIV. The drugs that are used belong to different pharmacological classes. Medication is taken every day and compliance with, and adherence to, the treatment regimen is mandatory (Spencer, 2005:14).



The appropriate use of potent combination antiretroviral therapy HAART and other treatment, as well as prophylactic interventions, is of critical importance in providing each patient with the best opportunity to live a long and healthy life, despite the presence of HIV infection. ART cannot cure HIV, but it can control the disease by reducing the viral load, followed by immune reconstitution (Isselbacher, *et al.*, 1999:1473 & Gerberding and Sande, 1999:1470).

In South Africa, the Government has compiled a standardized *National ARV rollout programme*, based on international best practices (South Africa, 2003).

Medical and psychosocial considerations are taken into account when deciding when to initiate ARTs. The initiation of HAART is never an emergency, unless administered as post-exposure prophylaxis. ART should be deferred until patients are prepared to commit themselves to long-term treatment and to maintaining good adherence to treatment. *The Gauteng Provincial Government Comprehensive Care and treatment of HIV/AIDS and TB rollout plan for Antiretroviral Treatment advocates that:*

- Strengthening of the prevention interventions is a priority;
- Not everyone who is HIV-positive needs ART; and
- Decisions regarding whether or not to put a patient on ART are based on medical and psychosocial criteria. (South Africa, 2004:4)

Most experts accept the above treatment principles (Gerberding and Sande, 1999:1470; Isselbacher, *et al.*; Kasper, *et al.*, 2005:1901; Southern Africa HIV Clinicians Society, 2005:23 and Jameson, 1999:1853).

The researcher opines that the biopsychosocial model will be of great value in assessing the circumstances of the patients regarding adherence to ART. The pursuit of an AIDS vaccine remains a critical international goal. Until there is an effective vaccine, social mobilisation toward healthier and safer sexual behaviour should be significantly increased and sustained. The high rate of HIV



infection in the sexually active population indicates continued high-risk behaviour.

During the last few years, a rapid change in the treatment strategies for HIV infection has taken place. ART currently available falls into two main categories:

- Nucleoside and Non-nucleoside reverse transcriptase inhibitors (NRTIs and NNRTIs); Protease inhibitors (PI).

In order to understand the modes of action of the above therapies, it is important to review the method of viral replication inside the human cell. Once the HIV has locked onto, and invaded a human cell, it uses an enzyme called reverse transcriptase (RT) to convert its genetic code (RNA) into the same form as the genetic code of human cells (DNA). This viral DNA then merges with the human DNA, converting the cell into a factory for producing the building blocks of the new virus. This new DNA is called "proviral DNA." Reverse transcription can be blocked by Nucleoside Reverse Transcriptase Inhibitors (NRTIs), and Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) (Gerberding and Sande, 1999:1470; Isselbacher, *et al.*, 1999:1853 & Kasper, *et al.* 2005:1901).

3.4.1 Nucleoside Reverse Transcriptase Inhibitors. (NRTIs)

NRTIs were the first ARV agents used to treat HIV infection. Their structures mimic those of natural nucleosides, which serve as building blocks for RNA/DNA synthesis. Drugs in this class act as false building blocks and they therefore terminate the DNA chain and prevent DNA synthesis from taking place (South Africa, 2006).

The NRTIs currently available in South Africa are:

- Zidovudine (ZDV or AZT);
- Didanosine (ddl);
- Zalcitabine (ddc);
- Lamivudine (3TC);



- Stavudine (d4T); and
- Abacavir (ABC)

3.4.2 Non-nucleoside Reverse Transcriptase Inhibitors (NNRTI)

NNRTIs are structurally distinct from the NRTIs and act by binding to the enzyme, reverse transcriptase, directly, downstream from the active catalytic site, thereby interfering with its transcriptional activity (South Africa, 2006).

- Two NNRTIs are currently available in South Africa: Nevirapine (NVP); and Efavirenz (EFV).

3.4.3 Protease inhibitors

Protease is a different HIV enzyme. After the HIV has successfully merged its DNA with the DNA of the human cell, the cell produces a string of protein. These long strings of proteins are cut up into smaller proteins by a viral enzyme, protease. These proteins serve a variety of functions; some become structural elements of new HI viruses, while others become enzymes, such as reverse transcriptase. Once the new viral particles are assembled, they bud off the host cell, and create a new virus. This virus is then able to infect new cells. Each infected cell can produce many new viruses. By blocking protease, protease inhibitors help to prevent an infected cell from producing new infectious virus particles (South Africa, 2006).

Six PIs are currently available in South Africa:

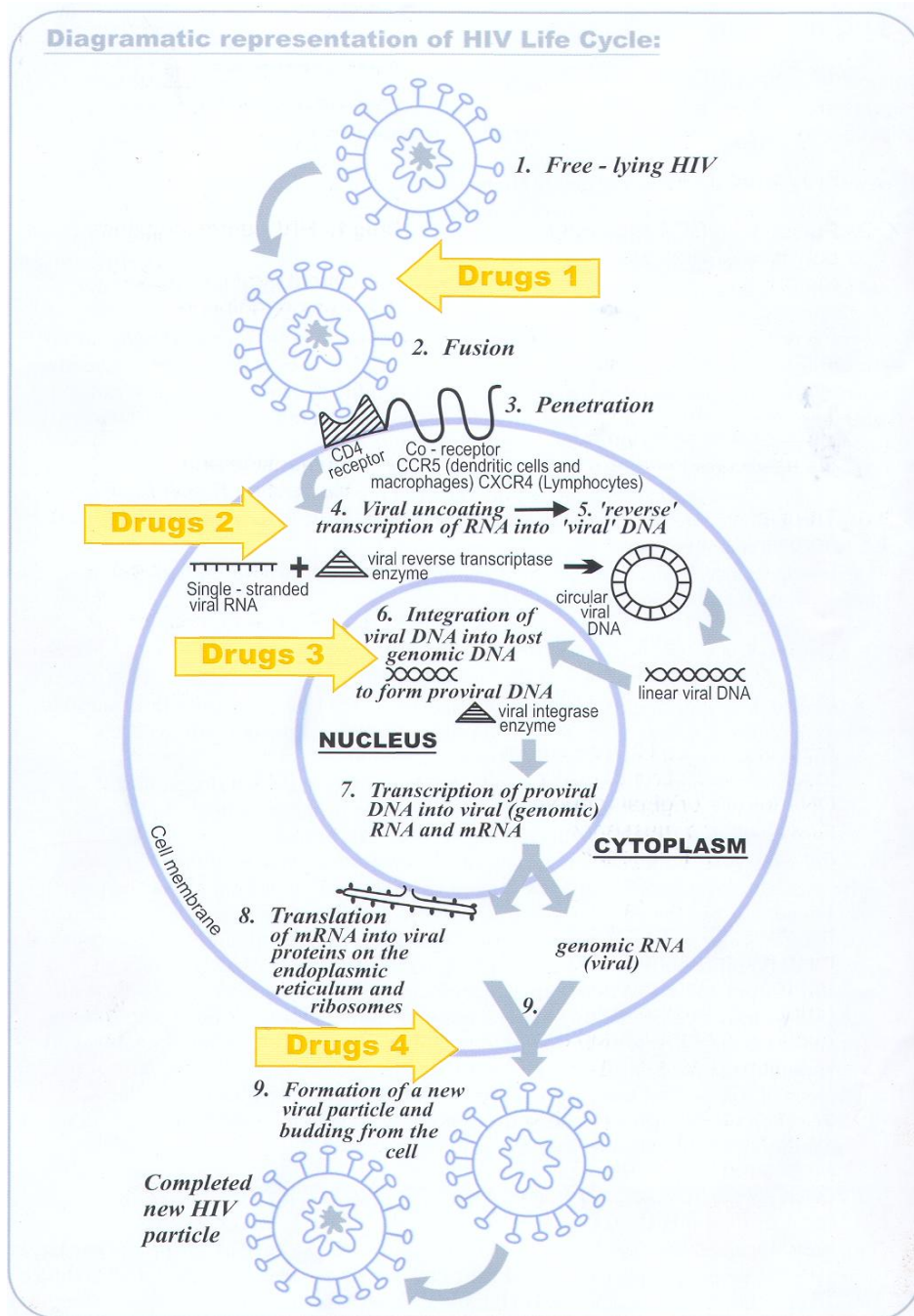
- Saquinavir, Ritonavir, Lopinavir, Indinavir, Nelfinavir; and Amprenavir

In addition to the above, there are also other classes of drugs that intervene with the functioning of the HIV and are currently in the process of being tested:

- Fusion inhibitors;
- Nucleotide Reverse Transcriptase Inhibitors (NtRTIs);
- HIV-entry inhibitors;

- Co-receptor antagonists (e.g. CCR5 inhibitors)
- Integrase inhibitors;
- Maturation inhibitors (Spencer, 2005:14; Jones & Nelson, 2005:18; Zuger, 2007: 1 & Wilkin *et al.*, 2007: 591).

Figure 2: The life-cycle of the HIV-1 virus and the role of therapy in its control. Spencer (2005:6, 7)



Spencer (2005: 6, 7)



The author explains the working of the different ART drugs, NRTIs/NNRTIs and PIs with the assistance of Spencer's illustration above:

- Free virus (HIV);
- Fusion with CD4 receptor/co-receptor and cell membrane; (Here the drug class HIV – entry inhibitors – with direct viral interaction, fusion inhibitors and co-receptor inhibitors, interfere with the functioning of the virus);
- Penetration and entry of HIV into cytoplasm of cell;
- “Uncoating” of virus and liberation of ‘free’ virus and its associated viral enzymes;
- Transformation of viral RNA into viral DNA; Reverse Transcription. (Here the drugs NNRTIs, and NNRTIs are able to block the functioning of the virus);
- Penetration of the nucleus of the cell and integration of viral DNA into host (genomic) DNA to form proviral DNA: Integration. (Drugs working here are the Integrase inhibitors);
- Activation of the CD4 cell leads to the transcription of proviral DNA into its original (genomic) viral RNA and messenger, mRNA: Viral Transcription;
- Viral RNA leaves the nucleus together with viral mRNA. mRNA is translated into appropriate viral proteins (structural, enzymic) on the Ribosomes of the endoplasmic reticulum:
- Translation - Translated viral proteins and genomic viral RNA are processed, assembled, packaged and released in the form of a new infectious virus: (By blocking protease, PIs help to prevent an infected cell from producing new infectious virus particles; and new viral assembly).

3.5 Response to antiretroviral treatment and Treatment failure

The advent of combination ART has substantially improved the prognosis of patients with HIV-infection and transformed HIV/AIDS into a treatable chronic condition for a significant proportion of those who have access to ART.

Response to ART can be assessed clinically, immunologically and virologically. Studies have proven adherence to be crucial to the sustained virological, immunological and clinical benefits of ART.



3.5.1 Clinical response

A person who responds to ART should indicate a reduction in HIV-related symptoms or opportunistic conditions as well as a generally slower progression towards AIDS, and hence, fewer episodes of hospitalisation.

Immune reconstitution inflammatory syndrome (IRIS) occurs when an improving immune function unmasks a previously occult opportunistic infection. Events occurring within three months of the commencement of ARVs might be immune reconstitution disease and not treatment failure. The aforementioned syndrome indicates that an infection was present in the patient's body, but was not clinically evident. Patients become ill during the first weeks of ARV, particularly those with a CD4 count of less than 50 cells/mm³, i.e. advanced HIV disease. Mostly patients present with fever of unknown origin. The immune system reconstitutes itself once the patient commences ARV. Initially, a response takes place in the memory cells, followed by a response in naïve cells, including those of thymic origin. An immune reconstitution illness is not indicative of drug failure or drug side effects. It is not a reason to stop ARV, or to change the ART regimen (South Africa, 2006).

If a patient develops new or recurring HIV-related symptoms or opportunistic conditions while taking ARTs, this might however also be due to treatment failure. This can be distinguished from IRIS by the timing of the onset of symptoms and the CD4 and Viral Load measurement. Treatment failure is defined as disease progression with a decrease in CD4 count and an increase in Viral Load, with the subsequent development of new opportunistic infections or malignancy (WHO, 2006).

In addition to immune reconstitution, clinical success is also realised by means of enhancing quality of life and improving the daily performance of a patient. It can be measured by applying the Karnofsky Score (WHO, 2004.)

The Karnofsky Score (WHO, 2004) is a widely accepted and appropriate measure to establish the physical wellness or performance status of

respondents. *The Karnofsky Scale (Karnofsky index)* was devised by two American doctors in the 1940s (David Karnofsky and Joseph Burchenal) in an attempt to try and measure the more subjective side of the outcome of cancer treatment. Nowadays it continues to be employed with regards to other chronic diseases. This scale has also been adopted in the South African National Antiretroviral Guidelines (South Africa, 2003):

http://www.cancerbacup.org.uk/Qas/AboutcancerQAs/AllQAs/related_faqs/Qas/993:28.02.2006

Table 6: Karnofsky Score, HIV/AIDS and antiretroviral therapy)

Physical Ability	Score
Normal	100
Independent with minimal symptoms	90
Independent with more effort and symptoms	80
Can do only activity of daily living	70
Partially independent	60
Partially dependent, requires more medical treatment	50
Dependent with specific care	40
Totally dependent, requires hospitalisation, death not impending	30
Moribund, needs hospitalisation with full medical treatment	20
Comatose	10
Death	0

(WHO, 2004)

An explanation of the above table follows. The scale relates purely to physical ability and covers 11 points, from normal health to death, each scored as a percentage. The researcher is aware that the definitions of each stage are not very precise, since they do not include feelings and emotions. Nevertheless, this remains a very useful scale against which to measure the functioning of the HIV/AIDS patient.

The researcher is of the opinion that counsellors in general are not familiar with the *Karnofsky Scale* and thus do not use it to motivate patients with regard to their adherence to ART and how this will affect their quality of life. She further holds the view that the counsellors should be more aware of the clinical facts



and how these influence quality of life. This knowledge would assist with the process of motivating patients to adhere to treatment. The aforementioned is a further indication for the reason why counsellors dealing with ART and adherence issues should be well-trained and experienced.

3.5.2 Virological response

One of the goals of ART is to suppress the viral load. The anticipated response to ART in a treatment-naïve patient, who adheres to treatment, is a viral load of less than 50 copies/ml at 24 weeks (6 months) of treatment (WHO, 2006).

If the viral load has not been suppressed after a few months of therapy, or, if it increases again after initially having been suppressed, it is a cause for concern, since it might indicate treatment failure. A detectable viral load measurement, on two separate occasions, in an individual who has had a previously undetectable viral load, needs further investigation and assessment.

Virological failure should also be considered in the following scenarios:

- A decline in viral load of not more than one log within 8 weeks after commencing therapy; and
- A sustained increase in viral load of greater than 0.6 log from its lowest point or a return to 50% of the pre-treatment value (WHO, 2006).

Poor adherence is the major cause of failure to achieve viral suppression with existing ART regimens. The greater the number of doses taken correctly, the more likely it is that virological suppression will be achieved, and therefore, maintained.

Table 7: Correlation between Adherence and Virological Response to ART

Adherence to ART*	Viral load <400 copies/mm³
>95% adherence	78%
90% to 95% adherence	45%
80% to 90% adherence	33%



70% to 80% adherence	29%
<70% adherence	18%
Number of doses dispensed minus tablets returned over number prescribed e.g. (30-5)/28=25/28=0.9 (90%)	

(Chesney, 1997:2 and Friedland, 2003:35)

The above table can be explained as follows: To achieve an 80% chance of complete viral suppression, more than 95% of doses need to be taken; for a twice daily regimen this means missing less than one dose every second week. There is a rapid decline in virological benefit as adherence drops. Someone taking 70% of the doses has only a 6% chance of achieving viral suppression at 1 year. The present writer firmly believes that it is important for the counsellors to understand the above and to be able to explain this to patients during their assessment for ART.

3.5.3 Immunological response

The researcher argues that the CD 4 count is one of the most useful markers of the state of the immunity in a person with HIV/AIDS and remains the cornerstone of judgment of the progression of HIV/AIDS in order to indicate to patients the restoration of their immune system; and thus motivates them to continue with ARV medication.

One of the goals of ART is that the CD4 count of the patient should rise and remain above the baseline count. According to the selection criteria of the National Antiretroviral Treatment Guidelines (2003:4), as previously mentioned above, the following patients are candidates for ARV treatment:

- CD4 count <200 cell/mm³, irrespective of WHO stage; or
- WHO stage IV disease, irrespective of CD4 count

In other words, treatment can only be initiated for patients who are diagnosed with AIDS. Patients whose CD 4 count are > 200, but who suffer from an AIDS-



related cancer, and possibly need chemo- or radiation therapy, also qualify for ART.

The CD4 response is generally a mirror image of the HIV/RNA decay curve, with increases that average 50-60 cells/mm³ in the first 4 months on ARV, with subsequent increases at a rate of 8-10 cells mm³/month or 100-150 cells/mm³ per year with good viral suppression. However, a discrepancy can exist between the viral load and CD4 count, where the viral load is at a lower than detectable level, but the CD4 count fails to rise. The cause of this cannot always be found, but probabilities are TB infection or CMV (cytomegalovirus) and EBV (Epstein-Barr virus) infection.

It is reported in Bartlett, Gallant & Joel, (2005:3) that a CD 4 count should increase by 50% after 8 months of treatment. However, this count has two major limitations, namely it is subject to considerable variation and it only reflects existing damage to the immune system. The CD4 cell count is therefore not ideal for predicting future damage to the immune system in any given individual. Patients on ART should be monitored regularly:

- Where possible at 6 to 8 weeks after commencing ART in order to assess initial response to therapy;
- Four- to six-monthly thereafter if the patient has responded to therapy or is clinically stable; and
- A repeat assessment of both CD4 cell count and viral load is indicated if routine measurements yield unexpected results, or the individual's clinical condition changes (South African, 2003).

Immunological failure Is defined as a 30% drop in the CD4+ cell count from the peak value or a return to the pre-treatment baseline or lower. Some patients obtain virological suppression but the immune system is so severely compromised that it is impossible to regenerate and as a result immunological and clinical treatment success is not achieved. Furthermore, it is important to understand that the CD4 count is affected by numerous other conditions, where



a marked diurnal and seasonal variation occurs, and also, any intercurrent infection, for instance influenza, can also cause a temporary decrease in the CD4 count according to the HIV/AIDS Bureau: Women's HIV Care Guide, 2005: <http://hab.hrsa.gov/publications/womencare05/WG05chap4.htm>

The CD4 cell count is one of the methods used to assess effectiveness of ARV therapy. Throughout this assessment, the multidisciplinary team involved in the field of HIV/AIDS's, faces additional challenges with regards to the availability of ART and in particular, issues of adherence. The present researcher contends that the issue of adherence to ART has brought the importance of multidisciplinary teamwork in health settings to the forefront, and calls for health providers to work together towards one common goal. Patients must be educated about the importance of adherence, which is an indication for teamwork since each team member, as a specialist in his/her field, will be able to contribute to adherence issues.

3.6 Strategies in Treatment Failure

Literature differentiates between three types of treatment failure: virological, clinical and immunological, as explained above (Abdool Karim and Abdool Karim, 2005:514). In many cases, the effects of anti-HIV drugs decrease over time and possible causes of treatment failure are as follows:

- HIV develops resistance to one or more of the drugs;
- Cross-resistance (resistance to a specific drug can afford resistance to the whole class);
- Low blood-levels because of decreased absorption of the drug – e.g. due to persistent vomiting or chronic diarrhoea, as found in HIV enteropathy; and
- Problems with adherence.

The optimal response to treatment failure will depend on the reason for the failure of the current regimen. If it seems likely that the patient has developed resistance to some or all of the current drugs, the best course of action may be to switch to new drugs. Switching to a new regimen as soon as the current



therapy seems to be failing is recommended, because the longer one remains on drugs to which the HIV is becoming resistant, the greater the risk of developing cross-resistance to other drugs (South Africa, 2006).

However, switching to a new regimen as soon as possible poses the risk of going through the available drugs too quickly. It is important to consider to which of the other drugs the HIV may have developed a cross-resistance, and to aim to select a new combination consisting of at least two drugs to which the HIV is still likely to be susceptible.

If problems concerning adherence or side effects do present, it is possible to switch medication to a more convenient regimen. If the patient regularly fails to take his/her medication correctly, the risk may simply escalate to the development of drug-resistant HIV strains. This may shorten the duration of benefits gained from the current regimen, and also limit future treatment options (South Africa, 2003).

Adding or changing a single new drug, within a combination, that does not suppress the viral load, is likely to lead to the development of drug resistance, because the impact of that single new drug is likely to be insufficient to block replication. Experts now advise that wherever possible, changes in treatment should always include at least two new drugs, because resistance to some drugs develops progressively and as more resistance mutations accumulate, sensitivity to the drug will decrease. However, resistance to drugs emerges at varying rates. In many cases, the effects of ARV medication decrease over time. At some point, the patient and the ARV team may decide that the current treatment is failing and that it is time to switch to other drugs.

A blood test that measures whether the patient is receiving sufficiently high levels of the drug, called the plasma concentration test, is not readily available. Furthermore, the therapeutic and adverse effects are not precisely quantifiable for all tests (Isselbacher *et al.*, 1999:403). If treatment failure occurs, despite taking drugs in the recommended manner, it may be necessary to increase the doses or attempt other ways to improve drug levels; for example, to take a



combination of drugs which interact and boost the levels of one or more of these. The class of PIs lend themselves to this type of intervention. The PI, Ritonovir, a very strong inhibitor of the liver enzyme system called p450, is responsible for the elimination of drugs from the body. By slowing down the metabolism and elimination of the other PIs, it increases their levels in the blood. It is thus a useful addition to any PI-containing regimen (South African, Medicine Formulary, 2006).

3.7 Side Effects and Drug Interactions of Art

A wide variety of ART drugs are currently available, but ARV drugs, like most chronic medications, do not come without their negative aspects such as a heavy pill burden (having to take too large a number of pills), drug interactions, drug toxicity and side effects. All these adverse event, coupled with adherence issues and individual factors, such as pill fatigue (patients become tired of taking medication on a daily basis), transport problems, long clinic queues and issues concerning disclosure, make ART a very complex issue.

3.7.1 Medication or drug interactions

These can be classified as pharmacokinetic or pharmacodynamic. Pharmacokinetic interactions involve the interaction of the medication with the body and may manifest in changes in drug absorption, distribution, metabolism and excretion. Pharmacodynamic interactions refer to interactions between different medications, in the body, and may result from competition at receptor sites, or the activity of two drugs in the same physiological system. The effect may be additive, synergistic or antagonistic. An additive effect occurs when the action of one drug is strengthened by the action of another. A synergistic effect occurs when the action of one drug enhances the action of another. Lastly, an antagonistic effect occurs when the action of one drug interferes with, or antagonizes, the action of another, thereby diminishing its effect (Isselbacher, *et al.*, 1999:403).

Interaction between medications is a frequent occurrence since not only is ARV medication prescribed for HIV-infected patients, but, also, multiple drugs for the



prophylaxis of opportunistic infections, side-effects, or the treatment of concomitant illnesses, both acute and chronic. All these medications can interact on different levels and cause additional problems. Patients may also seek medical care from more than one practitioner or healthcare facility, often causing duplication of medication with additive toxicity or significant drug interactions. Furthermore, patients make use of over-the counter and traditional, or herbal, remedies, as well as illicit and recreational drugs that might interfere with prescribed medication.

As access to ART expands in South Africa, the potential for drug interactions with ARV medication becomes increasingly important (Cohen, Andrews & Maartens, 2002:42). In South Africa, an additional factor exists: many people believe in traditional medicine, and according to the *National Comprehensive Treatment Plan in South Africa*, about 90% of HIV-positive patients take some complementary, herbal, or traditional medicine together with ARV medication. Research regarding herbal or traditional medicine is still very limited and patients should be counselled with regards to the possibility of drug interactions and toxicities (South Africa, 2006).

With the increasing availability of ART in South Africa, questions have arisen with regards to drug toxicity. Jones & Nelson (2005:18) state that drug resistance and ARV toxicities are emerging as major treatment challenges in the HAART era. Novel ARV drugs should be designed to overcome the resistance evoked by current agents and reduce toxicity, thus enhancing adherence. The *National Antiretroviral Treatment Guidelines* (South Africa, 2004) recommends the following principles for managing the adverse events of ART:

- Establish whether the adverse event is due to ARV agents, other medication, or illness;
- Never to stop only one ARV drug - if there is a need to discontinue ART, all ARV medication must be stopped together; and
- This is to prevent the development of resistance.



One of the major factors that influence adherence to ART is the treatment regimen, since pill burden and complexity of regimen are important contributors to poor adherence. Heyer and Ogunbanjo (2006:5-9), postulate that good adherence is associated with a low pill burden and optimum treatment regimens selected by patients include: two or less pills per day, no dietary restrictions, small pills, all drugs combined into one pill and once-a-day dosing. In the developing world, we are still very far from this ideal, with some patients taking up to 10 different medications daily, and some regimens requiring dosing three times a day. It is for this reason that support, counselling and monitoring patients on ARV is mandatory.

3.7.2 Adverse drug reactions and side effects

These side-effects of ART are realities of HIV treatment. The side-effects can be classified as acute- and long-term, and as mild to severe (rarely fatal) reactions. Pharmacokinetic variability of absorption, distribution and elimination of drugs varies from patient to patient, and flexibility in dosages is necessary (Davidson, 2002:153). Some of the most commonly reported side effects reported according to the Department of Health (South Africa, 2006), follow:

Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs)

Efavirenz is associated mostly with psycho-neurological side-effects, which include dizziness, insomnia, impaired concentration, drowsiness, abnormal dreams and hallucinations, and in more severe cases, manic and paranoid reactions, as well as severe depression or anxiety. This class is also prone to cause hepatic toxicity, and Nevirapine, in particular, is known for its association with a skin rash and systemic hypersensitivity (Rossouw, 2006).

Nucleoside Reverse Transcriptase Inhibitors (NRTIs)

This class can be divided into the D-drugs and non-D-drugs. The most commonly used D-drugs are d4T and ddI which are associated with mitochondrial toxicity, manifesting as myopathy (weakening of the muscles), peripheral neuropathy, pancreatitis, hepatic steatosis (fattening of the liver),



lipoatrophy and hyperlactataemia (build-up of lactic acid in the blood) and lactic acidosis (Rossouw, 2007).

AZT is mostly well-tolerated but can cause bone-marrow suppression with subsequent anaemia (reduction in the body's oxygen-carrying capacity leading to fatigue) and neutropenia (reduction in infection-fighting cells in the body leading to an increased susceptibility to infections) (Rossouw, 2007).

3TC is the best tolerated of the class, but can lead to the same non-specific side-effects of the class, such as headache, malaise, myalgia, anorexia and nausea (Rossouw, 2007).

Protease Inhibitors (PI)

This class of ART is very potent and has mostly long-term metabolic side-effects, such as dislipidaemia (increase in total cholesterol, especially an increase in low density lipoprotein – LDL – that is associated with an increased risk of cardiovascular events like heart attacks and strokes), insulin resistance leading to type 2 diabetes mellitus, hyperuricaemia (leading to gout), and lipodystrophy (where fat in the body is taken away from the legs, arms and face and redistributed to the abdomen, neck and breasts, leading to a characteristic appearance that is increasingly being recognised as the 'new' face of HIV (Rossouw, 2007).

Charalambous' study, as quoted by Churchyard and Metcalf (2005:10), found that adverse events were common in patients (41%) but that the majority of adverse events were mild to moderate (88%) and transient, usually only lasting two to four weeks. The most common side-effects were anaemia and elevated liver enzymes. Severe adverse events, which resulted in hospitalisation and death, occurred in only 1.2% of cases (Rossouw, 2007).

The researcher contends that the prevention and management of side-effects of ARV drugs offer an essential challenge to all involved in ART management. Side-effects and adverse reactions continue to affect the patient's decision to commence treatment, to continue, and to adhere to the prescribed regimens. It



is the responsibility of the treating clinic to educate and counsel patients with regards to the possible side effects. While a single dose of aspirin may be enough to treat a headache, in contrast, life-long, continuous adherence to ART is required in the treatment of HIV. This daily burden of taking pills and pill fatigue is a problem reported by ART patients, which is a serious factor that should not be underestimated when addressing adherence issues.

3.8 Other Uses of Antiretroviral Therapy

Prophylaxis can be defined as a means to prevent HIV infection from occurring. Since 1988, post-exposure prophylaxis, for occupational exposure to HIV, has been prescribed by doctors.

3.8.1 Post- exposure prophylaxis

Post-exposure prophylaxis is indicated in healthcare workers after exposure to infected blood products or fluid, and also in the general population after traumatic or sexual exposure (Spencer, 2005:235). *The National Antiretroviral Treatment Guidelines* (South Africa, 2004:72), acknowledge the fact that healthcare workers have a low, but measurable risk of HIV infection after accidental exposure to infected blood or body fluid. Accidental exposure to HIV, following a hollow needle-stick injury and percutaneous exposure to infected blood, remains frequent within the context of healthcare. The risk remains low at 0.3 % (Van Dyk, 2004:72).

Healthcare workers at risk are doctors, nurses, hospital cleaners, allied workers, such as physiotherapists, ambulance personnel and healthcare students, while non-healthcare workers at risk include rescue teams, police, crime scene attendants and sewerage-plan workers.

3.8.2 Sexual exposure or raped victims

All women and men presenting to a health facility after being raped or sexually assaulted, should be counselled concerning the potential risks of HIV transmission post-rape. It is important to know the HIV status of the patient prior to administering any anti-retroviral treatment, although it should always be kept



in mind that the patient might still be in the window period, and hence exhibit a false-negative HIV test.

There is strong non-experimental support that the use of ART in preventing HIV sero-conversion could be effective in preventing HIV transmission caused by exposure. The medication is used for a period of 28 days as prophylaxis. The importance of adherence should be explained to patients. Patients should present themselves to a health facility within 72 hours of being sexually assaulted. All post-rape prophylaxis cases should be carefully monitored and evaluated (Grimwood, 2004:73).

3.8.3 Prevention of Maternal-To-Child Transmission (PMTCT)

Programmes to prevent mother-to-child transmission of HIV (PMTCT) were initiated by the National Government in December 2000. PMTCT counselling and testing is the most common entry point into HIV care for women. Pregnant women have an opportunity to initiate ART treatment during pregnancy in order to experience the dual benefits of the reduction of vertical transmission as well as sustaining health, according to the *National Antiretroviral Treatment Programme guideline for carers* (Grimwood, 2004:66).

Notwithstanding the availability of prophylaxis, a sound support programme must be in place. The exposed person must be monitored and fully informed regarding ARV drugs, side effects, and sero-conversion. Counselling is a critical component of the management of the use of ARV drugs for the exposed, as well as PMTCT.

3.9 Summary

The worldwide increase in the prevalence of ARV resistance is of particular concern to researchers and practitioners. Since resistance remains one of the most significant threats to the long-term success of any HAART regimen, practitioners are anxious to learn from past mistakes, translate new knowledge into appropriate treatment strategies and develop new drugs that retain useful activity in the face of established resistance (Miller, 2004:23).



In this chapter, matters related to ARV that were considered are: the goals of ART, different ARV drugs, response and prognosis to ARV treatment, and treatment failure. The present researcher believes that it is only when one understands the pathophysiology of HIV/AIDS, the pharmacology of ARVs, and the response of the body of the patient to ART, coupled with the importance of adherence, that long-term strategies can be developed.

She will proceed to discuss resistance; adherence; predicting adherence; special adherence groups; patient, providers and regime matters influencing ART; placing a specific focus on the adherence team. Adherence support in the different adherence phases and strategies to support adherence, such as medication alerts and measuring adherence, will also be discussed in the following chapter.



CHAPTER 4: RESISTANCE AND THE ROLE OF ADHERENCE IN ANTIRETROVIRAL THERAPY (ART)

4.1 Introduction

The introduction of HAART has extended and improved the quality of life for people living with HIV by reducing their viral load, often to undetectable levels. However, the initial enthusiasm for these drugs has been dampened somewhat by the discovery that they require near-perfect adherence to prevent virus replication and mutation. Strict adherence to the antiretroviral treatment regimen is essential in order to obtain the desired benefit and to avoid the emergence of drug resistance and clinical failure.

Regarding the issue of adherence, Friedland (2003:39) states “Added to the challenge of more widespread and equitable access to antiretroviral therapy in South Africa and elsewhere, is the issue of adherence to these therapies. Clinicians need to develop and employ strategies to support antiretroviral adherence that are practical, relevant and appropriate to the African context.”

The multidisciplinary team involved in the field of HIV/AIDS, faces additional challenges with the greater availability of ART, particularly concerning matters of adherence. The researcher is of the opinion that the issue of adherence to ART has brought to the forefront the importance of multidisciplinary teamwork within health settings. It calls for health providers to work together towards a common goal.

For ART to be successful, education is at the core of the treatment programme. Patients must be educated with regards to the importance of adherence and the potential of developing resistance to ARV medication. As previously quoted, Isselbacher, *et. al.*, (1999:1910) confirm the above: “The cornerstone of HIV prevention strategy is education, counselling and behaviour modification”.



The social worker, who renders services to HIV/AIDS patients referred for ART, should focus on the provision of information in order to ensure the development of insight with regards to treatment, and, also, interventions that will motivate, support and promote adherence.

4.2 Adherence

Adherence is defined by the *R.S.A. Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment* (South Africa, 2003:4) as the act or quality of sticking to something, or of adhering to something.

Adhere is also defined by *The Concise Oxford Dictionary* (1995:272) as: “to behave according to; follow in detail, faithfully observing a rule”.

Adherence is also defined by Bartlett (2005:68) as the degree to which a patient carries out the clinical recommendations of a treating physician, that is, takes the correct dose of medication at the right times, every day.

Adherence behaviour is defined by Mosby’s *Pocket Dictionary of Medicine, Nursing & Health Professions* (2006:34) as “self-initiated action taken to promote well-ness, recovery, and rehabilitation”.

Compliance is defined by *Dorland’s Illustrated Medical Dictionary* (1994:388) as: “the act of conforming. Compliance, the act or an instance of complying, obedience to a request, command”. The term “adherence” is preferable to “compliance”, as compliance implies that some prompting is necessary to ensure that the medication is taken, whereas adherence is voluntarily carried out by the individual.

Adherence to ART, specifically, means how correctly a person manages to take his/her ART medication. It is important to take this medication exactly as prescribed, by sticking rigidly to the suggested dose and timetable, while also observing instructions concerning food. Taking too little of the drug (by missing



or reducing the doses), could allow drug levels in the blood to fall to inadequate levels, thus allowing viral replication to occur, and, therefore, increasing the risk of resistance.

Carter (2004:1) summarises adherence to HAART as:

- Taking all the medicine in the right quantities;
- Taking the pills at the right time;
- Taking the medication with or without food according to instructions; and
- Checking for interaction with any other medication or drugs.

The *Foundation for Professional Development* (2005:153) has differentiated between two different types of adherence:

- Ritual (more passive) treatment adherence behaviour manifested by absolutely following “to the letter” a prescribed therapeutic regimen, e.g. a patient continuing to take medicine without consulting doctor/health team even when he/she experiences serious uncomfortable/undesirable side effects.
- Regarding adherence in general, Kaplan, Sadock & Grebb (1994:11), postulate that in general, about one third of all patients comply with treatment, one third sometimes comply with certain aspects of treatment and one third never comply with treatment.

Venter (2005:22) reports and warns against “adherence overkill, multiple demands before initiation of ART, for example, for multiple visits before initiating ART or demand to disclose a patient’s HIV status”. The researcher is of the opinion that disclosure cannot be demanded, since this would go against the individual’s right to privacy and confidentiality, as well as the basic social work principles, such as self-actualisation. The role played by the social worker in the assessment of patients with regards to disclosure and referrals to alternative support and networking, is essential.



Most experts (Gerberding and Sande, 1999:1470; Isselbacher, *et al.*, 1999; & Kasper, *et al.*, 2005:1853) accept the following treatment principles:

In terms of ART, adherence means adhering to a regimen, while for the patient, it means:

- Taking all the pills and doses in the manner prescribed by the doctor;
- Maintaining certain lifestyle patterns, such as avoiding unsafe sexual practices in order to avoid infection by other strains of HIV or drug-resistant viruses;
- Attending follow-up appointments, collecting scripts;
- Maintaining a healthy diet; and
- Other therapeutic behaviours as indicated e.g. exercise and adequate sleep.

According to the Foundation for Professional Development: (2006), HAART is very complex, requiring a very committed and well-informed patient, and the following is presented in their HIV/AIDS management guidelines / protocol (South Africa, 2003) for lay counsellors.

- Different drugs have different requirements;
- Different drugs have different side- effects;
- Treatment is a life-long commitment;
- There is the issue of resistance, which has to be explained and understood, especially regarding why drugs cannot often be re-used;
- There is a strict monitoring and adherence procedure;
- ART drugs interact with other drugs, including herbs;
- Sexual behaviour modification has to be maintained; and
- Patients should never commence therapy until they are fully aware of and accept the implications of the treatment decision.

As previously stated by the present researcher, she opines that both compliance and adherence refer to the act of maintaining a treatment regimen. Adherence captures the increasing complexity of medical care by characterising



patients as independent, intelligent, and autonomous people, who take more active and voluntary roles in decision-making regarding their treatment.

Rier & Indyk, (2006:137) discuss the use of the term “concordance”, as it promotes power sharing between provider and patient, respecting the patients’ perspective. According to the above, concordance is based on the notion that the work of prescriber and patient in the consultation, is a negotiation between equals. The aim therefore is a therapeutic alliance between them. “Its strength lies in a new assumption of respect for the patient’s agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust or concealment”.

Adherence is an aspect that should be addressed by the multidisciplinary team involved in HIV/AIDS and ART. The need to assess and counsel patients regarding adherence, prior to treatment as well as at the time of the initiation of ART, is strongly indicated. Continuous assessment, monitoring and support are further indicated. The social worker, with specialized knowledge and skills, is equipped to be part of the multidisciplinary team that renders a service in this regard.

4.3 Resistance

Literature differentiates between three types of treatment failure: virological, clinical and immunological, as explained in the previous chapter. In many cases the effects of anti-HIV drugs decrease over time, and a major cause of treatment failure is the development of resistance (Gerberding and Sande, 1999:1470 and Isselbacher, *et al.*, 1999:1853).

HIV replicates at very high levels producing up to 28 billion particles per day. When HIV, RNA is converted to viral DNA, the mechanism is prone to error and the virus does not rectify mistakes. Inhibition of the reverse transcriptase enzyme, often places pressure on the transcription process and in the presence of low plasma levels of the drugs, causes selective mutations, which may lead



to drug resistance. Once the mutation arises, a new population of drug resistant virus develops which over time will become dominant and cause further disease progression and virological failure (Foundation for Professional Development, 2006).

Resistance can develop whenever the HIV continues to reproduce whilst ARV medication is being taken. Resistance is an important reason why many ARV drugs have limited or short-term effects. Whenever HIV is still able to reproduce in the body of someone who is on ARV medication, it is extremely likely that resistant strains will eventually emerge and the viral load will increase. A micro-organism is most likely to develop resistance to a drug if the blood level of the drug is too low to prevent it from reproducing, but high enough to affect how it evolves in one's body (Abdool Karim & Abdool Karim, 2005:514).

Studies have indicated that the risk of viral load rebound is related to the point to which viral load falls after commencing treatment, called the "nadir". The lower the nadir, the lower the risk of rebound, and therefore, the less the risk of resistance. People whose viral load falls, and remains, below 50 copies, are at a much lower risk of developing resistance. However, resistance may emerge even in these people, over the long term (Isselbacher *et al.*, 1999:1853; Spencer, 2004:10 & Van Dyk, 2004:66).

Cross-resistance

Once the HIV develops resistance to one drug, it may also be resistant to other similar drugs; thus cross-resistance occurs. A single mutation or set of mutations in the virus can produce resistance to several different drugs within the same class. This means that once resistance to one drug has emerged, this virus population may also be resistant to drugs, which the patient has not yet taken.

Cross-resistance may affect all currently available anti-HIV drugs to a greater or lesser extent. For example, it is possible that if one develops resistance to a protease inhibitor (PI) or a non-nucleoside reverse transcriptase inhibitor (NNRTI), the patient will also be resistant to all other inhibitors in the same



group. By using two or more ARV drugs (combination therapy), one could delay resistance, since a virus that is resistant to one of the drugs, may still be controlled by the other(s).

Several tests have been developed so as to indicate to which drugs a patient is resistant, and also, the level of resistance to these. Currently, it is not known how useful these tests will be in guiding treatment decisions. Where resistance typing is available and affordable, this will assist in making an informed decision. In resource-poor situations and in the current South African circumstances, these tests remain a luxury and are mainly used after second-line regimen failure. Two types of drug resistance tests are available.

Genotypic testing

This type of testing characterizes the nucleotide sequence of reverse transcriptase and protease. It then compares the test result with an existing data pool of mutations, which confirms resistance. Mutations can be detected before phenotypic resistance occurs. Only dominant species are detected. For the test to be conducted, a viral load of >1000 copies/mL is required. This test is less expensive and has a shorter turnaround time than phenotypic testing. (Spencer, 2005:30)

Phenotypic testing

This is a quantitative assay, which is analogous to bacterial antibiotic resistance testing and also requires a viral load of >1000 copies/mL. It is currently not freely available in resource-poor settings because it is very costly (Spencer, 2005:30).

With the great advances that have been made in ART, most literature confirms Miller's (2005:23) view, that in addition to all the challenges of ART, the patients must be educated with regards to the potential development of resistance to ARV drugs and its consequences as well as the implications of non-compliance and the resulting importance of adherence. The social worker possesses the necessary skills to facilitate the development of insight and provide clarity regarding this complex issue.



4.4 Predicting Adherence

Unfortunately, there are no absolute predictors of adherence. It is not possible for healthcare providers to reliably predict which individuals will ultimately be adherent to their treatment plan, since adherence does not correlate with gender, cultural background, socio-economic or educational level. It is known that people with a persistent alcohol problem, or those who are acutely depressed, will experience difficulty with adherence, so these issues must be thoroughly addressed prior to the commencement of ART.

British HIV Association (BHIVA:2003) suggest that the terms, low and high adherence, be used in preference to adherence and non-adherence. Low adherence can be described as adherence below the expected levels, which would enable successful responses to treatment. Low adherence increases the risk of treatment failure and disease progression, with the further threat of the transmission of a resistant virus. Omitting to take all the doses, taking an incorrect dose, or taking a drug in such a manner that insufficient quantities are absorbed, may lead to a more rapid development of resistance to the drug and the patient may cease to benefit from it. The consequences of low adherence are serious, because not only do they pose the threat of disease progression to the individual, but also to public health, due to acquired resistance (the increase in transmission of a resistant virus to newly infected individuals). High adherence describes adherence levels expected to enable successful treatment responses.

Barriers to adherence as outlined by Horizon (2003:33), and supported by the researcher are:

- Communication difficulties;
- Low literacy levels;
- Inadequate knowledge or awareness of HIV disease;
- Inadequate understanding of the treatment regimen;
- Discomfort with disclosure of HIV status;
- Patient attitudes and beliefs in treatment efficacy;



- Depression and other psychiatric problems;
- Alcohol and or active drug abuse;
- Difficult life conditions;
- Unstable living conditions;
- Negative or judgmental attitude of health providers; and
- System barriers.

The researcher holds the view that the individual circumstances of patients must always be taken into account concerning adherence issues. Venter (2005:23) states that wellness programmes usually call for an improved diet, the cessation of smoking, moderating the consumption of alcohol, the practice of safer sex, adequate exercise, and participation in support groups, routine clinic visits, and disclosure. There have been reports that people have been denied access to ARVs because they have not fulfilled one or all of the above criteria, each one of which is notoriously difficult to implement among the general population. Provision must be made for individual circumstances.

The said researcher promotes a thorough biopsychosocial assessment of each patient, taking into account the rights of the patients as independent, autonomous individuals, as well as their right to medical care National Health Act, 2003 (Act No. 61 of 2003) and with regards to the decisions concerning their treatment.

Discrimination and the denial of a patient's access to ART as well as the demand for certain behaviour, for example, that patients disclose their status; that, patients be accompanied by a "buddy" or a person to provide support; that they need to attend multiple clinic visits before initiating ART, and that patients need to produce identification documents, before treatment can be initiated, are contraindicated by the *Bill of Rights, in the Constitution of the Republic of South Africa 1996* (Act No. 108 of 1996).

Predictors of good adherence to therapy that have been noted are:



Availability of emotional and practical types of support, such as informed family and friends, adherence support groups, community-based case managers, peer educators, and a trusting relationship with the healthcare team;

- The ability to fit medication into a daily routine;
- The understanding that poor adherence leads to resistance;
- Feeling comfortable taking medication in front of people;
- Keeping clinic appointments;
- Belief in medication, by both patient and provider;
- Personal determination;
- Improvement of symptoms while on therapy; and
- Availability of adequate food and regular meals.

The researcher concurs with the *British HIV Association* (BHIVA: 2003) (2003) view that support for adherence should be provided to all patients on HAART. ART should not be withheld on the basis of assumptions regarding adherence. The researcher is further of the opinion that adherence support is an ongoing process which begins prior to the initiation of ART, with continuous monitoring throughout the treatment.

The social worker can motivate and provide ongoing emotional support to patients by employing various techniques such as clarification, catharsis, confrontation, interpretation and offering advice. Also, by simply listening, explaining, reflecting and summarizing, the patient can be successfully guided with respect to the development of insight into their treatment.

4.5 Strategies for Measuring Adherence

Adherence to therapy is difficult to measure accurately. The methods employed to measure the level of adherence include self-reporting by individuals, the doctor's estimates, tablet counting, pharmacy refills, and measurement of drug levels.

No measurement of adherence is completely accurate. Adherence to HAART can be measured by employing a range of methods. The purpose of



measurement tools is to support and emphasise adherence, not as a tool to “catch out” patients. Furthermore, the dynamics of provider-patient relationships may clearly impact on the willingness of individuals to disclose problems.

The said researcher distinguishes between some objective measurements of adherence, such as medication management, patient support and campaigns. Subjective measurements, as reported by Horizon/Population (2005:8), some of which were mentioned above, are: self-reporting, pill counts, pharmacy records, electronic devices and measurement of drug levels. The researcher is of the opinion that some modes of measurement appear to be more accurate than others and that no one measuring tool can be established as the one and only form of measurement.

- **Self report**

Patients can be prompted to report pill taking during any period or day in self reporting. Self-reporting agrees well with the actual intake of medication and viral load. It is inexpensive and easiest to implement in a clinic setting. Clients should be approached in a matter-of-fact and non-judgmental manner, and questioned with regards to the most recent days and missed doses.



- **Routine and random pill counts**

One of the most common modes concerning measurement of adherence, as evident from the literature, is clinic-based counting of tablet returns. It provides a reasonable estimate, in the majority of cases, and can be carried out at every visit. The counselling team can also perform a surprise tablet count at the patient's home once in a while, which is not always feasible due to the heavy workload of counsellors. A problem that occurs with respect to pill counting is that patients can dump pills prior to visits. It may also promote a sense of distrust between the patient and provider. This problem could be overcome by another available method, namely Electronic Medication Monitoring (MEMS), which has data incorporated into a memory chip.

- **Pharmacy and medical appointment records**

The pharmacy staff can play a major role in adherence issues by reporting their issuance of drugs, since in any case; they are required to maintain records of medication dispensed to patients. By monitoring the patient's medical appointment records, patients failing to keep their medical appointments can be contacted.

- **Biological markers of effectiveness of treatment and drug level monitoring**

Adherence levels can also be monitored by means of a laboratory investigation of the drug plasma concentration, plasma HIV1 (Viral load), RNA and CD 4 cell counts.

- **Direct observation (DOT)**

DOT is an intensive programme in which patients take their medication under the supervision of adherence staff. In the case of ART it is not practical to observe whether all the doses are being taken.

Most HAART regimens comprise multiple doses and treatment is lifelong. Therefore, only some doses are observed for a fixed period of time. This is called modified DOT or directly administered antiretroviral therapy (DAART),



which can be carried out at health centres, in community-based organizations or even at a patient's home. DOT seems to provide a better account of adherence, since patients are unable to prepare their returns in advance; however, this is labour-intensive. Our present primary care service is not able to provide this support continuously for a twice- daily regimen.

Measuring pill-taking behaviour has its limitations and the present researcher wishes to emphasize that none of the measuring aids are perfect. Adherence is still an individual matter. A thorough assessment of the biopsychosocial matters influencing, or imposing on, adherence is indicated for each patient (Webster & Barr, 1999:1-16). The social worker should promote alerting strategies to enhance adherence by means of education and constantly reminding team members and patients being monitored.

4.6 Medication Alert Strategies to Enhance Adherence

The use of medical alerts and reminders, such as pillboxes, can overcome some of the scheduling demands. These methods are also associated with good adherence. There are a variety of alerts available to assist patients to remember to take their medication, since forgetfulness is a very common reason why people do not take their medication. Horizon (2005:8) distinguishes between the following methods of enhancing adherence counselling: medication diaries, pill boxes, a "buddy" system, incentives, electronic devices such as pagers, alarms, beepers:

- **Pill diaries and medication charts or booklets**

Confusion over which pills to take, when and what; times to eat or avoid food may be a problem when starting a new combination. A written daily schedule which patients can tick off after taking a dose could be helpful. Patients who experience difficulty with which pills to take, when to take them, and with remembering or understanding medication schedules will benefit from clear written instructions. A written daily schedule, on which the prescription is specified, can be ticked off after taking a dose. This is



a useful tool in order to identify patterns of use and reasons for missing doses.

- **Labelling pill boxes**

Labelling pillboxes for dosing and dosing instruction cards can be supplied by the provider, doctor, and pharmacist or adherence counsellor, while taking into account the literacy level of the patient. Patient planners, such as newsletters, videos, or booklets, are also recommended in order to reinforce the central role which patients themselves play in managing their own adherence.

- **Pill charts**

Pill charts are used to visually display pills (their colour and shape), while the names and dosage for each medication are used by the nurse or health provider during counselling.

- **Electronic devices**

If the problem seems to be forgetfulness and a need for a reminder is apparent, cell phones, computers, alarmed or programmable wristwatches or alarm clocks, can be useful. The alarms are saved in the memory, the watch does not have to be reset every day and an eight-letter message can be set to scroll across the watch or cell phone together with an alarm. Computer technology, with message software-scheduling programmes, can also be adapted for this purpose. Electronic devices need to be discreet to avoid stigmatism and confidentiality-related issues. Internet-based confidential reminder services are also available.

- **Telephone reminder**

Telephone reminders are being tried out in some studies of adherence. This is labour-intensive and its high costs are borne by the staff only, and also, patients must have a telephone available at all times.



- **Medication containers/Pill boxes**

Special containers are available for storing and transporting pills. These partitioned containers can be filled once a week, or every few days, with the individual daily doses. Some versions allow one to take out a single day's dose, or several, if need be. Attention should be paid to ensuring that the box is large enough and that the drugs are suitable for storage outside of their original container. Some pills deteriorate if not stored correctly. Patients who are illiterate or very ill may need assistance to fill the pillboxes correctly.

- **Incentives**

Incentives such as telephone cards, transport and food or shopping coupons, movie tickets, or tickets to sports events can be employed to motivate patients.

- **“Buddy” system**

The “Buddy” system relies on a friend or family member to assist and remind the patient to take medication regularly and on time, offer encouragement to persevere, help to keep hospital appointments and provide support. *The National Guidelines* (South Africa, 2004) promote HIV/AIDS status disclosure to at least one friend, family, buddy or patient advocate.

Venter (2005:22) warns that disclosure to a “buddy” may appear to be adopted as a form of punishment, rather than a mechanism to provide adherence support. As noted previously, disclosure cannot be forced, since this would go against the individual’s right to privacy and confidentiality, as well as basic social work principles, such as self-actualisation. The role of the social worker is to assess patients with regards to disclosure and referral to alternative support and networking.



- **Mass-media adherence campaigns**

Another adherence intervention, which could play a major role in adherence issues, includes mass-media adherence campaigns. Most people will respond to education, support and re-education.

The above strategies to enable and support patients to organize their treatment and take responsibility for their health can be supported, particularly, at each phase of the treatment with ART. The social worker possesses the necessary skills to educate patients regarding adherence and to facilitate alert strategies and reminders.

4.7 Adherence Support during the Different Phases

Healthcare workers are faced with a clear and extremely important responsibility to provide comprehensive information, to ensure that this information is understood, and to obtain the active consent of the patient to treatment. A responsible attitude to therapy is crucial in all healthcare facilities.

Adherence issues can be divided into different phases, which correlate with the different stages of antiretroviral medication:

- The pre-treatment phase – screening, supporting and educating patients regarding ART; Initiating phase – the day the patient is initiated with ART and educating patients regarding pill-taking matters; Monitoring adherence – would be the entire period a patient is on ART, which is, presently, lifelong; and Step-up adherence – when low adherence is suspected or reported or treatment failure is reported.

4.7.1 Phase 1: Patient pre-treatment (preparation)

Patient assessment and preparation is important in the pre-treatment phase and needs to be carried out over a few sessions prior to the initiation of HAART. This will lay the foundation for improved adherence and is an ongoing process between the provider and patient.



Thorough pre-treatment, and education, are vital in order for patients to develop a full understanding of ART, prior to commencing therapy. Realistic expectations in terms of expected health benefits, possible side effects, and the daily tablet burden, need to be explored. The patients should have a treatment plan. Furthermore, it is recommended that everyone commencing therapy must attend a number of pre-treatment education sessions. The initial assessment of patients by an experienced counsellor or social worker should include establishing the following:

- Patient's health history;
- Prior ART used;
- Medication (including traditional medicines) currently being taken;
- Patient's beliefs and attitudes concerning HIV and ART;
- Sources of social support;
- Socio-economic situation; and
- Barriers to adherence.

The above adherence support strategy is not to exclude people from ART, but rather, to reinforce daily medication-taking behaviour from the initiation phase onwards. The aim is to identify potential problems prior to commencement of ART.

The preparation of patients for treatment readiness should also include the following:

- Introduction to the treatment;
- Review social circumstances;
- Establish a treatment programme;
- Discuss the proposed adherence strategy and principles (why and how ART works, reasons for adherence, what happens to the viral load and CD4 count when on ART);
- Detail of specific medications, number of tablets and dosing instructions; and
- Expectations on the part of the clinic team of a patient on therapy.



The *National Guidelines* (South Africa, 2004) recommends a readiness assessment screening 2 - 4 weeks before starting ART, including a thorough clinical assessment, and also information and education sessions.

The researcher strongly advocates the involvement of the social worker in the pre-treatment or preparation phase. During this phase problems can be identified and addressed before they impose burdens on adherence to ART. A thorough assessment of the patient's biopsychosocial circumstances should form the basis for service delivery to HIV/AIDS patients prior to initiation of ART. The patient must be aware that adherence counselling for the patient, as well as treatment counselling, is available.

4.7.2 Phase 2: ART Commencement

Most literature confirms that, in most cases, ART is not an emergency treatment and that the patient should be fully prepared and motivated prior to commencing it. A pharmacist, with specialized knowledge of medication, should play a major role in educating patients regarding adherence issues.

Horizon (2005:36) recommends that the assessment of a patient's readiness before commencing ART should include the following:

- The patient should demonstrate an understanding of the disease and accept her/his health status;
- The patient should demonstrate an understanding of his/her treatment regimen and follow-up plan;
- The patient should appear to make a commitment toward adhering to treatment. The patient should appear to be ready to begin HAART.
- Potential barriers should have been identified and addressed to the best possible extent.

Government (South Africa, 2004) recommends the re-assessment of a patient's readiness:



- A pill count, if a 28-day supply of co-trimoxazole was supplied;
- Provision of a detailed description of the drugs;
- Discuss further information and adherence issues with the patient and his/her counsellor or advocate;
- Reinforce drug dosing details before the patient leaves the clinic;
- Ensure that instructions are clearly written on the container with a permanent marker;
- Ascertain/confirm the patient's acceptance of his/her status and ART;
- Ensure that the medical criteria are met – severe medical contra-indications (active disease that is not stabilised, including depression) should be absent; and
- Ensure understanding of the importance of adherence to and attendance at all scheduled pre-treatment visits.

The researcher argues that the assessment of the patient's biopsychosocial circumstances should be completed at the commencement or initiation of the treatment. Problems should have been identified, addressed and referred to appropriate team members. Upon the initiation of ART, the role of an experienced pharmacist and adherence counsellor, with specialized knowledge of the specific regimen, is strongly indicated.

4.7.3 Phase 3: Monitoring adherence

There is evidence that adherence decreases as time progresses. Thus, monitoring and support of adherence are essential.

Principles of monitoring

- At each visit the adherence should be monitored;
- An ART pill-returns count (note doses missed) would be ideal, but this would depend on the clinic load and capacity. The goal is >95% doses taken. Patients with adherence <80% require increased adherence support;
- Missed/late clinic visits should trigger concerns about adherence;
- Routine discussion of adherence with the counsellor (education) is recommended. This should be an open-ended discussion, with time for



questions and repetition. Feedback from therapeutic counsellors to the rest of the team is important in order to obtain a better profile of the patients and their environment;

- Continued monthly visit with therapeutic counsellors for the first three months, and quarterly thereafter; and
- Encourage participation in a support group. Patients must meet with the multi-disciplinary team for group and individual information sessions.

The researcher asserts that the continuous involvement, of the social worker throughout the treatment of HIV/AIDS patients with ART, which is lifelong, is strongly indicated. Monitoring and support of adherence is essential. New problems can be identified and addressed before they affect adherence to ART. Follow-up assessments of the patient's biopsychosocial circumstances should be carried out regularly, and an open-door approach is advisable.

4.7.4 Phase 4: Managing of low adherence

The discovery of a non-adherent patient should not come as a surprise. Management of low adherence is indicated when adherence is <80% at any visit, with or without viral or clinical failure.

A correlation between adherence and virological response to ART has been found. Fully effective adherence levels have not been defined for HAART, but as mentioned above levels below 95% have been identified with a poor response. Other data suggest that levels near 100%, if not 100%, provide the greatest benefit: thus, the better the adherence the better the virological response (Kasper, *et al.*, 2005:1853; Van Dyk, 1999: -16 & Bartlett, 2005:68). The indication is that a patient's adherence to ARV should be >95% in order to expect a 78% increase in viral load. Asking a patient to achieve 95% adherence at all times is not a small matter. Life factors, such as deaths, new relationships, financial stresses, and side effects, can result in a decrease in adherence.

According to the Guidelines of the Gauteng Provincial Government's Comprehensive Care and Treatment of HIV/AIDS and TB rollout plan for



Antiretroviral Treatment (South Africa, 2004:4), the success of ART hinges on tablet-taking behaviour. Ideal adherence means that a patient must take more than 95% of their doses (i.e. missing less than 3 doses in a month). If patients take less than 95% of their doses, they risk developing viral resistance, and ultimately, virological failure. Patients who take <80% of their doses are unlikely to have any durable virological suppression. They should be urgently targeted for an adherence improvement programme.

Some indications that would constitute low adherence and could adversely affect short or long-term adherence are:

- Missing a dosage;
- Altering a dosage (take too much or too little);
- Terminating the medical regimen;
- Self-medication with other drugs;
- Missing healthcare appointments;
- Skipping or shortening periods, between medications;
- Not following dietary requirements;
- Experiencing an alcohol or drug abuse relapse (Horizon/Population Council, 2005:7)

Around 400 B.C. Hippocrates observed that patients often do not tell the truth about whether or not they are taking prescribed medication, and cautioned his physicians to be alert to this fact. Unfortunately, more than 2000 years later, adherence is still a problem for patients and their providers. When someone's health and their survival/lives are at stake, it is difficult to understand why they will not follow their doctor's instructions, and why they do not want to play an active role in their own care.

According to the DSM IV (1994:683) the reasons for non-compliance with treatment may include discomfort resulting from treatment (e.g. side effects of the medication); the expense of the treatment; decisions based on personal value judgments, religious or cultural beliefs with regards to the advantages and



disadvantages of the proposed treatment; maladaptive personality traits or coping styles (e.g., denial of illness); or the presence of a mental disorder (e.g., Schizophrenia, Avoidant Personality Disorder). The latter category should be applicable only when the problem is sufficiently severe to warrant independent clinical attention.

As discussed in the previous chapter the, CD4 count is one of the most useful markers of the state of the immunity in a person, since its well-defined role assesses response to antiretroviral therapy. The CD 4 count in conjunction with the viral load remains the cornerstone of judgment of the progression of HIV. If the role of the CD4 count is well explained in counselling, patients tend to gain a better understanding of ARV treatment. The CD4 count is used as a reflection of the damage incurred by the immune system as well as of the restoration of the immune system in patients on ART. Thus, the level of CD4 cells in the peripheral blood is the key parameter to note in monitoring any changes within the immune response. It is reported in Bartlett, *et al.*, (2005:3) that a CD4 count should increase by 50% after 8 months of treatment.

The social worker's role in the prediction and management of low adherence cannot be overestimated. A comprehensive assessment of a patient's circumstances can provide insight into problematic circumstances and the way in which these can impose on adherence, for example, alcohol abuse. The patient can be supported by the development of insight in order to understand the influence of their behaviour on adherence and, ultimately, their health.

4.7.5 Step-up adherence package for people with reduced adherence or virological failure

Patients should not feel that they are being judged for not succeeding, but rather, that adherence is being monitored in order to allow the healthcare team to advise them and offer support additional to what has been mentioned.

The researcher advocates that because of the myriad of physical and psychosocial problems associated with HIV/AIDS, adherence should be



supported by an experienced adherence team. In addition to doctors, nurses, psychologists, and social workers, other people can readily be encouraged and trained to provide adherence counselling and support. Each team member is expected to contribute his/her own knowledge and skills directed at supporting adherence to ART. (South Africa, 2004:4)

Suggested steps for management of low-adherence:

- At the outset of the treatment patients should be advised that certain behaviour is counter-productive for effective ART treatment and may jeopardize his/her prognosis. These discussions should be documented, e.g. alcohol abuse.
- Patients should be monitored and any inappropriate behaviour or changes in their circumstances should be addressed by the appropriate team members and documented.
- Patient, family and healthcare team responsibilities for participating in all aspects of healthcare management need to be clarified. Notes of this meeting should be recorded in the patient's file.
- If these measures fail to change the patient's behaviour for the better, a meeting should be held between the healthcare team and the patient. The mutual responsibilities of the clinic and the patient should be set forth at this meeting and the patient should understand that failure to uphold his/her part could result in treatment failure.
- Try to reach an accommodation with the patient so that she/he assumes greater responsibility for his/her well-being.
- If the patient has the ability to understand the need for certain restrictions, i.e. diet, alcohol and medication – and has chosen to be non-compliant, then that is his/her choice.
- If the patient fails to comply, the patient should or could be given advance notice of his/her treatment failure.
- Discharging a patient from a treatment programme should be pursued as an option only when all else has failed.



- The therapeutic counsellor/nurse, or doctor, needs to re-educate the patient (and “buddy”) concerning the importance of adherence. The long-term benefits need to be re-emphasised.
- Evaluate the support structures, including the family situation; are they appropriate; how can these be improved? What alternatives are there?
- Consider the use of pill boxes and/or daily dosing diary.
- Insist on participation in a support group or link with a patient advocate.
- Consider doing a psychological profile.
- Redo the assessment for substance abuse.
- Increase home visits by therapeutic counsellors/patient advocates to a daily or weekly frequency, at a minimum (spot pill counts to be done at home). Consider directly-observed therapy for an agreed period.

The researcher emphasises that it is not easy for anyone to maintain such high levels of adherence. Many South Africans struggle to complete a 5-day course of antibiotics or 6 months of tuberculosis therapy. ART demands twice-daily medication, every day, including weekends, and for life. No clinic system possesses the capacity to take responsibility for monitoring every dose taken. The social worker should incorporate the abovementioned strategies in her counselling and other delivery of services to HIV/AIDS patients on ART.

4.8 Special groups with regards to adherence

The researcher argues that, in adherence issues, the different stages of psychological development, as discussed by Louw, Van Ede, & Louw (2005:149), as well as other life-influencing matters, should be taken into account. For example, to assess adherence issues in a child will hold a different dimension to those of an adult. Discussion of adherence issues with a mentally disabled person will take on yet another dimension.

The said researcher would like to propose the following groups in adherence:

- **Neonatal (0-28 days); Infancy (28 days-2 years); Childhood (2 years-12 years)**



In working with children, adherence issues can only be discussed with the primary caregiver, parents or guardians. Hanging over the process of adherence for any HIV positive child, is the potential or actual death of one or both parents, other family members or of the children themselves. This reality influences the child's perception of life, both in its possibilities and vulnerabilities.

The same antiretroviral drugs are used with children as with adults, except that the dosages are smaller and adjusted according to the age and weight of the child. Children who use ART exhibit normal growth and development. Physical functioning can be improved, complicated infections can be prevented, and the child's life can be prolonged and restored, together with the child's quality of life (Van Dyk, 1993).

- **Adolescents (12 years-20 years)**

In discussing adherence with adolescents, the focus will be different from that of children and adults, since different issues will be taken into account. Adolescence teenage development brings with it its own complications. As adolescents struggle to achieve independence, some find medication adherence, or the lack thereof, an obvious way to assert their autonomy.

Adolescents and young adults do have many unresolved issues and such matters should be discussed with the greatest of support. The adolescent can be motivated to take responsibility for their own lives.

- **Adults (21 years-60 years); Elderly (60 +)**

In these groups, adherence issues can be discussed, taking into account the biopsychosocial functioning of the individual. Children often support their parents in adherence issues.

- **Couples**

In couple counselling, confidentiality should always be ensured first. Also, matters such as disclosure, the client's readiness for disclosure, domestic



violence, and gender-related issues, should be taken into consideration in such counselling.

The researcher associates herself with Saloner's (2004:88) view, that couple counselling or couple therapy is a much more complex intervention and should be referred to somebody sufficiently skilled to carry it out.

- **Pregnant women**

With regards to pregnant women, adherence should focus on prevention of mother-to-child (PMTCT). If possible, and if the issue of confidentiality allows for it, the prospective father should be included in adherence counselling

- **Mentally and physically disabled or terminally ill people**

As with children, adherence issues should be discussed with the primary caregiver. The mentally, and/or physically disabled person often demonstrates no insight into the treatment programme and are not able to take care of themselves and would thus not be able to adhere without support.

- **Substance abusers**

Groups with special needs include drug users and alcoholics. Dependency issues should be considered and resolved on an individual basis, as it could affect adherence. Networking and referral to the appropriate team member and or institution is advised.

The said researcher emphasises that adherence is an individual matter, so that all circumstances and factors including the patient's life-stage, and other life-influencing matters, should be taken into account when assessing patients for adherence to ART.

4.9 Factors Influencing Adherence to Art

The researcher firmly believes that without a thorough assessment of the patient's biopsychosocial circumstances, adherence issues cannot be



addressed. Single interventions, to support adherence without taking into account all the enablers and barriers of adherence, will prove to be unsuccessful. In addition to assessing individual circumstances, factors with respect to the provider and the regimen, need to be assessed.

The assessment of a person's total functioning will always be arbitrary, with a degree of overlap between factors, because human interaction is so complex. Green and Shellenberger (1991:19) postulate that the biopsychosocial approach to health and wellness is the result of the interaction of biological, psychological and social factors. Identifying and predicting adherence has become a significant challenge for health care professionals.

The said researcher shares the view of British HIV Association (BHIVA, 2003:3) that low adherence is not restricted to certain social classes, but is widespread and unpredictable. Adherence rates vary over time, not just between individuals, but with the same individual. Adherence is considered to be a variable behaviour, rather than a stable characteristic of an individual.

Horizon/Population (2005:8) also distinguishes between disease characteristics, treatment regimens, patient variables, clinical settings and patient-provider relations. The myriad of factors which may contribute and influence an individual's adherence to ART can be divided into 3 main categories: patient, provider, and regimen factors, which will be discussed by the author hereafter.

4.9.1 Patient Factors

Adherence support must be provided to all patients on the premise that any individual is capable of adherence. Low adherence is widespread and predictions concerning adherence cannot be made on the basis of socio-demographic characteristics. To withhold treatment solely on the grounds of assumptions with regards to an individual's personal circumstances, cannot be justified (British HIV Association (BHIVA, 2003:3).



The researcher supports the opinion of Venter (2005:23) that the individual circumstances of patients must always be taken into account where adherence issues are concerned. Wellness programmes usually call for an improved diet, the cessation of smoking, moderating alcohol, the practice of safer sex, exercise and participation in support groups, as well as the routine clinic visits, and disclosure. There have been reports that people have been denied access to ARV's because they have not fulfilled one or all of the above criteria, each one notoriously difficult to implement among the general population.

The biopsychosocial factors, that could influence adherence, mentioned below, will be discussed in more detail in the following chapter.

4.9.1.1 Physiological / biological factors influencing ART

Kaplan, *et al.*, (1994:1) postulate that the biological system emphasises the anatomical, structural and molecular substrate of disease and its effects on the patient's biological functioning. As a result the researcher believes that the physical wellness or performance status of respondents will influence adherence.

The Karnofsky's Scale, which is widely accepted as a measuring tool for performance, can be utilized in an attempt to try and measure the more subjective side of a patient's functioning. The scale relates purely to physical ability and covers 11 points, from normal health to death, each scored as a percentage:

http://www.cancerbacup.org.uk/Qas/AboutcancerQAs/AllQAs/related_faqs/Qas/993:28.02.2006

4.9.1.2 Socio, cultural and socio-economic/interactional issues and characteristics

Predictors based on socio-demographic characteristics, for example, gender, race, age and education level, produced inconsistent results. The desire to link low adherence to deprived social groups is a well-established tendency. Low adherence is not restricted to certain social classes but is widespread and unpredictable (British HIV Association (BHIVA), 2003:3).



Cockerham (2001:54) holds the view that the time is rapidly approaching when racial/ethnic HIV/AIDS differences will no longer be based primarily on comparisons between whites and blacks. Living conditions associated with poverty however influence the onset and cause of a variety of health problems. Socio-economic status and, particularly, poverty, knowledge, education, literacy and access to medical treatment, are consequently important in adherence issues. The researcher corroborates this perspective and is further of the opinion that the language of educational and adherence material should take literacy levels into account.

4.9.1.3 Psychological matters influencing adherence to ART

According to Kaplan, *et al.*, (1994:1), the psychological dimension of the biopsychosocial model emphasises the effects of psychodynamic factors in order to understand the patient's perceptions of his/her condition and the extent to which he/she is motivated towards obtaining help.

The involvement and education of family members, as well as community interventions, such as adherence groups, may be of assistance. Supportive and non-judgmental attitudes of the providers will encourage patients to be honest with regards to their adherence and the problems they may experience. It is vital that the patient commits to adherence to the treatment plan and understands that this is a chronic disease.

4.9.2 Provider Factors Influencing Art

Responsibility for successful, long-term viral suppression must lie with the individual who is on therapy, but it is equally vital that selection criteria for ARV therapy be set up and communicated to providers and the public. A trusting relationship between the patient and care providers is essential, as noted earlier.

Because monitoring and supporting adherence is essential, the *Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment accepted during November* (South Africa, 2003:4), has



acknowledged the need for psychosocial support for patients and makes provision for social workers, dieticians, lay counsellors and a support structure.

4.9.2.1 Multidisciplinary Team Members Involved in Rendering Services to the HIV/AIDS Patient on ARV

“A multi-disciplinary health team can be defined as a team whose members represent the widest possible spectrum of individuals and organisations concerned with, or involved in, any aspect that has a bearing on the health and welfare of the community, in an attempt to provide effective, comprehensive health care that will assist in the achievement of optimal health for all people.”
Dennil *et al.*, (1995:111).

Adherence is a team effort: the cooperative effort between an active and engaged patient, a communicative and responsive team, strong support from family and friends, and a free flow of communication between all Significant persons, both in the social and professional setting must support adherence behaviour because of the myriad of physical and psychosocial problems associated with HIV/AIDS. In addition to doctors, nurses, psychologists, and social workers, other people can readily be encouraged and trained to provide counselling support.

Each profession is expected to contribute its own knowledge and skills directly to the decision-making process. Information is assessed according to its applicability to the needs of the patients, rather than on the basis of professional hierarchy.

According to Nason (1990:310), successful teamwork is the “allowance for the independence and equality of the contributing professions and its pressure for a consensus about group goals and priorities.” According to Davidson and Clarke (1990:273), collaboration and co-operation have to be the major characteristics of the multi-disciplinary health team for it to meet the needs of the patients.



There must be a clear role-identity, which will enable each team member to perform his/her role. Even though there could be an overlap of roles amongst the team members, collaboration could facilitate the team's efforts in order to provide a comprehensive service. This also applies to ART matters, where all the team members are required to work together for the benefit of the patients. No team member must be perceived as being more important than the others.

For all healthcare team members, specific training regarding ART and adherence should be offered and updated periodically. In addition to doctors, nurses, psychologists, and social workers, other people can readily be encouraged and trained to provide counselling support. The counselling services should be monitored and supervised by a professional like a qualified and experienced social worker. Supportive and non-judgmental attitudes and behaviours will encourage patient honesty regarding adherence and their problems.

The multi-disciplinary team should meet and assess patient readiness. They should take all the available information into account. The support of the physician is crucial and very significant, since the treatment plan cannot succeed unless the physician is consistent. Inconsistencies create conflicting messages for the patient and staff. It is important for the entire staff/team to meet with the physician, in order to discuss their concerns and to determine the level of support that they will receive in managing the patient, since the staff needs to feel safe when setting limits with non-compliant patients.

The multi-disciplinary team, concerning adherence matters, is defined by the present researcher as a group of people, professional or non-professional, each with his/her own specialist knowledge, working together to enable optimal social functioning of patients, the family and the community, with the ultimate goal of adherence to ARV and successful treatment. The researcher is of the opinion that the ARV adherence team should commit itself to the following:

- An individualized treatment plan must be developed for each patient. ARV staff should act consistently with the treatment plan;



- The health team must commit to a feasible mechanism for communication between visits and to timely and appropriate responses to adverse reactions;
- There is evidence that adherence may wane over time, even in highly adherent patients; ongoing support and monitoring are therefore important. If there is sub-optimal adherence, there should be extra support;
- Provide education and advice. Specific training regarding ART and adherence should be offered;
- Improve/develop problem-solving and life-skills of patients;
- It is essential to ensure that the health team receives adequate training on ARTs and that this training be updated regularly for all healthcare team members;
- As a process, (ongoing) assessment involves gathering, organising, and making judgments regarding information. As a product, assessment is a verbal or written statement concerning the functioning of the group (client) and its members, which is useful in the development of intervention plans;
- A trusting relationship between the patient and members of the healthcare team is essential. Initiating and supporting patients on ART should be an intensive process, yet one that should provide one with the satisfaction of treatment success.

Due to the acute needs of the patients, the needs of the staff taking care of them are often overlooked. For persons involved in the care of patients with HIV and AIDS, both paid as well as volunteers, burnout is a common issue due to the tremendous emotional and psychological stress that accompanies work where recurrent illness, hardship and death is a constant aspect to which people are exposed. Furthermore, many staff members are themselves infected and affected by HIV and AIDS, which makes their involvement very challenging.

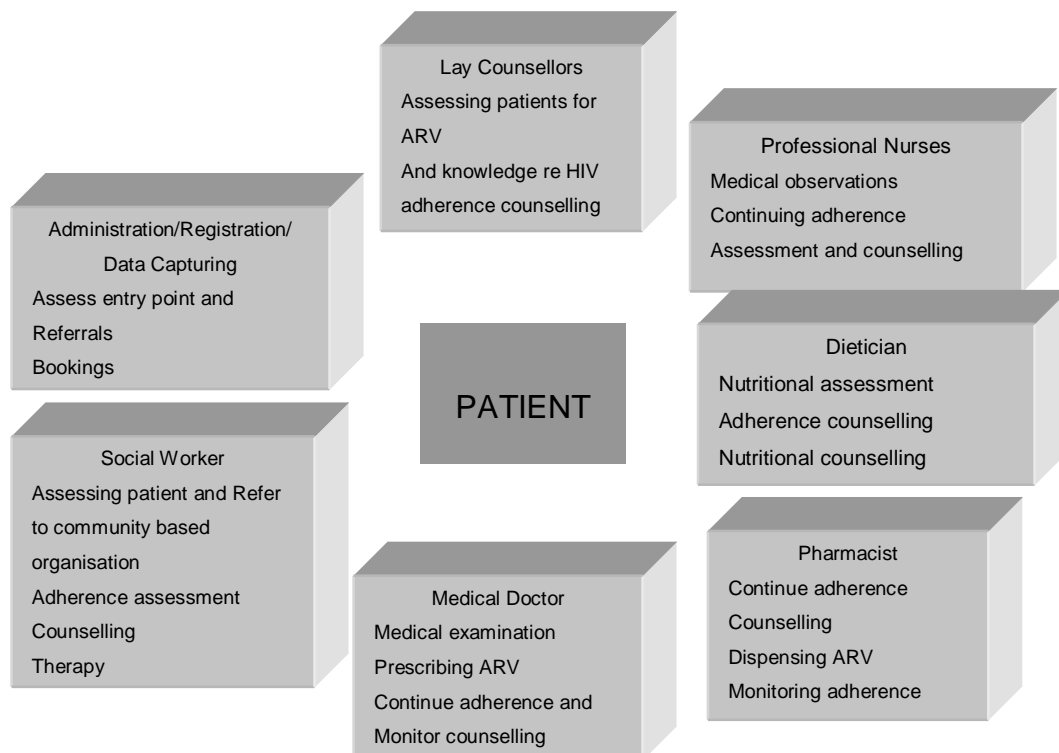
The provision of time and structured programmes for debriefing and grief management for staff members is recommended. Given the constraints on time resources, and the availability of trained psychologists, social workers can play an important role in supporting co-workers and team members. The

development of staff support-programmes will assist healthcare facilities to attract and retain personnel and will offer benefits that stretch far beyond the HIV and AIDS care and treatment programme. Motivated and talented persons who have committed their lives to caring for persons living with HIV and AIDS are essential and precious commodities. Therefore, team members should be supported, continuously trained and educated since HIV/AIDS is a dynamic illness with new research and reports reaching us via the media daily.

Each facility and HIV healthcare team must develop strategies and programmes that meet the individual needs of their site and team members. Working in the field of ART is challenging, provides hope, and motivates patients in an otherwise dark situation.

The team approach, with its different perspectives, emphasises and demonstrates the value of each member, particularly the contribution of the social worker as a mediator and facilitator. The present researcher will summarize the role of each team member as far as adherence is concerned.

Figure 3: Adherence team members





4.9.2.2 Administration staff

The administration staff plays an important role in ARV matters, and are usually the first team members to meet the patient. They receive referrals, do the bookings and are responsible for data capturing. They should:

- Be aware of confidentiality;
- Be aware of procedure, regarding ARV referrals, protocols and guidelines;
- Maintain an open door policy between the administrative staff and the rest of the multidisciplinary team; and
- Take responsibility for keeping records, filing and statistics. (South Africa, 2003).

4.9.2.3 Counsellors

In this study, counsellors refers to lay counsellors. The *Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment, accepted during November 2003* (South Africa, 2003:4), specifically makes provision for lay or voluntary counsellors and social workers to address the psychosocial needs of patients.

A strong emphasis is placed on counselling in the realm of HIV/AIDS. Terms like VCT, PMTCT, pre-test, post-test, and adherence counselling, are now well known in terms of HIV/AIDS matters. The Department of Health (South Africa, 2003) makes special provision for counselling and lay counsellors, but the researcher is of the opinion that counsellors should not be labelled and fragmented into adherence counsellors or VCT counsellors. The counsellors working at ART sites are voluntary, lay counsellors, specifically trained in HIV/AIDS/ART matters, who should be able to render a holistic and comprehensive service with regards to the assessment of patients.

Counselling is a procedure used by the helping professionals to guide individuals, families, groups and communities towards the development of insight, with the aim of improving the social functioning of the client. As suggested, counsellors need not be formal healthcare providers or



professionals, but can include teachers, health educators, religious and community leaders, youth group workers; and members of self-help groups and can also provide supportive counselling.

There is often confusion and role-blurring between the social workers and the lay counsellors at the ARV clinics. The researcher has found from her experience, that social workers need more recognition and have a need to fulfill more of a managing role in training, monitoring and supervision of these lay counsellors. The lay counsellors often see themselves as being on the same level of the social worker and expect the same recognition. No provision was made for the Psychologist in the *Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment, accepted during November 2003* (South Africa, 2003:4) and they are very seldom part of the team at an ARV clinic in South Africa.

Although the Department of Health places a high priority on counselling, the encounters of the present researcher have revealed that there are no general or minimum standards for lay counselling services, nor any formal monitoring, training and support for counsellors. The said researcher feels strongly that people in such a position of responsibility regarding the most intimate circumstances of patients, should adhere to common standards. The recruitment of lay counsellors, and the motivations for their involvement, specifically in HIV/AIDS matters, should be explored. There is no register for either counsellors or support groups where credibility and motivation can be evaluated. The standardization of counselling services could increase confidence in counselling in general and demonstrate to patients and the general public a commitment to high standards and abilities. The public service should start turning the abovementioned situation around by being both a guardian of standards and supporter of the committed support structure. The said researcher concurs with Baran, Byrne & Branscombe (2002:88) that self-interest, often equated with egoism (an exclusive concern with one's own personal needs and welfare rather than with those of others), features strongly in counselling. The researcher has through her experience at the ART clinics, found that inexperienced and unsuitable lay counsellors are often employed by



the Department of Health. These counsellors are often HIV positive, unemployed; in need of the stipend they receive for their services. Unfortunately nepotism features strongly in the appointment of such counsellors by the Department of Health. This is also the experience of most social workers at other ART sites.

Counsellors in general, including both lay and professional counsellors, should be skilled and trained to conduct thorough assessments of clients.

- Conduct an assessment of the patient's circumstances;
- Improve the patient's knowledge concerning HIV/AIDS as a disease and also antiretroviral therapy, including side effects;
- Provide patients with information regarding treatment, including expectations;
- Integrating the treatment regimen into the patient's daily routine, encourage family involvement and provide reminder cues;
- Support and monitor adherence;
- Help the patients to set goals and to develop a positive attitude, beliefs, perception, self-efficacy and commitment;
- Facilitate a support system regarding disclosure;
- Identify and address barriers; and
- Receive regular training regarding HIV/AIDS, ART and adherence matters.

4.9.2.4 Dietician

The government seeks to implement a Comprehensive Nutritional Programme for HIV/AIDS patients, together with the implementation of the nutrition supplementation intervention programme, in addition to the existing nutrition programmes, which includes the National Emergency Food Programme and the Nutrition Supplementation Intervention for TB and HIV (South African, 2004).

The tasks of the dietician in adherence matters are:

- Assessment of the nutritional status of each patient;



- To support the introduction and use of anthropometric measurements in the assessment of patients;
- To ensure nutritional risk screening;
- To implement nutritional care plans for individuals/groups of patients in order to contribute to the patient's general health and adherence;
- Continuous nutritional evaluation of each patient on a monthly basis;
- Nutritional education on healthy balanced eating habits and hygienic food practices;
- Comprehensive nutritional counselling services;
- Identification and treatment of HIV-related food interactions;
- Referring the patient to the relevant multi-disciplinary member for further treatment;
- Assessing the use of herbal medicine, traditional medicine and vitamins by patients;
- To liaise with members of the multi-disciplinary team to ensure that the nutritional needs of patients are met (Tshwane District Hospital. ART Guidelines, 2005).

4.9.2.5 Physician

The physician assumes overall responsibility for, and control over, the patient's treatment. She or he takes the patient's history, noting any features that may prove of value at the examination, assessment and treatment stages.

The physician's role is very significant, since the treatment plan cannot succeed unless s/he is consistent in diagnosing and treating. The physician, while working closely with the other healthcare team members, is in charge of ensuring that the patient is considered in totality: that readiness, nutritional, mental and social states are firmly established in order to determine the optimum course of action available.

The above forms part of all the responsibilities of the doctor in charge of all clinical aspects of the patient's care, treatment and management. Specific tasks of the physician are:



- Examine the patient, while adopting the integrated approach;
- Administer ARVs, making whatever adaptations that the specific situation and circumstances of each patient demands;
- Request clinical tests;
- Diagnose symptoms. Deals with any medical problems and opportunistic infections;
- Monitor the patient's response to treatment; deals with drug side-effects, and immune reconstitution, being guided by such responses in working out an appropriate modification or change;
- Prepare the patient in a case of treatment failure and possible palliative care;
- Perform an educational role such as restating the role of adherence to ART;
- Refer patients to other health specialists, such as psychiatrists, psychologists, mental health nurses, phlebotomist, in order to perform clinical tests and also palliative support to one or more members of the multi-disciplinary healthcare team.

It is important for the entire staff/team to meet with the physician to discuss their concerns. The AIDS epidemic has shown, more than any other illness that the physician is not the "Messiah" with all the answers, and that multidisciplinary team members should address the psychosocial dimensions of a patient's life. The doctor has to give the patient hope at all times, over and above the counselling provided by other healthcare team members (Tshwane District Hospital, ART Clinic protocol, 2005).

4.9.2.6 Pharmacist

The pharmacists should take responsibility, not only for assisting the patient regarding pill-taking, but also adherence. Patients should be encouraged always to mention their problems to the ARV pharmacist. Pill-taking can be a problem, depending on their size, shape and texture, and the pharmacist should play an active role in counselling patients. The specific roles of the ARV pharmacist are to:



- Ensure that the pharmacy facility is safe and adequate and meets the necessary requirements;
- Ensure proper control over the procurement, storage, prescribing, issuing, dispensing and record-keeping procedures;
- Dispense and counsel in private to ensure patient confidentiality;
- Clearly label dispensed medication;
- Counsel in detail patients whose treatment has been initiated with regards to all aspects of ARV medication such as medication storage, usage, reconstitution, drug interactions, side effects, adherence issues and the use of a diary card;
- Reinforce adherence at every visit, to all the above aspects of medication.

The researcher is of the opinion that the pharmacist bears a heavy responsibility with regards to educating the general public, concerning the importance and responsibility of not only adherence, but all pill-taking regimens, especially with respect to chronic disease. The community should be educated by means of mass campaigns concerning adherence, in general, and the importance of treatment. Furthermore, information leaflets should accompany medication instructions for patients, regarding side-effects and contra-indications of ART.

4.9.2.7 Professional nurse

HIV/AIDS has also dramatically shifted the emphasis of the role of the nursing professional, as stated by Van Dyk (1992:63): "AIDS forces the nursing profession to re-examine its role in health care and to shift its emphasis from curing to caring." The researcher would like to add to this that the nursing profession has now also, shifted the emphasis of their role from caring to counselling and managing HIV/AIDS patients. More and more nursing professional's play the role of counsellors and/or manage HIV/AIDS programmes. The professional nurse in ART matters is responsible for:

- Monitoring the overall health status of patients;
- Assisting the physician with the examination of the patient;



- Noting and monitoring treatment failure or non-response;
- Observations, blood tests and pathology;
- Monitoring of therapy, including side effects, adverse events and psychosocial problems. Informing the physician of problem areas;
- Monitoring and adherence-related follow-up and data collection;
- Adherence counselling for patients. Continuation of adherence counselling, working in close collaboration with other team members, especially the physician;
- General management of the patient, once inducted into the programme;
- Prophylaxis therapy;
- Referral and liaising with the different specialities involved in case management, for example TB services, other specialists, home-based care; and
- Working in close cooperation with other disciplines or members of the multi-disciplinary team.

4.9.2.8 Social worker

For the purpose of this section, the social worker as team member will be briefly discussed. A detailed discussion of the social worker follows in chapter 5.

The social worker operates within the scope of the multi-disciplinary team, where all the members of the team are concerned with providing the patient with a comprehensive service. The major function of the social worker in this context is to improve the quality of life of the patient and his/her social functioning by supporting adherence.

The government recognizes the social work profession as part of the multidisciplinary team, which renders services to HIV/AIDS patients referred for ART. The intervention of social workers in an ART setting demands experience and knowledge regarding HIV/AIDS, ART, and a high level of outcome evaluation skills.



The social worker must understand the interaction between the individual, social and medical systems. Knowledge of the biopsychosocial model would be an advantage in service-rendering within a health setting. The social worker, as a facilitator, must also be prepared to contribute to the development of clinical pathways in order to enhance treatment outcomes. The specific roles of the social worker regarding ART matters in a healthcare setting will be discussed in more detail in the next chapter. The specific roles of the social worker in an ART setting, as experienced by the present researcher, are:

- Being able to conduct a thorough biopsychosocial assessment of patients;
- Motivating patients and developing their insight in preparation for treatment, thereby ensuring adherence;
- Providing continuous supportive counselling throughout the treatment period;
- The social worker's role regarding counselling is further indicated as being an advocate for the patient's rights, educator and supervisor of standards in counselling.
- Knowledge of the applicable community resources, and knowing when it is appropriate to refer a patient;
- Possessing efficient therapeutic skills, e.g. in crisis intervention, skills in short-term and bereavement counselling;
- Possessing respect for the rights of patients, their, confidentiality and stigmatisation;
- Possessing adequate skills to implement the social work methods and techniques, e.g. casework, group and community work;
- Functioning in an inter-disciplinary team or the ability to collaborate and be assertive;
- Educating other professionals, students, and patients, as well as the community, regarding the roles and tasks of the medical social worker, the psychosocial effects of HIV/AIDS treatment on the patient and his/her family; and
- Innovating, facilitating, organizing and co-coordinating services.



4.9.3 Other community support

As the HIV/AIDS epidemic escalates, healthcare needs and the means of satisfying the needs of people infected and affected by it also increase. New dimensions of care and support evolve, and bring with them new members to be included in the multidisciplinary team in the provision of holistic care and support to HIV/AIDS

The researcher considers that a wide variety of non-professional and indirect service providers should be, and are currently, involved in HIV/AIDS matters, other than the involvement of the professional health team directly involved, as discussed. A tight network of community organisations involved in service-delivery to people infected or affected by HIV, including people living with HIV, the faith sector, employers, hospices, home based care organizations, support groups, traditional healers, various government departments, non-government organizations (NGOs), education institutions, and all relevant partners should be fully informed and trained about ARV support.

- **Faith-based organisations**

Religious and spiritual counselling is important, since many people are members of some religious or spiritual denomination. The role of faith-based organisations should be to motivate and support people regarding treatment, promote stable relationships and emphasise norms and values in general. Faith has always been supportive in illness, but certain faith-based organizations who promote faith healing, praying, holy water and other means of healing, could jeopardize and confuse patients and create barriers to adherence to ART (Viljoen, 2005:23).

- **Traditional healers**

Anecdotal and early scientific evidence warns of significant interactions between traditional and Western medicine. Alternative healing methods and the influence of culture and beliefs should not be underestimated. Traditional healers are encouraged by the government to become involved



at all levels, which have proven to be relatively successful (Viljoen, 2005:430).

Health-seeking behaviours are largely affected by cultural norms and personal belief systems. A large percentage of patients, specifically in S.A. with its diverse cultures, have deeply rooted traditions with regards to maintenance of health and treatment of illness and utilise traditional health practitioners or indigenous medicines, as their first point of contact for healthcare. Traditional health practitioners are more accessible and hold positions of authority within the community and thus their advice is widely respected.

The researcher is of the opinion that as a well-established and accepted form of healthcare in South Africa, it is essential that traditional medicine and its practitioners be recognized, respected, and engaged in co-ordinating care for HIV-positive patients that wish to utilize both disciplines. Traditional practitioners could play an important role in raising public awareness and promoting acceptance of VCT as well as adherence to TB and antiretroviral therapy. Rossouw (2006:18) postulates that traditional healers and traditional medicine has become one of the most complex issues when dealing with ART. The WHO (2005) estimates that 80% of African populations consult traditional healers.

- **Networking with community organizations (NGOS)**

The Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment accepted during November 2003 (South Africa, 2003:4) has acknowledged the need for psychosocial support of patients and makes provision for social workers, dieticians, lay counsellors and other support systems as well as the involvement of NGOs at each ART site.

Community support should be provided to patients in a confidential and nurturing environment. When referring patients to community organizations (NGOs) it is essential to make use of community resources where credibility



and confidentiality can be guaranteed. HIV/AIDS is a sensitive and traumatic experience for patients who fear discrimination. Issues regarding HIV/AIDS always carry a sexual connotation, which is a sensitive issue in all cultures. Patients perceive their status as confidential and do not want to share it with strangers or the general community.

- **Education and training**

The involvement and education of family members, as well as community interventions, such as adherence groups, is essential in supporting the patient regarding adherence. There is rarely a need to rush the commencement of ART and patients should be educated about adherence. The Government's Rollout Plan for Antiretroviral Treatment (South Africa, 2003:4) does make provision for such education.

A study undertaken by O'Brien (1990:212) on dialysis patients shows that people tend to cope with health and illness-related problems according to the knowledge they possess. Friedland (2003:370) claims that, in the USA, studies have found that low literacy levels are associated with poorer adherence. The current researcher however holds that illiteracy should not be an excluding factor in assessing patients for adherence to ART, but that education and knowledge regarding HIV/AIDS and ART should rather receive priority because they constitute a means of developing insight, and may contribute to the improvement of motivation and adherence to ART.

The said researcher believes that education regarding adherence to ART at all educational levels is important. A culture of health education and awareness is needed for the successful implementation of ART. The service provider's role in the successful implementation and adherence to ART cannot be overemphasized.

4.9.4 Regimen Factors Influencing Adherence to ART

Regimen factors influencing adherence issues were considered in the previous chapter. Antiretroviral drugs, like most chronic medication, are not without



negative aspects. Regimen complexity is an important contributor to poor adherence.

The treatment regimen, pill burden, drug interactions, drug toxicity, adverse events, co-committant illnesses, side-effects and contra-indications influence adherence. Heyer and Ogunbanjo (2006:5-9) postulate that good adherence is associated with low pill-burden. Optimum treatment regimens selected by patients include: two, or less, pills per day, no dietary restrictions, small pills, and all drugs combined into one pill, and once-a-day dosing.

Adverse drug events are constantly reported and linked with poor adherence. Multiple drugs are often prescribed for HIV infected patients for: prophylaxis of opportunistic infections, as antiretroviral medication, side-effects of medications, and treatment of concomitant illnesses, both acute and chronic. Patients may seek medical care from more than one practitioner or healthcare facility. Patients also make use of over-the-counter and traditional or herbal remedies, as well as illicit and recreational drugs. As access to ART expands in South Africa, the potential for drug interactions with ARV drugs, becomes increasingly important (Cohen, Andrews & Maartens, 2002:42). Scheduling demands, including clinic visits, work difficulty, fitting medication and clinic visits into a daily routine, are consistently associated with decreased adherence. The researcher wishes to summarize by reiterating that the myriad factors that contribute to, and influence adherence to ART, discussed above, according to the three main categories, patient, provider and regimen factors, make ART and adherence to it a very complex issue for people infected and affected by HIV/AIDS including the multidisciplinary team involved in service rendering.

4.10 Summary

The aim of this study is to explore the biopsychosocial circumstances related to adherence that should be assessed when screening patients for ART, describe the factors influencing adherence to ART, and formulate guidelines to support ARV adherence screening that are practical, relevant and appropriate in the African context. In this chapter the present researcher explored adherence to



ARV treatment, in order to obtain the desired benefit and to avoid the emergence of drug resistance and clinical failure. Adherence calls for meticulous adherence to medical regimens, and continual support between health providers and patient.

Matters that were discussed are: resistance; adherence; predicting of adherence; special adherence groups; patient, providers and regimen matters influencing ART; with a specific focus on the adherence team. Support during the different adherence phases and strategies to support adherence, such as medication alerts and measuring adherence, were also discussed.

The researcher argues that a thorough and detailed assessment of each individual regarding adherence to ARV treatment is essential. It is not possible for healthcare providers to reliably predict which individuals will ultimately be adherent to their treatment plan, since adherence does not correlate with gender, cultural background, socio-economic status, educational level, or language barriers between provider and patient. Adherence has been rightly called the Achilles heel of ART (Wilson and Fairall, in Abdool Karim & Abdool Karim, 2005:489).

In the next chapter, the researcher will explore the biopsychosocial factors influencing the adherence of HIV/AIDS patients to ART. Factors that will be discussed include the three dimensions of health and illness, namely, biological, psychological and social. The role of the social worker in utilizing the biopsychosocial model in assessing HIV/AIDS patients for ARV therapy will also be considered. A guideline for utilizing the biopsychosocial model in assessing the HIV patients for adherence to ART will be proposed.



CHAPTER 5: THE SOCIAL WORKER'S ROLE IN ASSESSING THE HIV/AIDS PATIENT FOR ANTIRETROVIRAL THERAPY UTILISING THE BIOPSYCHOSOCIAL MODEL

5.1 Introduction

The broad framework of the HIV/AIDS and STI strategic plan for South Africa (2007-2011 (South Africa, 2007)) which represents the country's multi-sectorial response to the challenge of HIV infection and the wide-ranging impact of AIDS, focuses on four key priority areas: prevention and treatment; care and support; human and legal rights; monitoring, research and surveillance, by promoting the provision of appropriate packages of treatment, care and support to HIV positive individuals in terms of improving screening and diagnosing and strengthening the implementation of social safety network programmes for people living with AIDS (South Africa, 2006).

The worldwide increase in the prevalence of ARV resistance is of particular concern to all involved in HIV/AIDS matters. Since resistance remains one of the most significant threats to the long-term success of any HAART regimen, practitioners are anxious to learn from past mistakes, translate new knowledge into appropriate treatment strategies, and develop methods to complement the treatment.

The current HIV/AIDS epidemic in South Africa poses major challenges to all professions and, in particular, to the social work profession. The focus of social work falls on the improvement of the social functioning of people in interaction with their environment. Social work deals with the needs and problems that people experience in their effort to cope with the demands of their environment and emphasise the idea of "ubuntu" (namely that people will always need other people to realise their humaneness and individual potential) (Sheafor, Horejsi & Horejsi, 1994:6 in Potgieter, 1998:27).



The social worker, who possesses specialized knowledge and skills, is equipped to be part of the multidisciplinary team that renders a service in an ARV setting. The ability to assess and counsel patients regarding adherence, prior to treatment and while on initiation of ART, is strongly indicated. Continuous assessment, monitoring and support and education are further indicated, since adherence tends to fade over time. The researcher is of the opinion that the social worker can provide a meaningful service as part of the multidisciplinary adherence team in assessing the patient's circumstances, as well as in developing the insight of the patient regarding the implications of treatment and networks with available resources for support.

ART is a complex procedure, which is accompanied by severe biopsychosocial implications as discussed in previous chapters. As a result of this state of affairs, there is a need for a comprehensive service, which will ensure that the patients are able to adhere to ART for life. Literature has shown that, particularly in the field of HIV/AIDS, which is accompanied by a variety of psychosocial implications, the treatment will not be complete without the accompanying social support and counselling services. Karoly (1985:434) argues that the biopsychosocial orientation involves an interdisciplinary systems orientation to health care. This orientation enables the service providers to consider the biological, psychological and environmental information about a patient, in order to make an appropriate diagnosis and develop a treatment programme that encompasses all these three areas.

The researcher is of the opinion that the biopsychosocial model, in recognizing the interaction between the medical, social and psychological dimensions of illness, is the appropriate model to provide the HIV/AIDS patient with a comprehensive service that is responsive to their needs. The aim in this chapter is therefore to explore the territory of the social work profession in HIV/AIDS and ARV matters. The social worker, as a member of the multi-disciplinary team in ARV matters, has a specific role to fulfil, in order to ensure that the patients are adequately assessed for ART and receive a comprehensive service.



5.2 The Social Work Profession

Social workers have been defined by the National Association of Social Workers, in Zastrow (2004;40) as: “Graduates of schools of social work (with either bachelor’s or master’s degrees), who use their knowledge and skills to provide social services for clients (who may be individuals, families, groups, communities, organizations or society in general). Social workers help people increase their capacities for problem solving and coping and help them obtain needed resources, facilitate interactions between individuals and between people and their environments, make organizations responsible to people, and influence social policies.”

Cowles (2000:43) also defines social work as the professional activity of helping individuals, families, groups, or communities to enhance or restore their capacities for social functioning and of creating societal conditions favourable to this goal. Thus, as a profession, social work claims to possess specialized knowledge and skills that better qualify its members, as opposed to non-members, to provide such helping services. The four areas of core knowledge essential for all social work interventions, as identified by Cowles (2000:46), are:

- Human behaviour and social environment;
- Social welfare policy and programmes;
- Social work practice-theory concerning the social work helping process, methods of social work practice, skills, techniques and intervention modalities, values and ethics; and
- Research methods.

Social work in healthcare is defined by the *New Dictionary of Social Work* (1995:39) as follows: “Specialized field in social work practised in hospitals and other health care facilities and aimed at the social and personal implications of sickness and health.” Social work in healthcare is also defined by Barker (1991:141) as follows: "Social work in health care is the social work practice that occurs in hospital and other health settings to facilitate good health prevent



illness and aid physically ill patients and their families to resolve the social and psychological problems related to illness."

According to Zastrow (2004:529), the social worker in the health field requires skills and knowledge about how to counsel people with regards to a wide variety of medical conditions. Social workers provide a service with respect to, not only direct casework with patients and their families, but also group work with certain patients, consultation, and training of other professionals. They are also involved in planning and the development of policy within the hospital.

The social worker in the field of health needs to possess knowledge of:

- Client population and pro
- Community and resources;
- Specific intervention modalities and
- Research evaluation and documentation (Cowles, 2000:46).

Social work within the health services will require a broad-spectrum intervention repertoire supported by a complex set of competencies and skills, including administrative, leadership and accountability. The challenge facing social work within the transforming healthcare world is whether a sufficient number of capable social work practitioners will be able to staff the delivery systems and meet the growing recognition of the need for psychosocial care and services or whether other providers will increasingly step in, to meet the expectations and demands presented by HIV/AIDS. Education of social workers for the brave new world of health care is essential (Vourlekis, Kathleen, and Padgett, 2001).

According to Skidmore, Thackeray and Farley (1994:146) social work intervenes with medicine and other related professions in the study, diagnosis and treatment of illness at the point where social, psychological and environmental forces impinge on role effectiveness. The social workers in healthcare employ problem-solving methods for assisting individuals, families, groups and communities in solving health-related problems. Skidmore *et. al.*, (1994:146) further define social work in healthcare as the application of social



work knowledge, skills, attitudes and values in healthcare, where the social worker addresses himself/herself to illness brought about by, or related to, social and environmental stresses that result in failures in social functioning and social relationships.

According to the researcher, social work in healthcare is the delivery of critical, comprehensive social work interventions, to the individuals, families, groups and/or communities who are associated with, or affected by, illness. These medical conditions can be brought about by, or related to social and environmental factors that impose on psychosocial functioning.

The social work intervention should be a holistic approach that could ultimately improve social functioning and quality of life in general, including the prevention of illness and promotion of health by means of education. In acknowledging the physical, mental, emotional, social, economical, cultural and spiritual dimensions of human life and utilizing the biopsychosocial approach, an individualized, comprehensive assessment can be performed (Spies, 2006).

5.2.1 Background

The first social welfare agencies were founded in the early 1800s in an attempt to meet the needs of the people living in urban areas. Prior to 1930, social services were provided primarily by churches and voluntary organizations.

Richard C. Cabot introduced medical social work at Massachusetts General Hospital in 1905. Gradually, social workers were employed in schools, courts, child guidance clinics and other settings. In 1917, Mary Richmond published the first text to present a theory and methodology for social work. A training school for psychiatric social work was established at Smith College in 1918. What began as social work in healthcare was divided into medical and psychiatric social work around 1920. Following both World War I and World War II thousands of servicemen returned home with psychological as well as physical scars.



Since the inception of social work in the general hospital setting in 1905, social work within the health field has expanded to include practice in a variety of healthcare settings, such as psychiatric and other speciality hospitals, public health agencies, nursing homes and rehabilitation centres, health maintenance organizations, community-based clinics, private medical practices, home care agencies and hospice programmes.

From the 1920s to the 1960s, most social work programmes employed a medical model approach to assess and change human behaviour. In the 1960s, social workers began questioning the usefulness of the medical model. Environmental factors were shown to be at least as important internal factors in causing a client's problems. Social work shifted some of its emphasis to a reforming approach, which seeks to change systems to the benefit of clients, and look beyond the client's presenting problems in order to assess the complexities and interrelationships of the client's life situation.

In recent years, social work has increasingly focussed on using a systems ecological approach, integrating both treatment and reform by conceptualising and emphasizing the dysfunctional transactions between people and their physical and social environments. An ecological model seeks to identify such interpersonal obstacles and then apply appropriate intervention strategies (Cowles, 2000:10 & Zastrow, 2004:45).

5.2.2 The goals of social work

Social work is the professional activity of helping individuals, groups, families, organizations and communities to enhance or restore their capacity for social functioning and to create conditions favourable to their goals. The goals of social work that have been identified by Zastrow (2004:38-58) are to:

- Enhance the problem solving, coping and developmental capacities of people;
- Link people with systems that provide them with resources, services and opportunities;



- Promote the effectiveness and humane operation of systems that provide people with resource and services;
- Develop and improve social policy;
- Enhance human well-being and alleviate poverty, oppression and other forms of social injustice;
- Pursue policies, services, and resources by means of advocacy and social or political actions that promote social and economic justice;
- Develop and use research knowledge and skills that advance social work practice; and
- Develop and apply practice in the context of diverse cultures.

Cowles (2000:14) distinguishes between curing and caring in health interventions. Today the major health problems stem from chronic, rather than acute, infectious diseases. The healthcare delivery system comprises three basic levels of services that represent stages of health status, primary, secondary and tertiary. These stages revolve around prevention, repair and compensation. Curing and caring comprise the two basic approaches to helping within the realm of health and other human problems. Curing refers to efforts to correct the underlying condition, while caring refers to the provision of supportive assistance to:

- Promote healthy growth and development;
- sustain function and relieve distress during a temporary problem episode;
- maximize comfort and function when a problem is permanent or even terminal.

5.2.3 The characteristics and role of the social worker

Barr (1979:106) in Zastrow, (2007:35), identifies the following competencies or core practice skills that social workers should possess:

- Identify and assess situations in which relationships between people and social institutions need to be initiated, enhanced, restored, protected or terminated;



- Develop and implement a plan for improving the well-being of people, based on problem assessment and the exploration of obtainable goals and available options;
- Enhance the problem-solving, coping, and developmental capacities of people;
- Link people with systems that provide them with resources, services and opportunities;
- Intervene effectively on behalf of the populations most vulnerable and discriminated against;
- Promote the effective and humane operation of the system that provides people with services, resources and opportunities;
- Actively participate with others in creating new, modified or improved services, resources, or opportunity systems that are more equitable, just and responsive to consumers of services, and work with others to eliminate unjust systems;
- Evaluate the extent to which the objects of the intervention plan were achieved;
- Continually evaluate one's professional growth and development by assessment of practice behaviours and skills; and
- Contribute to the improvement of service delivery by adding to the knowledge base of the profession as appropriate and supporting and upholding the standards and ethics of the profession.

According to Germain (1984:78), the roles and tasks of the social worker are to assist patients to cope with the stress of illness, injury or disability. Potgieter (1996:42) proposes the following principles when dealing with people. The researcher acknowledges these as relevant.

- Individualisation
- Acceptance
- Controlled emotional involvement
- Non-judgmental attitude
- Self-determination



- Accountability

The said researcher also supports Potgieter’s (1998:99) view of the characteristics that the social worker should possess with regards to service delivery, especially concerning ARV matters:

- Acceptance and respect, warmth, trust, congruence and genuineness, empathy, concern for others, commitment and obligation, authority, competence and power, concreteness and objectivity, humour, confidentiality.

When working with individuals, groups, families or organizations, the social worker needs to be knowledgeable and skilful in a variety of roles. Such roles, identified by Zastrow (2004:77-79) are those of:

Table 8: Roles of the social worker

Enabler	Articulates needs, clarifies and identifies problems
Broker	Links individuals and groups with community
Advocate	An active, direct role, advocates for clients rights
Activist	Seeks change, shift in power, resources to disadvantaged groups
Mediator	Intervention in disputes, finds compromises, reconciles, reaches agreements: a neutral role
Negotiator	Conflict bargaining and compromise: mutually acceptable agreements
Educator	Giving information, teaching adaptive skills, communicator
Initiator	Calls attention to a problem
Empowerer	Helps to increase strengths by improving circumstances
Coordinator	Brings components together in an organized manner
Researcher	Studies literature, evaluates outcome
Group facilitator	Leader of group activity
Public speaker	Informs regarding available resources, advocates new services

Zastrow (2004:77-79)



The present researcher is of the opinion that the above principles and characteristics also relate specifically to service rendering in HIV/AIDS issues. It is important to know that all patients should be accepted as individuals, including all sectors of a community, such as criminals, prostitutes, homosexuals, children, elderly, and adolescents. The patient's personal circumstances and the reason why and how they contracted the HI virus are not important; the important issue is that they are in need of social work intervention, while always bearing in mind the patient's right to self-determination.

The social worker, involved in service delivery in HIV/AIDS and ARV issues, should specifically convey acceptance, warmth, respect, empathy and confidentiality. HIV/AIDS patients not only suffer from the disease but, often, are also subjected to discrimination and disrespect. The social worker should convey confidence, knowledge, competence and commitment. In the past, HIV/AIDS has been notoriously linked with death, homosexuality and promiscuity, thus care must be taken to meet every patient with respect and care.

Individuals diagnosed with HIV/AIDS experience a variety of psychosocial stressors that can negatively affect their lives. One of the stressors that have emerged since the introduction of ART is the awareness that their existence will depend upon being sustained by artificial or chemical means. This understanding raises a number of issues, including unique social and financial pressures, lifestyle and role changes, as well as apprehension regarding the ability to maintain employment and relationship changes. The onset of these stressors usually begins with the diagnosis of AIDS and the necessity for adherence to ART.

5.3 The roles and skills of the social worker in ARV matters

Medical advances alone, no matter how effective in reducing the number of AIDS-related deaths, cannot decrease the number of new infections nor can they support the needs of the many HIV-positive people now regaining health



and lost roles as a result of ARTs. People on ART are doing so with guarded optimism about how long this medication will be effective and feel limited in their ability to live life fully.

Strug, Grube, and Beckerman, (2002:7) postulate that social workers will increasingly become involved in primary prevention efforts due to the fact that medical intervention alone is insufficient to prevent new infections. Infected persons will need a wide variety of medical and psychosocial support services for long periods of time, since HIV/AIDS becomes a chronic condition for persons living with the disease.

According to the *South African Council for Social Service Professions (SACSSP)* there are 11 803 registered social workers in South Africa, not all of whom are actively involved in service rendering within the profession, or related to HIV/AIDS matters. South Africa has an estimated 5.54 million people living with HIV; of these 5.54 million, 500 000 are estimated to have AIDS and are thus in need of ARVs. If the Government's plan to supply ART to all patients who meet the criteria succeeds, the need for social work intervention in supporting people living with AIDS will be exceeded.

The impact that the various psychosocial needs of millions of HIV/AIDS people living on ART will have on current social structures and services, will challenge the available professional social services. The importance of the social worker being involved in HIV/AIDS and ARV matters, where all the team members will provide the patients with a comprehensive service, cannot be underestimated. Without the involvement of the social worker in ARV matters, there is no other team member who will be able to meet the comprehensive, psychosocial needs of the patient.

Social work interventions and the role of the social worker in the field of HIV/AIDS, which has been primarily, linked with loss and grief, have fundamentally changed with the introduction of ARVs. These interventions need to be shifted to support the millions of HIV/AIDS survivors now living with a chronic disease.



The social worker in ART settings, as a member of the multidisciplinary healthcare team, should possess the necessary experience, knowledge and skills as well as those skills that distinguish it from the other professions. He/she must possess a clear knowledge base of social work in general, as well as social work with regards to health, HIV/AIDS and ART. Rizzo and Abrahams (2002:269) state that social workers are the only professionals who receive professional training in case management and this makes social workers indispensable. Therefore it is necessary to identify gaps in the present system in order to bring about change at policy level and also to allow them to advocate for clients.

Knowledge and skills must be clearly communicated to other team members in order to avoid the blurring of roles amongst the team members, especially counsellors. The present researcher agrees with the viewpoint of Cowles (2000:133), that for the social worker to claim a place in the interdisciplinary team, the claim must be based on expertise. Collaborative skills are essential in order to be recognised, and render a meaningful service. Without this expertise, the role of the social worker will be confused with that of other role players.

Without the involvement of the social worker, the patients are denied the specialized knowledge and skills that would otherwise facilitate their treatment. The researcher would like to apply some of the generic roles of the social worker identified by Skidmore, *et al.*, (1994:151) and Saloner, (2002:154) to the social worker within the healthcare field who deals with HIV/AIDS patients referred for ART.

5.3.1 Caring for and protecting vulnerable populations, social justice and equity

Social work should identify the individuals and groups in society that are most vulnerable and seek to strengthen their potential and capacity by providing protection where this is warranted. Poverty hinders access to a number of services; most people are vulnerable because of their socio-economic conditions and thus are more susceptible to HIV infection. Improving the lives of



poor communities is therefore necessary to ensure that people do not place themselves at risk of infection, for example by prostitution (Viljoen, 2005:82).

Women, in particular, are disproportionately more affected by poverty and HIV/AIDS because of the inequalities in society and a general lack of resources, yet they are traditionally responsible for caring for the sick. They are also more vulnerable to HIV infection due to their inferior position and therefore, often cannot negotiate safe sex and/or resort to selling sex for money or material goods, in order to improve their living conditions.

The establishment of a climate of social justice is one of the purposes of social work in ART practice to enable all members of society to enjoy an equal share in the rights and opportunities afforded by society. The high rate of unemployment and poverty hinders access to a number of services, including adherence to ART.

5.3.2 Healing and caring

It is the function of social work to identify needs and problems that affect the social functioning of people and facilitate actions that might resolve or minimize these. The purpose is to interrupt and prevent the development of social dysfunction by discovering harmful conditions in time and to develop strategies that can control and eliminate problems.

The social worker's role should focus on providing supportive assistance to maximize the comfort and function of persons diagnosed with HIV/AIDS. Owing to the introduction of ART, HIV/AIDS is now a treatable and manageable disease, though still incurable.

The introduction of ART has brought unique biopsychosocial needs to patients. Social workers will need to assist greater numbers of families with complex psychosocial matters such as:



- Adjusting to living with a chronic illness of one or more members living with HIV/AIDS; adherence issues; re-evaluation of personal commitments and relationships; re-introduction to employment; discontinuation of disability and social support; and regaining of lost roles and health, for example, sexual roles.

5.3.3 Serve as a broker of community services, providing linkages of patient needs with appropriate resources

Knowledge of HIV/AIDS-related resources is at the centre of successful interventions. The social worker therefore needs to be able to identify resources in any given person-in-environment situation and successfully form network linkages to these services, in order to meet the needs of clients. Social workers cannot deliver effective service without resources. Resource management refers to three kinds of action by the social worker:

- Linking people to resources;
- working with resource systems to make them more responsive; and
- stimulating the development of new resources.

As a broker of community services, the social worker must ensure that the community is provided with resources, mobilize communities, and also identify and network to ensure that resources are responsive to the needs of patients. The community should be equipped with knowledge regarding adherence to ART, by the social worker in the health service. The social worker has to facilitate community services, such as NGOs, to be responsive to the needs of HIV/AIDS patients.

People affected by or living with HIV/AIDS find themselves confronted by stigma and discrimination. People continue to be denied employment, discharged from jobs, denied medical care, ostracized from the community, or even killed, often solely because of their HIV-positive status (Viljoen, 2005:144). Once successfully on ART, people with HIV/AIDS are not so easily identified by their



physical appearance and medical symptoms and can return to lost roles and functioning.

Discriminatory responses to the scourge of AIDS, reactions attributable to society's fear, ignorance and refusal to deal with HIV/AIDS, should be addressed by the social worker as advocate, mediator, negotiator, and if need be, activist for the rights of the HIV/AIDS patient.

5.3.4 Policy and programme development

The social worker who delivers services to HIV/AIDS patients should possess a sound knowledge of HIV-related policies and guidelines. The social work profession's concern for human needs and its commitment towards social justice places it in the forefront of policy and programme development.

For the service to be responsive to the needs of the patients, the need exists to have appropriate policies formulated and implemented to this effect. Bearing this in mind, the researcher is of the opinion that social workers can, and should, play a much larger role in formulating policies regarding HIV matters by means of advocacy and social planning.

5.3.5 Professional education and practice development

The provision of professional education and training, as well as the development of practice, are important functions of the social work profession. Even though some social workers may not choose to work directly in the field of HIV/AIDS, it is impossible to avoid the epidemic.

Social workers should be experienced and have the appropriate skills and knowledge regarding HIV/AIDS and ART matters, factual knowledge concerning the disease, its route of transmission, as well as ART. Saloner, (2002:154) recommends the dissemination of basic social work skills, knowledge and attitudes to other lay and professional team members. Each social worker bears the obligation to ensure that a portion of his/her role involves an education and training component. There are many social workers who lack



various adequacies with respect to their skills, knowledge and attitude with regards to HIV/AIDS and ART matters.

Every social worker has a moral and ethical responsibility to introduce the issue of sexual practices, in relation to AIDS prevention, to particular client groups. According to Woods (1992:37), human sexuality is often a neglected issue in social work curricula, largely because of the:

- Emotive nature of human sexuality; differences in prevailing values and morality; and widespread ambivalence towards the recognition of sexual functioning.

According to Woods (1992:3-47), social workers should gain specific knowledge regarding human sexuality and the act of sexual intercourse (by virtue of its central role in HIV transmission). Woods, furthermore states an increasing number of social workers are indicating an interest in the topic of AIDS and are moving from resistance in dealing with AIDS-related issues to an appreciation of the rewards experienced by those professionals involved in AIDS work.

The Department of Health makes special provision for counselling and social work services (South Africa, 2003), so that much emphasis is placed on counselling related to HIV/AIDS matters. Terms such as voluntary counselling and testing (VCT), prevent-pregnant-mothers-to-children-transmission (PMTCT) and adherence counselling are now well-known terms in the field of HIV/AIDS. Social workers should be aware of these and be skilled in counselling persons infected and affected by HIV/AIDS.

5.3.6 Heightened awareness of ethical and legal issues

The modelling and mentoring role of the social worker regarding basic morals and ethics is very important. The HIV/AIDS epidemic has shown a consistent pattern which indicates that discrimination, marginalisation, stigmatisation and lack of respect for human rights and the dignity of individuals and groups, increase their vulnerability. HIV/AIDS is a condition among humans being driven



by human behaviour and by the nature of relationships between individuals and groups in society. Human rights, ethics and laws enter into almost every aspect of the experience of an individual and community when confronted with HIV/AIDS (HIV/AIDS and the law, 1997).

Issues such as disclosure and confidentiality raise ethical dilemmas in specific HIV/AIDS matters. The South African legal and policy framework, over the years, has evolved to offer some of the best human rights protection in the world. However, the gap between practice and official policy remains a problem (Viljoen, 2006:99). The specific role of the social worker is to advocate for the rights of patients.

Human rights, ethics and law, should be a tool by which the social worker, in delivering service to HIV/AIDS-infected and -affected individuals, empowers and protects human dignity. The social worker should possess a sound knowledge of common law, ethical and professional guidelines, the Constitution as well as National policies and guidelines regarding HIV and ART matters.

5.3.7 Engage in research, to assure a broadening of the knowledge base

In order for social work practice to be responsive to the needs of patients, specifically in HIV/AIDS matters, ongoing research, continuous exploration, and developmental thought, is necessary and critical.

Westerfelt, (2004:237) states: “it is required that social workers educate themselves about antiretroviral medication and side effects. Because of the rapid changes in HIV care, social workers must continually scrutinize medical journals, talk to other health care social workers, pharmacists, nurses and physicians. They also need to learn from clients with whom they work and partake of their expert knowledge.” It is evident from the above functions that the social worker involved in ART matters should be experienced and possess the necessary knowledge in order to deliver a comprehensive service.



This must begin with prevention and education programmes, assessment of patient's circumstances, facilitating social work intervention, and include research and policy-making. The social worker, being a member of the multidisciplinary health team, could ensure fulfilment of the above roles.

5.3.8 Collaboration with the multi-disciplinary team in the delivery of services, to assure maximum utilization of skills and knowledge

Due to the difference in knowledge and skills of the team members, especially in the ART clinic, a need exists for collaboration, in order to ensure that the patients are provided with a comprehensive service.

Schlesinger (1985:225) and Erickson and Erickson (1994:8) state that, inherent in the concern for providing good health care by means of collaborative interdisciplinary teams, it is necessary for social work to function as an autonomous profession. With the maintenance of this autonomy, the blurring of roles could be avoided.

Davidson and Clarke (1990:273) are of the opinion that these collaborative skills include the strategies of interpretation, negotiation, marketing and education. With these skills, the social worker enables other team members to understand the psychosocial problems of the patients and the stressful impact of a chronic disease and adaptation. In the health setting, the social workers need to develop collaborative skills in order to be recognised, as well as render a meaningful service.

Cowles (2000:30) states that social workers will be moving away from the traditional tendency of relying on referrals from physicians and nurses. This will allow the selection of the kinds of clients and problems that the social worker should address. This calls for the social worker to make the team members aware of his/her specific roles and functions, specifically regarding the assessment of the biopsychosocial circumstances of the patients concerning adherence to ART.



5.3.9 Counselling

Counselling is defined in the *New Dictionary of Social Work* (1995:15) as comprising “interviewing procedures aimed at guiding the client towards insight, with a view of promoting his social functioning”. In the *Dictionary of Counselling* (1994:63), counselling is similarly defined as a “helping process in which one person, a helper, facilitates exploration, understanding and actions about developmental opportunities and problem conditions presented by a helper or client”.

The *Social Work Dictionary* (1991:52) in similar vein defines counselling as “a procedure often used by clinical social workers and other professionals from various disciplines in guiding individuals, families, groups and communities by such activities as giving advice, delineating alternatives, helping to articulate goals and providing needed information”.

HIV counselling is defined as a confidential dialogue between a client (patient) and a care provider aimed at enabling the client to cope with stress and be assisted in taking personal decisions related to HIV/AIDS (WHO, 2006). Counselling is defined by Van Dyk (2005:200) as a structured conversation, aimed at facilitating a client’s quality of life in the face of adversity.

From the above definitions, it can be asserted that counselling is a procedure used by the helping professionals to guide individuals, families, groups and communities towards insight development, with the aim of improving the social functioning of the client.

The South African Government (South Africa, 2003) recognizes the social work profession as part of the multidisciplinary team assisting HIV/AIDS patients on ART and makes special provision for counselling and social work services. Much emphasis is placed on counselling related to HIV/AIDS matters. Patients need to be assessed and counselled, as part of this comprehensive service to ART patients.



Social workers operate within the scope of the multi-disciplinary team, where all the members of the team are concerned with providing the patient with a comprehensive service while assuming the role of counsellors.

The major function of the social worker in this context is to improve the quality of life and social functioning of the patient. It has been established from the literature, that adhering to ARV treatment can be a complex process with severe psychosocial implications for the individual. As a result of this, there is a need for a comprehensive service, which would ensure that the patients are able to adhere to ART for life, while taking all biopsychosocial factors into account, in order to prevent the development of resistance and the spreading of the resistant virus to the community.

In ART matters, counselling is focussed on adherence to ART. Adherence counselling can be defined as: A structured conversation aimed at facilitating the treatment process. The ultimate goal is to develop patients' insight into adherence to ARV medication, in order to review their problems, options and choices and make adjustments to facilitate life-long medication, articulate recourses and provide required information and education to individuals, families, groups and communities. Counselling people with HIV/AIDS is an ongoing process. Skills in comprehensive HIV and AIDS counselling encompass all aspects of counselling

- Voluntary counselling and testing (VCT), which includes pre- and post-test counselling, has been established as being critical, in order to identify HIV infection in individuals. Since the advent of the HIV/AIDS pandemic the concept of voluntary counselling and testing has gone far beyond the mere testing of people.
- Prevent-pregnant-mothers-to-children-transmission (PMTCT)
- Adherence counselling can include crisis intervention, palliative care, family therapy, counselling.



- Ongoing counselling of HIV-positive patients becomes mandatory cornerstones in the long-term management of HIV/AIDS (South Africa, 2004).

The present researcher is of the opinion that counselling should not be labelled and fragmented. The needs of patients often exceed the indicated counselling, for example pre- and post-test counselling. Patients do experience various biopsychosocial needs that should be addressed by a qualified and experienced professional.

A comprehensive assessment by an experienced counsellor and knowledge of resources is often needed. Counsellors should be able to render a holistic and comprehensive service in assessing patients. In such an instance, the social work profession, with its specialized skills, could play an important role in assessing the patient and rendering the necessary therapeutic interventions where necessary. The counsellors should possess knowledge of community resources and networking with organizations, and assist the family to cooperate with treatment, and to support the patient's utilization of medical services.

The role of the social worker in counselling the patient's family (with the consent of the patient) would be to develop insight into the patient's situation to provide him/her with the necessary support. If the family of the patient are not made aware of the need for adherence and the possibility of developing resistance to ART, they would not be able to assist and remind the patient regarding ART. The social worker could play a role in motivating the patient to disclose their HIV status to at least one family member, friend or support system in order to provide him/her with the needed support with regards to their ARV treatment, which could influence their adherence. The social worker could facilitate cooperation, so that the patient could ultimately benefit from the treatment as well as the support from his/her family. To take ARV medication in secrecy can contribute to patients being anxious, demotivated and possibly non-adherent, with devastating results not only to the individual, but also to society as a whole.



The researcher concurs with Cowles (2000:30), that social workers will have to move away from the traditional tendency of relying on referrals from physicians and nurses, and be actively involved with all patients at the ART clinic.

Assessment, reassessment and continuous assessment are, collectively, the cornerstone of social work intervention in ART adherence issues, since adherence is not a static process and the circumstances of the patients change, they can influence adherence.

The social worker can provide a meaningful service not only during the assessment stage prior to initiating ART, but throughout treatment, since patients usually need continuous counselling. By assisting patients to develop goals with regard to behavioural change, the social worker can enhance adherence to ART by means of motivational training. The aforementioned refers to inducing a state of readiness to change (Taylor, 2003:479).

5.4 Assessing the HIV/Aids Patient for Adherence to ART - Utilizing the Biopsychosocial Model

5.4.1 Assessment

According to Cournoyer (2000:231), assessment is a fundamental process in professional social work practice. Assessment is defined as a process (ongoing); assessment involves gathering, organising, and making judgements about information. As a product, assessment is a verbal or written statement of the functioning of the group (client) and its members, which is useful in the development of intervention plans.

Skidmore, *et al.*, (1994:151) postulate that the social worker must make a thorough assessment of the patient's psychological and environmental strengths and weaknesses, so as to enable the team to understand the patient better, which is necessary for the patient to be provided with appropriate treatment. The role of assessment of the patient's circumstances is in agreement with, and applicable to, assessing HIV/AIDS patients for adherence.



It is necessary for the team to work toward the goal of, developing a better understanding of the motivation of the patient, taking into account all the psychosocial issues, the factors affecting a patient's ability to cope with his/her illness; and to interpret behaviour and provide recommendations. For the social worker, in ARV matters it might be difficult to perform the traditional psychosocial assessment, since the patient may refuse to discuss his concerns, fearing that what he says will be used against him; the patient may also refuse to have his family contacted, because he had not disclosed his HIV status. All staff members are encouraged to provide input regarding the functioning of the patient.

An individual treatment plan must be developed, including

- potential problematic situations;
- behavioural expectations;
- patients' needs and motivations;
- staff intervention; and
- consequences for the patient

The patient seeking ART experiences various difficulties; not only suffering from AIDS-related symptoms, but also suffers from psychological and social implications, would benefit from a comprehensive service. As has already been indicated, social work professional knowledge and skills equip the social workers to provide this most needed assessment to ensure that all the aspects pertaining to clients' circumstances will be attended to. Shannon's (1989:32) view that the social workers, as the primary providers of psychosocial care, can close the gap between physical and mental health, applies specifically to the ART clinic.

Without this understanding, the patient will be provided with an incomplete assessment, with various aspects not being attended to, which could lead to treatment failure. This is the reason why the researcher is of the opinion that the biopsychosocial model is the most relevant model to be used in assessing the



patient at the ARV Clinic. All interventions planned are based upon a comprehensive assessment. The researcher is of the opinion that assessing the HIV/AIDS patients “readiness” to commence ART is an important factor. Westerfelt (2004:237) asserts that the transtheoretical model is appealing in assessing individuals' readiness to change

It is argued by Green and Shellenberger (1991:19) that the biopsychosocial approach to health and wellness is viewed as the result of the interaction of biological, psychological and social factors. This implies that no wellness can be attained without utilising all three dimensions. Green and Shellenberger (1991:19) further indicate that the biological factors include genetics, environmental factors and behaviour that affect biological functions, whilst psychological factors include personality, feelings, stress management, life goals, perceptions of health and sickness behaviours, and social factors include social values, customs and social support. Of importance here is to note that the interaction of these factors impacts on the person's wellbeing. If only one aspect is attended to and the others are neglected, wellness cannot be attained.

5.4.2 The Biopsychosocial Model

Since 1907, after the work of Ida Cannon at the Massachusetts General Hospital, the underlying theoretical perspective of social work in the health field has been that physical, psychological and social environmental conditions tend to influence one another and must be taken into account in order to understand and help clients and their families in health settings. The person-in-environment-, biopsychosocial-, and general systems theories all view a person's health status as reflecting the interdependency of physical, psychological and social environmental systems. The general systems theory holds that all levels of organization in nature are inked so that change in one affects change in the others (Cowles, 2000:12).

As discussed above, it is important for health practitioners not to deal with human beings in a fragmented manner. Every human being, who seeks medical attention, must be seen as possessing the three components, namely



biological, psychological and social dimensions, which are in constant and continuous interaction with each other. It must be remembered that it is this interaction that determines the state of health of a person. The biopsychosocial model recognizes the interaction between the medical, social and psychological dimensions of disease and illness in order to provide the patient with a service that is responsive to his/her needs.

Engel (1980:535) asserts that the biopsychosocial model is based on the systems approach. The biopsychosocial model is further defined by Engel (1980:535), as a scientific model constructed to take into account the missing dimensions of the biomedical model, which has governed the thinking of most health practitioners for the last 300 years. The biomedical model disregards the interaction between the medical, psychological and the social aspects in illness or human behaviour.

Brannon and Fiest (1992:11) argue that a systems approach emphasises the mutual dependence of each system within the whole and suggests that a change in one system will produce changes in the others. The systems approach is not a necessary component of the biopsychosocial model but it helps one to understand the interaction among the biological, psychological and social components of disease and wellness.

The term biopsychosocial is also defined by Barker (1991:23) as "a term applied to phenomena that consist of biological, psychological and social elements." It becomes evident that the biopsychosocial model came into being after the realisation that, in order for the person's illness to be understood, it is necessary to consider these three dimensions in his/her life.

Kaplan, *et al.*, (1994:1) further indicate that Engel, a psychiatrist, is the most prominent proponent of the biopsychosocial model, in looking at the patient as a whole. This is vital in treating the patient as a unity, with all the aspects that are relevant to his/her situation taken into consideration. Kaplan, *et al.*, (1994:1) further argue that Engel's model does not assert that the medical illness is a direct result of a person's psychological or socio-cultural makeup, but rather



encourages a comprehensive understanding of disease and treatment. Kaplan, *et al.*, (1994:1) in addition stress an integrated systems approach to human behaviour and disease, because of the continuous interaction between the individual's body, mind and social context.

As mentioned, the researcher is further of the opinion that it is clear that the biopsychosocial model is the most relevant model when assessing patients for ART, to ensure that all the circumstances of the patient are evaluated. This model enables the medical team to understand the patient, which leads to designing an appropriate treatment plan that is responsive to the needs of AIDS patients considered for ART and ultimately improvement of quality of life.

The researcher acknowledges Boyer and Indyk's view (2006:151), that there is a tendency to treat clients' maladies in accordance with two basic premises: the medical needs of the client (as perceived by the clinician) can be successfully addressed by focussing solely on that aspect of the client's life and if the client is not able or ready, then there will be someone in the client's support system to take responsibility for administering the prescribed therapy. In many cases these assumptions hold true, but for certain sub-populations they do not:

- Individuals with substandard/chaotic lives; and
- Those with multiple, confound diagnosis who possess neither personal adherence ability nor adequate support systems.

The researcher would like to add, however, that there are individuals, despite substandard and chaotic lives, who are able to adhere due to specific personality traits, and a strong motivation to live.

Successful adherence can only be accomplished by rethinking what constitutes care and tailoring that care to the individual. Adherence requires the interweaving of three sets of needs, namely:

- needs perceived by the client,



- client's needs (motivation) as observed by an objective recorder (counsellor) and assessed for impact on the client's ability and willingness to be adherent
- medical needs as identified by a clinician

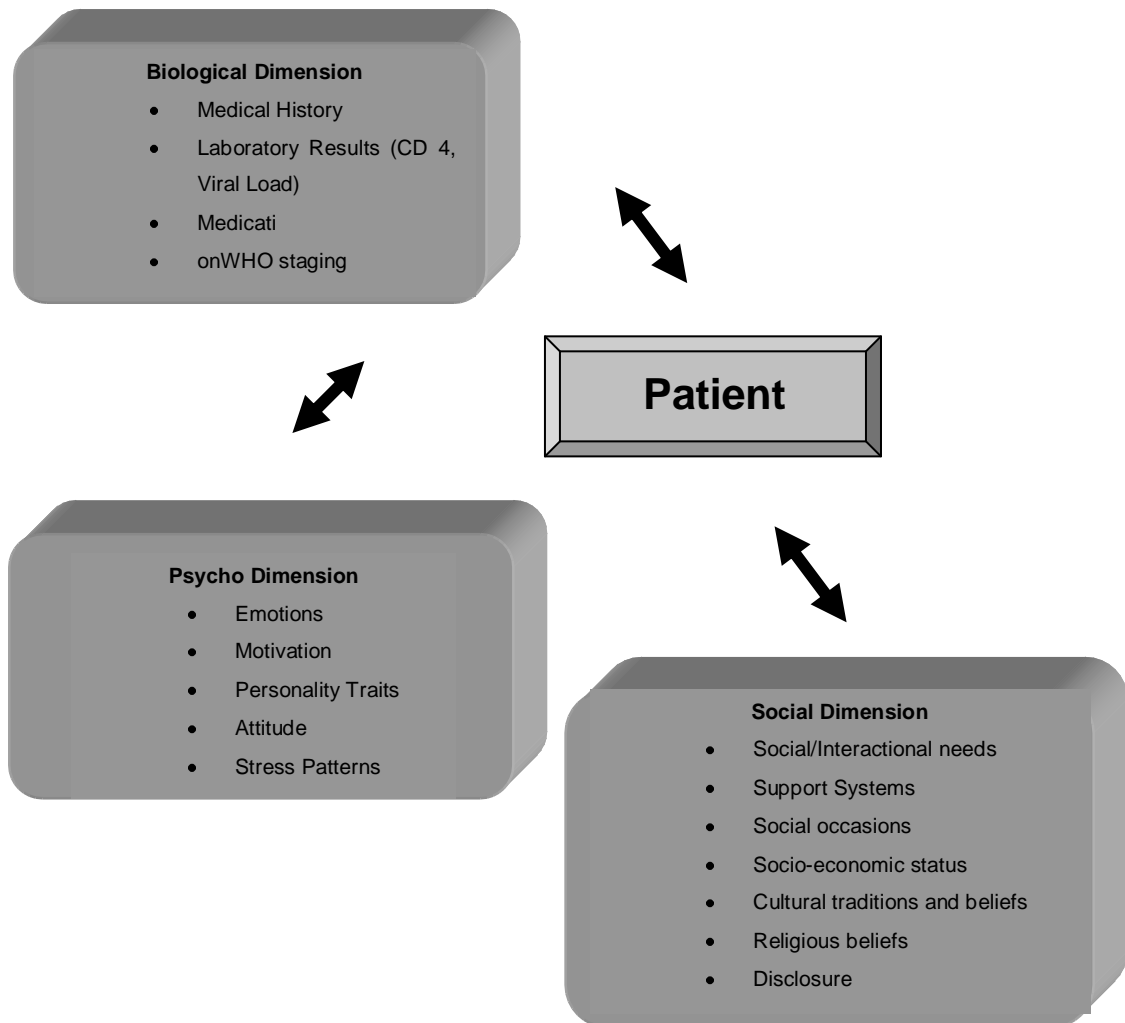
The process of adherence is not static, but is constantly being affected by external factors. (Childs and Cincotta, 2006:189). The researcher will explain the role and task of the social worker regarding the biopsychosocial matters as follows:

Bio - A physically weak, ill bed-ridden patient would have difficulty adhering without social and practical support: for example, to fetch medication, water, or prepare food. The social worker's task would be to facilitate appropriate care. Such a person could be institutionalized for a period or home-based care could be arranged.

Psycho - A negative, unmotivated or depressed patient would possibly not adhere. The social worker's task would be to motivate such a person, or to refer such a patient to the necessary resources such as a psychologist or psychiatrist for therapy.

Social - A socially isolated, homeless patient with no income would find it difficult to adhere. The social worker's task would be to facilitate support regarding financial matters, transport, grants and nutrition.

Figure 4: The different dimensions of the bio-psychosocial model can be illustrated as follows:



5.4.2.1 Assessing the biological/ physiological dimension

Kaplan, *et al.*, (1994:1) postulates that the **biological** system emphasises the anatomical, structural and molecular substrate of disease and its effects on the patient's biological function. According to Bernard and Krupal (1994:13), the biological aspects include the person's genetic predisposition, physiological reactivity, pathogens and immune responses.

This aspect of the person is the place where the medical practitioner always begins when consulted by a patient (Engel, 1980:538). This happens within the doctor-patient relationship and the medical practitioner will collect the data that



will enable him/her to reach a diagnosis. The symptoms of HIV/AIDS are the biological aspects. The service provider, usually a hospital or clinic, is approached because of the patient's biological condition (suffering from a illness), and in taking into consideration the other 2 dimensions (psychological and social) that are related to the condition will contribute to a more comprehensive assessment.

The researcher has found from her own experience that the following aspects should be assessed in adherence matters regarding the bio dimension.

- Gender
- Age
- Performance status
- Medical history
- Laboratory tests such as CD 4, viral load
- WHO staging of illness
- Side effects
- Symptoms
- Opportunistic infections
- Physical functioning in general
- General appearance

The researcher believes that the physical wellness or performance status of respondents will influence adherence. The Karnofsky Scale can be utilized in an attempt to try and measure the more subjective side of a patient's functioning. The scale relates purely to physical ability and covers 11 points, from normal health to death, each scored as a percentage:

http://www.cancerbacup.org.uk/Qas/AboutcancerQAs/AllQAs/related_faqs/Qas/993:28.02.2006

The researcher is of the opinion that biological or physical matters cannot be ignored in adherence matters. The service provider comes to know the patient because of the biological condition and the presentation of symptoms or AIDS-related diseases, but in understanding the psychological and social dimensions



of the disease, certain aspects of the biological dimension could be addressed more effectively.

Golub, Indyk and Wainberg (2006:167) assert that non-adherence is framed as a “treatment problem” and explain that barriers to adherence are constructed in terms of the patient’s experiencing of the medication regimen itself. Framing of adherence as a treatment problem forces a distinction between the experience of treatment and the experience of illness. Practitioners talk about the cost of non-adherence in terms of illness, relapse and recovery but few talk about the cost of adherence to the patient in terms of her/his quality of life and identity.

For HIV-positive people, treatment becomes part of the process of living with a chronic illness. The ultimate goal of intervention should be to enhance the quality of life of patients. HIV/AIDS challenges the patient’s body image and identity, and their sense of self-change, their social and familial relationships and life roles are also affected. Meanwhile they are obliged to deal concurrently with psychological distress, physical pain, prolonged medical treatment and increasing interference in or restrictions of their daily performances and activities.

5.4.2.2 Assessing the psychological dimension

The adoption of the biopsychosocial model in ART settings will make it possible for the patient’s feelings and perceptions regarding their biological state to be attended to. In this way his/her coping capacity and adherence can be improved. Engel (1980:538) argues that in collecting data regarding the biological aspects of the patient, it is crucial also to explore her/his psychological being, because the course of the illness and the care of the patient may be importantly influenced by processes at the psychological level. This dimension forms an important component of the biopsychosocial model, in the sense that it assists the medical practitioner to understand the patient’s perceptions of his/her condition and the extent to which he/she is motivated towards receiving help. When using the biomedical model these aspects are neglected, with a negative impact on the patient.



Kerns and Curley (1985:150) further argue that the individual's cognitive, affective and behavioural functioning greatly influences the extent and meaning of perceived psychological and social losses, as well as the person's coping with or adapting to these losses. This clearly shows that an individual's condition cannot be successfully treated with the biomedical model that is, disregarding the interaction among the biological, psychological and the social dimensions of his/her condition.

According to Kaplan, *et al.*, (1994:1), the psychological dimension emphasises the effects of psychodynamic factors, motivation and personality on the experience of illness and the reaction to it. This dimension forms an important component of the biopsychosocial model, in the sense that it helps the medical practitioner to understand the patient's perceptions of his/her condition and the extent to which he/she is motivated with respect to help.

The researcher has in her experience found that the following psychological matters could impose on adherence positively or negatively and should be addressed in rendering service to the HIV/AIDS patient in adherence matters.

- Psychological comprehension
- Personality
- Intelligence
- Feelings
- Personality traits: sense of responsibility, self-discipline, organization
- Emotions and emotional stressors (adolescence), negative feelings, grief, denial, guilt, anger, anxieties, bargaining, sadness, loss
- Attitudes towards medical care, health and illness
- Knowledge and understanding
- Health beliefs: concerning threats to health, regarding efficacy of action
- Stress pattern
- Fears
- Motivation or lack of motivation
- Ongoing or past psychiatric illness, such as mood disorders



- Psychologically ready and willing

In exploring the patient's feelings, the social worker will be able to understand the patient's needs and motivations in perspective. It is evident that during this period the patient is overwhelmed with a variety of emotions, because of the treatment. If the patient's emotions are not explored and attended to, they could find themselves with emotional problems that will affect adherence. Exploration of these feelings will assist the patient to identify them and deal with them.

Friedland (2003:35) broadly defined motivation as including all variables that encourage or discourage adherence. These might include attitudes and beliefs with respect to HIV treatment and a specific medication, social support, trust in the physician, the patient's psychological status, and the presence of competing priorities in the patient's life.

The researcher further identifies with Meyer, Moore and Viljoen, (2003:296) view on motivation: "Instead of attributing motivation to specific motives or drives, the social cognitive learning theorist regards motivation - as the result of two processes, namely interaction and learning. Their basic idea here is that individuals are not motivated only by specific intrapersonal drives, nor are they motivated only by external stimuli. They are motivated by the interaction between individual and situation".

By helping patients develop behaviour-change goals, the social worker can enhance adherence to ART through motivational training, which refers to inducing a state of readiness to adhere." (Taylor, 2003:479). The researcher believes that motivation is a very strong deterrent for adherence.

The researcher is of the opinion that the patient's needs are a strong determinant of adherence. The researcher is further of the opinion that Maslow's hierarchy of needs, as described in Louw, van Ede & Louw (1998:68) is very applicable to HIV/AIDS patients. That is, if the basic needs such as hunger, thirst, sex and the maintenance of the internal state of the body are not



fulfilled, respondents will not be aware of higher psychological needs, such as emotional needs.

5.4.2.3 Social dimension

The social environment refers to the quality and characteristics of one's life situation, including interpersonal relationships, resources for meeting one's needs and one's position, roles and participation in the society. Social institutions or social systems denote the economy, politics, the family, education, health care, transportation and religion, functioning in social roles. According to (Cowles, 2000:11) including attitudes, feelings, values, beliefs, behaviour, mental and physical health status, it constitutes the person-in-environment perspective.

Engel (1980:543) points out that in using the biopsychosocial model, the medical practitioner is able to identify and evaluate the stabilising and destabilising potential of events and relationships in the patient's social environment. Furthermore, neglecting the destabilising effects of the patient's illness on others may rebound as a further destabilising influence on the patient. This argument emphasises the importance of the patient's social environment as regards his/her health and illness. This is an indication of the need to belong in a social and familial sense and to be accepted and affiliated to others, and could include the need to reach self-fulfilment.

Kaplan, *et al.*, (1994:1) also argue that the social dimension emphasises the cultural, environmental and familial influences on the expression and the experience of illness. It is important to note that these social aspects of the person's life not only affect mental health but also health in general, which illustrates the important role played by the social system in as far as an individual's health and mental health is concerned.

Patients diagnosed with life-threatening diseases are usually smothered with sympathy and support, yet the diagnosis of HIV/AIDS is often characterised by stigmatisation, subsequently social rejection and emotional isolation. This



stigmatisation reminds us of the rejection that met a person diagnosed with leprosy in the biblical period (Holy Bible: Luke 17:12 and Leviticus 13).

Adherence to therapies has been shown to be influenced by behavioural difficulties such as substance abuse (e.g. alcohol and mood-altering drugs) and social isolation. In her experience the researcher has found that the following social/environmental matters could affect adherence positively or negatively.

- Accommodation: housing, rural/urban, prisoners
- Substance abuse: alcohol/drugs abuse,
- Relationships: familial, support systems, marital status, sexual matters, disclosure
- Rape and incest
- Social stability
- Social occasions
- Literacy; knowledge/education,
- Socio-economic status: financial circumstances, employment/pension/income, poverty
- Nutrition
- Ethnics, cultural traditions and religious beliefs
- Transport

Healthcare providers must achieve a level of cultural competence in their practice, to be able to develop adherence intervention strategies that take into account cultural differences between clients. Cultural competency addresses the ability to recognise, understand, and be sensitive to ethnic and lifestyle differences. Cultural diversity influences perceptions of illness and wellness as well as of healing beliefs and practices. Understanding these variations is critical to developing culturally competent HIV treatment and care.

Ross and Deverell (2004:16) are of the opinion that cultural considerations definitely affect whether members of a population choose to participate in prevention campaigns and whether they choose to believe, internalise and



accept the messages propagated by such campaigns as adhering to antiretroviral treatment.

As defined by Leininger (1978), culture refers to patterns of learned behaviours and values which are shared among members of a designated group and are usually transmitted to others of their group through time." Culture includes, but is not limited to geographic origin, language, traditions, values, religion, food preferences, communication, education, and lifestyle. Cultures consist not only of racial and ethnic groups but also of groups of individuals who share common lifestyles.

The researcher is of the opinion that traditional beliefs and values should be taken into account regarding adherence, as culture has been identified by various sources as one of the primary barriers to preventing the spread of HIV/AIDS. Culture and specific cultural beliefs, values and traditions could also influence treatment and adherence to therapy (Friedland, 2002:35-40).

The social elaboration of HIV/AIDS and poverty is endorsed by Mashologu-Kuse (2005:378) as well as Strydom, Cronje, Roux, Strydom, and Wessels (2005:68), confirming that poverty and the high level of unemployment, coupled with families being headed by women, no support from their partners, leading to almost total dependency on child support grants, are an indication of the plight of disadvantaged families. The researcher endorses this view and also the view of Abdool Karim and Abdool Karim (2005:381) that whilst there is a general relationship between poverty and poor health, there is also a specific relationship between HIV and poverty.

Friedland (2002:37) postulates that social isolation predicts poor adherence levels and he therefore encourages patients to have supportive family members accompany them to clinic visits. Regarding adherence and age, Friedland (2002:35-40), also states the following: "With regard to patient related characteristics, the literature in the developed world indicates that age and race consistently predict adherence. Older adults are likely to be more adherent. In the USA studies have found that the black race and people with low literacy



levels are associated with poorer adherence. Whether this finding will hold in Africa remains undetermined”.

To disclose HIV status in an effort to obtain adherence support is another matter of concern. Disclosure appears to be used as a form of punishment rather than a mechanism to provide such support (Venter, 2005:22). The researcher is of the opinion that disclosure cannot be forced, as this would go against the individual’s right to privacy and confidentiality, as well as the basic social work principles, such as actualising. The social worker’s role here is to assess patients regarding disclosure or not and refers to alternative support and networking.

It is therefore clear that the biopsychosocial model, which takes into account all three dimensions of a person, is appropriate when assessing and monitoring HIV/AIDS patients on ART, to ensure that all the aspects pertaining to the patient’s condition are considered. This model enables the service providers to understand their patients, which leads to designing an appropriate treatment plan that is responsive to the needs of the latter, specifically the AIDS patients on ARV. If a provider has a significant bias that could potentially affect the helping relationship, another team member may need to intervene Saloner (2004:41).

It is clear that HIV/AIDS patients are struggling to adapt to the confusion and conflict of being cast in the “sick/not sick” role. Unfortunately, the recognition of the life paradox of such persons is only the beginning. Neither the healthcare team nor the patients themselves can, by individual effort, hasten the tedious process of assimilating this new role, produced by chemicals, into the social order: we are still mapping behaviour topography, emotional currents and role boundaries. Social frameworks must become restructured in order to accommodate millions of HIV/AIDS people living on ART. A task shared by health team, professionals, family and the community as a whole.

The researcher consequently proposes an adherence assessment schedule, **(Appendix 7)** to be used as a standard tool, in assessing the patient’s



circumstances as discussed above. The schedule makes provision for assessment of all three dimensions of the Biopsychosocial model. The schedule was introduced to other professions supporting adherence. The said schedule has been successfully implemented by the researcher, in assessing HIV/AIDS patients for ART, at the ARV clinic, Tshwane District hospital. Specifically, lay counsellors, with no formal training and little experience, found the schedule to be extremely helpful. If a problem which they cannot address is identified by the counsellors, a referral to an appropriate service providers or multidisciplinary team member is done.

5.5 Summary

If the social work profession could have fabricated a condition, imposing on all aspects of human functioning, to challenge and test social workers' service delivery regarding knowledge and skills; goals and roles; norms and values; characteristics and principals – on individuals, groups or communities - it would have been called HIV/AIDS – and seemed rather far fetched...

In the following chapter the researcher will offer a brief discussion of the research methodology and the research findings, which are presented according to the subsections in the questionnaire used for the quantitative part of the study, in terms of the biographical, medical and psychosocial data. The qualitative part of the study is presented throughout the discussion wherever applicable, including the narrative relating to the themes and sub-themes.



CHAPTER 6: EMPIRICAL FINDINGS FROM THE QUANTITATIVE AND QUALITATIVE PHASES OF THE STUDY: THE BIOPSYCHOSOCIAL FACTORS INFLUENCING HIV/AIDS PATIENT ADHERENCE TO ANTIRETROVIRAL THERAPY (ART): A SOCIAL WORK STUDY

6.1 Introduction

The general purpose of this research is to explore and gain insight into the biopsychosocial factors related to adherence as regards antiretroviral therapy for HIV/AIDS patients, within the South African context, since little is known about this field.

This chapter consists of a discussion of the research methodology and the research findings, which are presented according to the subsections in the questionnaire used for the quantitative part of the study, in terms of the biographical, medical and psychosocial data. The qualitative part of the study is presented throughout the discussion wherever applicable, including the narrative quotes from interviews and the themes and sub-themes.

6.2 Research Methodology

6.2.1 Type of research, and research approach and design

Applied research, was employed in this study since the general purpose of this study was to stimulate thought and action concerning the challenges faced by patients on ART. The knowledge generated from the findings will be aimed at improving adherence and sets out to solve practical problems (Grinnell, 1993:15; Fouche, 2002:108; Neuman, 2003:21). The aim of the research is to provide improved service delivery. "Applied research ... is aimed at solving specific policy problems or at helping practitioners accomplish tasks. It is focused on solving problems in practice" (Fouche, 2002:109; Rubin & Babbie, 1993:79).



The researcher sought various types of sources that could provide insight into the research question. She is of the opinion that the combination of the two approaches, qualitative and quantitative, led to more reliable results. According to Creswell's dominant-less-dominant model Fouche, (2002:365) confirms that the above two approaches are often employed in the same study with one approach being used more than the other, according to the demands of the study.

For the quantitative phase the quantitative descriptive design was used and for the qualitative phase collective case studies were used. In addition to this the quantitative approach was primarily utilized, employing a questionnaire as a method of data collection. In the qualitative part of the study a collective case study was utilized as the less dominant part. The intention was to unearth the knowledge, perceptions, feelings and attitudes of the participants in the research regarding factors that influence adherence. The specific aim of the qualitative phase of the study was to explore the views of the multidisciplinary team members with regards to biopsychosocial aspects that could influence adherence of HIV/AIDS patients on ART.

6.2.2 Research questions and hypothesis

The researcher aimed to obtain answers to the following research questions:

- What are the biopsychosocial factors that influence adherence to ART, as perceived by multidisciplinary team members involved in the service delivery to HIV/AIDS patients on ART?
- What are the existing biopsychosocial circumstances influencing adherence of HIV/AIDS patients already on ART?
- How can these identified biopsychosocial factors be utilised in service-rendering to enhance adherence to ART by HIV/AIDS patients thereby minimising the development of resistance?

A hypothesis is defined by Kerlinger (1986:17) in De Vos (2002:36) as a conjectural statement of the relationship between two variables. The researcher has formulated the following hypothesis for this research.



- The biopsychosocial circumstances of HIV/AIDS will influence adherence to ART.

6.2.3 Goal and objectives

The specific goal of the study is to explore the biopsychosocial factors that influence patient adherence to ART, in order to make recommendations for practical and relevant factors which should be considered in assessing patients for ART.

The researcher has identified the following objectives for the study:

- To explore the importance of adherence and the implications of non-adherence, and subsequently, the development of resistance to ART by means of an extensive literature search;
- To explore the biopsychosocial factors that influence adherence (negative and positive) to ART as experienced by HIV/AIDS patients on ART;
- To explore, and describe the biopsychosocial factors that influence adherence to ART in patients, as perceived by the multidisciplinary team members actually involved in service delivery to HIV/AIDS patients on ART;
- To explore and analyse circumstances in order to determine whether the predictive generalization of the theory holds true, and to make recommendations regarding the biopsychosocial factors that should be considered in screening HIV/AIDS patients for ART that are practical, relevant and appropriate in the African context.

6.2.4 Methods of data collection

Data collection methods for both paradigms were employed; i.e. semi-structured interviews with an interview schedule for the qualitative data collection methods. The interview was tape recorded and transcribed. A structured questionnaire and documents (CD4 laboratory results of patients) were used for the quantitative data collection (Bless & Higson-Smith 1995:113; Delport 2002:172; Greeff 2000:302 & 306-317; Rubin & Rubin in Mouton, 2003:196; Strydom, 2002:292.)



Various sampling techniques were employed for the two research groups. A sample of two hundred and one (201) respondents was selected by means of the probability simple random sampling technique, for the quantitative research from patients attending the ARV clinic at Tshwane District Hospital.

The respondents to the quantitative study were asked to complete the structured questionnaire after providing their informed consent. The questionnaire is attached in Appendix 5 of this thesis. The research was conducted during October and November 2005. The questionnaire was self administered but the researcher had individual and personal contact with each respondent and assisted with the filling in of the questionnaire.

6.2.5 Sampling method and sample

The total population consisted of participants, male and female, older than 18 years, of all races and socio-economic groups, who are HIV-positive and have been referred for ART to the ART Clinic at the Pretoria Academic Hospital, which became Tshwane District Hospital during 2006. The clinic is in the Tshwane/Metsweding Region of the Gauteng Department of Health and forms part of the Comprehensive HIV/AIDS Treatment Clinic of the Gauteng Provincial Government. With regards to the quantitative-descriptive (survey) design, random sampling methods were employed for the selection of respondents. According to Strydom, (2002c:197) maintains the following regarding drawing a random sample: "As mentioned above some methodologists suggest that drawing a 10% sample of a known population has become convention which serves as a handy rule of some". The researcher decided on 201 (10%) of the total population of 2 000 registered ART patients at the time of the research.

In addition to this, the collective case study strategy was utilised for the qualitative approach of the research, which aims to understand and interpret the meaning that the subjects give to their everyday lives (Creswell, 1998 in Fouche, 2002:273 & Neuman, 2003:142 & 148).



The non-probability sampling method was implemented in the qualitative research utilizing the purposive sampling technique (Neuman, 2003:211 & 223), in order to select 20 multidisciplinary team members. A collective case study was employed for the qualitative study (Fouche, 2002:275). The aim was to ensure that rich information on the subject was obtained.

The multidisciplinary team members are knowledgeable and possess experience in the area of the current study. The researcher wanted to understand a certain issue (i.e. factors influencing adherence) and according to Fouche, (2002:277), “the collective case study furthers the understanding of the researcher about a social issue or population being studied. The interest in the individual case is secondary to the researcher’s interest in a group of cases”. (Strydom & Venter, 2002:201) The researcher purposively selected multidisciplinary team members, experts who are practising in the field of ART, or possess knowledge, regarding ART, to participate in the study. The said researcher interviewed respondents from the multidisciplinary team in various ART settings.

The criteria for the selection of this sample required that the respondents must be:

- Multidisciplinary team members, male or female, any race and age; and
- Professional as well as non-professional individuals (medical doctors, professional nurses, social workers, dieticians, pharmacists, lay counsellors).
- The individuals must be actively involved in the rendering of service to HIV/AIDS patients, particularly those on ART, for at least one year or are perceived to be experts due to their contribution to this field of study (i.e. published authors, academics, policy writers). The team members could include individuals from the private sector, as well as the public. The selection of experts is illustrated in Table 2 in Chapter 1.



6.2.6 Methods of data analysis

In conducting data analysis during data collection, the researcher made use of triangulation, and sought different sources that could provide insight regarding the data. Triangulation denotes the mingling of qualitative and quantitative styles of research in data collection and the recording of data in order to keep it intact, complete, organized and accessible.

As De Vos (1998:48) observes, data analysis follows data collection. Mabutho (2004:28) defines data analysis as a search for a pattern in recurrent behaviours or objects of a body of knowledge. Once a pattern is identified, it is interpreted in terms of social theory or the setting in which it occurred.

Data analysis is, therefore, a process of bringing order, structure and interpretation to the mass of data collected and should include examining, categorizing, tabulating or otherwise recombining the evidence in order to address the research problem. The researcher agrees with the aforementioned definition and applies it in her study. The quantitative data analysis in this research was performed with the use of computer software for quantification (De Vos, Fouche & Venter, 2002:224).

The quantitative data will be presented in percentages and frequencies and by means of tables and graphs according to the various sub-sections in the questionnaire. The researcher presented quantitative data in text, tabular and figure form, thus creating a visual image of the information, making use of the Department of Statistics, University of Pretoria.

Qualitative data analysis and interpretation was therefore carried out by means of the identification of themes, recurring ideas and patterns or beliefs, and was interpreted in order to perceive patterns and increase credibility.

The qualitative data analysis and interpretation was carried out by means of the data recorded from the transcribed interviews, classified into themes, recurring ideas and patterns or beliefs, and presented as direct quotes (De Vos,



2002:354). The grounded theory analysis of the data was conducted in the following manner: She clustered the categories that emerged most prominently; various themes emerged from these clusters. She then searched for commonalities in or contradictions to the findings and, thereby forming sub-themes.

The research findings of the qualitative part of the research will be presented as verbatim quotes from the interviews according to the different themes and sub-themes. These themes are discussed in the light of relevant literature or supporting narratives.

According to Strauss and Carbin (1998:10-11), a qualitative research approach is an approach that elicits participant accounts of meaning, experience or perceptions. They add that it also produces descriptive data in the participant's own written or spoken words (Bailey, 1994:62-63, Grinnell, 1997:12, Neuman, 1997:14, and Fouchè, 2002:271-272).

The steps in qualitative data analysis are not as linear as they may appear, but are outlined as such for the purpose of the current study. The researcher employed her powers of reasoning in order to reach conclusions based on evidence collected (De Vos, 2002c:341; Neuman, 2003:430).

The researcher followed the process of analyzing data qualitatively as described by Creswell and presented by De Vos (2002c:340). The data analysis comprised the following aspects: Collecting and recording data, managing the information, reading, writing memos, describing, classifying and interpreting, presenting and visualizing the data.

6.2.7 Collecting and recording data

Collection and recording of data was carried out through interviewing. The researcher used an interview schedule to produce findings. Interviews were based on the biopsychosocial model. This data consist of field notes and tape



recordings. As data were gathered they were managed and analysed by the following methods:

6.2.7.1 Managing the data

The data obtained from the interview schedule were dealt with as follows: the tape recordings of the interviews were transcribed, organized, taking notes and also making use of computer programmes so that the information was easily retrievable.

The researcher evaluated the merits of the transcribed interviews and determined whether the data was authentic, valid, true, worthy, manageable, and of value for the research.

She converted the files into sentences or an entire story for the purposes of analysis. During this phase she kept the literature review, the previous data and earlier analytic memos in mind.

6.2.7.2 Reading, writing memos

After the collection of the transcribed data, they were studied to enable the researcher to become familiar with the content as a whole.

The researcher read the transcripts in their entirety several times in order to describe, classify and interpret the data, prior to categorizing it in order to identify similarities that might exist in the various categories. She kept memos of the different themes uncovered.

6.2.7.3 Describing, classifying and interpreting

The data were subsequently sorted and interpreted to bring order and structure and to give meaning. De Vos (2002c:344) states that, in this regard, classifying means taking the text or qualitative information apart and searching for categories, themes or dimensions of information.



The researcher also sought to identify the salient themes, noting regularities or patterns of meanings held by the participants that would then be reduced to small, manageable sets of themes and sub-themes to be written into the final report.

She sought explanations and identified similarities from the views of the various multidisciplinary team members and compared them before describing these, employing descriptive statistical analyses for the purposes of summarizing, describing and analyzing the major characteristics of the collected data.

In particular, she interpreted and reviewed data, about factors influencing adherence, piecing together patterns in order to accord meaning to them before conclusions were drawn.

Mark (1996:211) states that findings may be presented in the form of categories or statements about the nature of persons, groups or events under study. Hence the researcher defined specific categories, to represent the research findings. The categories defined are:

- Bio- or medico-physical factors affecting adherence;
- Psychological factors influencing adherence;
- Social circumstances impacting on adherence;

Discrete themes and sub-themes were further derived from the above categories to:

- answer the research questions;
- supplement the quantitative analyses;
- present solid descriptive data, leading to a better understanding of the phenomenon of biopsychosocial factors possibly affecting adherence.

6.2.7.4 Representing, visualizing

The researcher presented data in qualitative findings by means of narratives, themes, sub-themes, and quotes from interviews supported by the literature. A presentation and visualization of data and reporting of the findings follows:

Table 10: The themes and sub themes, derived from the interviews for the qualitative part of the study:

CATEGORY: BIOGRAPHICAL	
THEME	SUBTHEMES
Gender plays a role in adherence to ART	<ul style="list-style-type: none"> • Women comprise the majority of patients attending ART clinics. • Females are perceived by respondents as more adherent than males.
Age plays a role in adherence to ART	<ul style="list-style-type: none"> • Younger people show more insight, are motivated to live longer and tend to be more adherent. • Young adults have further issues (psychological changes and psychosocial challenges) to deal with, other than adherence to ART. • Older people are more reliable and responsible, but they do not evidence much insight and are often supported by younger family members.
Language, culture and traditions influence adherence to ART	<ul style="list-style-type: none"> • Different ethnic groups hold to different traditions, values and beliefs that influence adherence • Certain cultures do influence adherence through myths and certain traditional beliefs and values. • Certain traditional healing methods can jeopardize adherence to ART.
CATEGORY: BIOLOGICAL OR MEDICAL	
THEMES	SUB-THEMES
The period a patient has been on ART influences adherence	<ul style="list-style-type: none"> • The period on ART does not indicate non-adherence, but patients tend to stop ART once they feel better. • After a lengthy period on ART some patients tend to get tired of pill taking (pill fatigue). • Patients are not always aware that ARV medication is for life. • Monitoring of adherence throughout ART treatment is indicated.
Knowledge of the CD 4 count could influence adherence to	<ul style="list-style-type: none"> • The CD4 count is a reflection of the improvement of the immune system and tends to serve as a



ART	<p>motivation.</p> <ul style="list-style-type: none">• The CD4 count can also influence adherence negatively in some circumstances, e.g. the CD 4 count might not improve and patients may tend to become disillusioned.• If the CD 4 count increases, some patients do not adhere for fear of losing their disability grant, which requires the patient to be in stage IV or CD 4 count under 200.• The CD4 count is a difficult concept to try and explain in counselling.
Performance status (Karnofsky) of patients influences adherence to ART indirectly	<ul style="list-style-type: none">• This status is not used directly in counselling patients at clinics.• It is a difficult concept to try and explain to patients.• The performance status is a confirmation of the improvement of the physical functioning and could serve as a motivation to adhere to ART.
WHO staging does not influence adherence to ART directly	<ul style="list-style-type: none">• WHO staging is only used by clinicians prior to initiation in clinics and is not used by counsellors.• It is also a difficult concept to try and explain to patients.• WHO staging is an indication of the improvement of the medical condition and could likewise serve as a motivation.• WHO staging does not influence adherence, since patients just see an improvement of their functions and the regaining of lost roles.
Patients experience various difficulties regarding adherence to ART	<ul style="list-style-type: none">• Patients do experience side-effects and complications of ART.• These side-effects and complications are contra-indicated for adherence.• Financial difficulties and material needs do influence adherence to ART.• Patients are not educated regarding various grants that they qualify for.
Patients do require various or holistic counselling throughout	<ul style="list-style-type: none">• Common standards are required in counselling, specifically regarding adherence counselling.



ART treatment	<ul style="list-style-type: none"> • Patients need holistic help. • Patients need trained counsellors to support them.
SOCIAL CATEGORY	
THEMES	SUB-THEMES
Marital status influences adherence to ART	<ul style="list-style-type: none"> • Marriage, specifically supportive relationships, influence adherence to ART positively. • Disclosure of HIV status to the partner is indicated for adherence to ART. • Marriage, if not a supportive relationship, coupled with non-disclosure to the partner, influences adherence to ART negatively.
Education influences adherence to ART	<ul style="list-style-type: none"> • Better educated people demonstrate greater insight regarding adherence to ART. • Better educated people are more open to training. • Formal education should not play a role in adherence issues. • People can be educated by means of counselling and training to help improve adherence.
Residential area influences adherence to ART	<ul style="list-style-type: none"> • Rural people prefer to travel to urban clinics; they perceive the clinics to offer better treatment. Urban clinics are thus valued more by patients than rural clinics. • Patients still fear discrimination and prefer to attend clinics far away from home. • Easy access to a clinic influences adherence positively, due to transport costs.
Living conditions influence adherence to ART	<ul style="list-style-type: none"> • Overcrowded living conditions influence adherence negatively. (Urban –flats) • Chaotic living conditions are contraindicated for adherence. • The type of house (shack or house) does not influence adherence. • Homeless people have difficulty in adhering.
Social support is very important in adherence Support from a comprehensive ARV clinic is important	<ul style="list-style-type: none"> • Family support appears to be the most common form of support to patients. • A comprehensive ARV clinic can offer good support.



<p>Support groups are essential and this form of assistance needs attention</p> <p>Employers are not seen as supporting adherence</p>	<ul style="list-style-type: none"> • Support from all team members involved in a comprehensive ART clinic is recommended • Common standards should be adhered to by all team members regarding adherence issues. • The health team is an important form of support. • The private and public sectors should maintain common standards regarding ART matters. • Support groups are not valued by patients • Support groups should comply with common standards to promote credibility. • Patients experience anxiety due to their non-disclosure to employers and their need for absenteeism from work to attend medical appointments.
<p>Patients experience various psychosocial needs</p> <p>Various forms of support and aids are necessary to enhance, adherence to ART</p> <p>The social worker with her specialize skills is very important in supporting patients</p>	<ul style="list-style-type: none"> • Material needs feature strongly in adherence. • Financial assistance and disability grants are major needs. • Nutritional assistance is needed by many patients. • The need for psychosocial support regarding adherence is reported. • Family support, especially mothers appear to be the most common form of support to patients. • Patients use mainly cell phones as reminders. Some patients plan pill-taking around TV or radio programs. • Patients do not use aids, like pillboxes, to support adherence. • Patients do use diary charts if supplied by clinic. • Pill counts done at clinics are a good form of supporting adherence and detecting adherence problems. • Social worker can assess needs and refer to appropriate resources. • Social worker can network. • Social workers can co-ordinate services.
<p>Drug abuse not reported to be prominent at ART clinics</p>	<ul style="list-style-type: none"> • Drug abuse is not reported by patients. • Patients are too poor to afford drugs



	<ul style="list-style-type: none"> • People do not easily disclose drug abuse. • Drug abuse is more prominent amongst white or financially stronger patients.
Alcohol dependency not reported at ART clinics	<ul style="list-style-type: none"> • Alcohol dependency or abuse does not feature strongly at ART clinics. • Alcohol abuse is not often or willingly disclosed.
Criminal involvement Minimum influence on adherence to ART	<ul style="list-style-type: none"> • Criminal involvement does not feature in adherence to ART. • Prisoners should receive treatment in prison and not visit local clinics as is the present practice in local clinics in S.A.
<p>Psychosocial needs of patients featured strongly</p> <p>Psychosocial needs of counsellors featured strongly</p>	<ul style="list-style-type: none"> • Patients need support structures that are supportive and standardized. • Patients have a need for maintenance of confidentiality. • All patients need a thorough assessment of personal circumstances and needs • Lay counsellors concerning adherence matters need formal training. • Lay counsellors in general need better working conditions and expect formal employment with benefits. • The standards governing lay counsellors need to be standardized and uplifted.
Disclosure influences adherence to ART	<ul style="list-style-type: none"> • Disclosure of HIV status features as a major issue in adherence to ART. • Disclosure or non-disclosure of HIV status causes anxiety and influences adherence to ART. • Patients tend to disclose mainly to immediate family for support. • Patients try to avoid disclosing to employers and strangers. • To demand disclosure of status to at least one person prior to initiation not always possible and cause anxiety.
Sexual relationships do influence adherence to ART	<ul style="list-style-type: none"> • Sexual matters are not specifically discussed in counselling. • Disclosure of HIV status influences sexual

<p>People do not practice safe sex</p> <p>Sexual matters are reported to be associated with ART</p> <p>People do not practice safe sex</p> <p>Sexual matter are reported to be associated with ART</p>	<p>relationships as well as adherence to ART.</p> <ul style="list-style-type: none"> • Non-disclosure of status to sexual partners influences adherence to ART negatively, specifically if patients must visit clinics for follow-up appointments and take medication in secrecy. Patients also experience problems when developing side-effects from ART. • Female patients increasingly report being pregnant on ART. • Patients moreover report STI's at clinics. • Patients (both sexes) report an increase of libido on ART. • Sexual dysfunction is reported by males, specifically erectile dysfunction while on ART.
<p>Traditional healing influences adherence to ART in S.A.</p>	<ul style="list-style-type: none"> • Certain traditional beliefs and rituals are contraindicated for adherence to ART. Like cleaning of the body. • Traditional healing does interfere with ART.
<p>Accommodation needs do not play a role in adherence</p>	<ul style="list-style-type: none"> • Most people are content with their accommodation.
<p>Economic factors influence adherence to ART</p>	<ul style="list-style-type: none"> • Lack of money influences adherence to ART. • Poverty should not prevent adherence. • People need financial support to adhere to ART and to attend clinics. • Unemployed patients, dependent on disability grants, fear discontinuing of grant, when adhering and the subsequent improvement of CD 4 count.
<p>Financial difficulties are reported by respondents influencing adherence to ART</p>	<ul style="list-style-type: none"> • Supporting patients financially is important for adherence • Unemployed patients need disability grants to support adherence. • Patients rely mainly on financial support from families.
<p>Religion can influence adherence to ART</p>	<ul style="list-style-type: none"> • If patients are religious, the church and spirituality will convey hope and motivate them to adhere. • Some churches issue special instructions regarding treatment (faith-healing, cleaning of body and other rituals) which could be

	<p>contraindicated for adherence.</p> <ul style="list-style-type: none"> • The concept of faith healing and patients believing that they are cured can result in non-adherence to ART.
The quality of life of most patients had improved on ART	<ul style="list-style-type: none"> • A dramatic improvement if on ART is shown, if patients are adherent with no complications. • The quality of life has improved and most patients can assume lost roles.
PSYCHOLOGICAL MATTERS	
The need of patients to stay alive (survival) features as their strongest motivation to adhere to ART	<ul style="list-style-type: none"> • Patients are mostly motivated to adhere in order to improve their health in general and to be symptom-free. • Patients are motivated to adhere so as to be able to care for their families. • Patients are frequently urged by external pressure to adhere to ART.
Patients reported in general positive feelings and feelings of optimism, hope and gratitude	<ul style="list-style-type: none"> • Feelings of anxiety were reported regarding disclosure of status. • Complications, treatment failure and side-effects lead to feelings of despondency and depression.
Depression not reported to be prominent at ART clinics	<ul style="list-style-type: none"> • Depression is more often reported in white patients. • Depression did not feature frequently in patients attending the clinics where research was conducted.

6.3 Research Findings

As mentioned above, the quantitative data, which were collected by means of questionnaires, will be presented and interpreted by means of percentages and frequencies. The more significant data will also be represented by means of tables and graphs. The questionnaire consists of questions that explore the biographical, medical, as well as the psychosocial circumstances of respondents.

The qualitative data will be presented using verbatim quotes from the interviews, which were transcribed and classified, scientifically, into themes and

sub themes, and will then be supported with the literature. The data from the qualitative element of the study will be provided throughout, where applicable, in conjunction with the quantitative findings.

6.3.1 Biographical Data

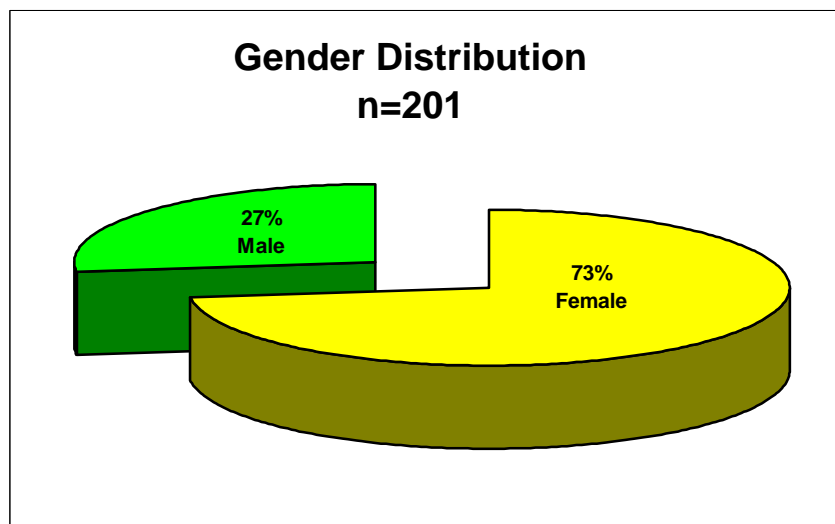
In this subsection, personal information was collected from the respondents, in order to gain a better understanding of their circumstances.

Biographical data were gathered with regards to gender, age, marital status and educational level. An intensive literature search revealed that marital status, level of education, race and living conditions of respondents do influence adherence to ART, and that certain groups are more adherent than others (Friedland, 2002:35-40). The researcher wished to ascertain whether these results could be verified by means of the current study.

6.3.1.1 Gender of Respondents

This question formed part of the biographical data in order to establish the gender distribution of the respondents, since gender has always been a prominent issue in HIV/AIDS discussion.

Figure 5: Gender Distribution



The above graph illustrated the following:

54 (27%) of the respondents were male

147 (73%) of the respondents were female

It is evident from the above research results, that the majority of respondents were women: 147 (73%) and only 54 (27%) were males. This correlates with the National HIV and Department of Health's Syphilis Antenatal Sero-Prevalence survey in South Africa (2005:1), which reported that, globally, 40.3 million people worldwide are living with HIV, of which an estimated 25.4 million live on the African continent. Of these, 17.6 million were women. The above survey further estimated the number of infected women in South Africa to be 3.12 million and, 2.19 million infected males from a total population of 5.30 million.

The data from the qualitative part of the study correlates with the findings from the quantitative part of the study.

Theme:

- Gender plays a role in adherence to ART.

Sub-themes:

- Women comprise the majority of patients attending ART clinics.
- Females are perceived by respondents as more adherent than males.

Table 9: Theme: Gender plays a role in adherence to ART

Respondent	Verbatim interview quotes from the research interview.
Social Worker	"Yes, gender plays a role in adherence. Women are better at adhering because they have better coping skills".
Pharmacist	"Women are better adherents they seem to be more responsible".
Medical doctor	"Gender plays no role in adherence".
Counsellor	"Woman wants medication because they want to care for their children. The males are in denial".

The above research findings are supported by the following literature:



Abdool Karim & Abdool Karim (2005:276) state the following with respect to gender: “The importance of gender as a dominant force in young people’s relationships has been shown through research in a number of settings. Women represent the majority of those living with HIV/AIDS in sub-Saharan Africa.”

Regarding the gender issue Venter (2005:23) observes that men are grossly underrepresented in all the large ARV clinics that have reported data, with women accounting for over two-thirds of the numbers. This probably reflects the social behaviour of men who tend to seek healthcare services less often and at a later stage of the disease. VCT attendees are predominantly women and active discovery of cases among women occurs by means of pregnant-mother-to-child-transmission (PMTCT) programmes. Factors contributing to this situation could be the high incidence of HIV in women in general, or it could be speculated that women seek medical treatment more often than men. Thus, gender seems to play a role in adherence and it was found that women are thought to be more adherent and evidence more determination to do so because they feel responsible for their children.

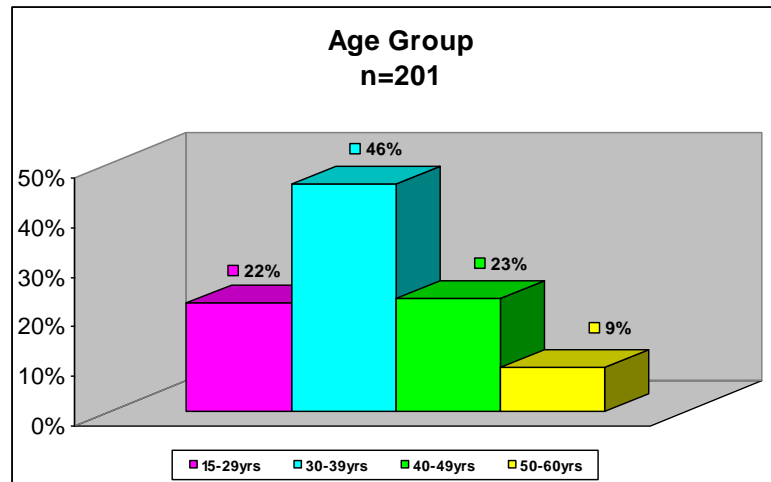
The above research data also correlate with the high response rate of female respondents, 143 (73%), in the quantitative part of the present study. The present researcher is of the opinion that these findings indicate a need for active programmes that specifically focus on men, such as workplace programmes, or male wellness clinics. Such a clinic could possibly be attached to an antenatal clinic, since, for every pregnant woman there must be a sexually active man who could be actively involved in HIV awareness, education and/or testing at such a clinic.

If men are actively focused on it could lead to an increase in VCT and awareness. Wilson and Fairall, in Abdool Karim & Abdool Karim (2005:489) state the following regarding gender:” This is explained by HIV/AIDS programmes which to date have prioritised access to antiretroviral for PMTCT and PEP. Until this imbalance is addressed, and men distanced from blame for the spread of the disease, intervention to encourage safe sex practices can be expected to be of limited effectiveness.”

6.3.1.2 Age Group

The purpose of this question is to establish the age of respondents who receive ART.

Figure 6: Age Distribution



The above graph illustrates the following:

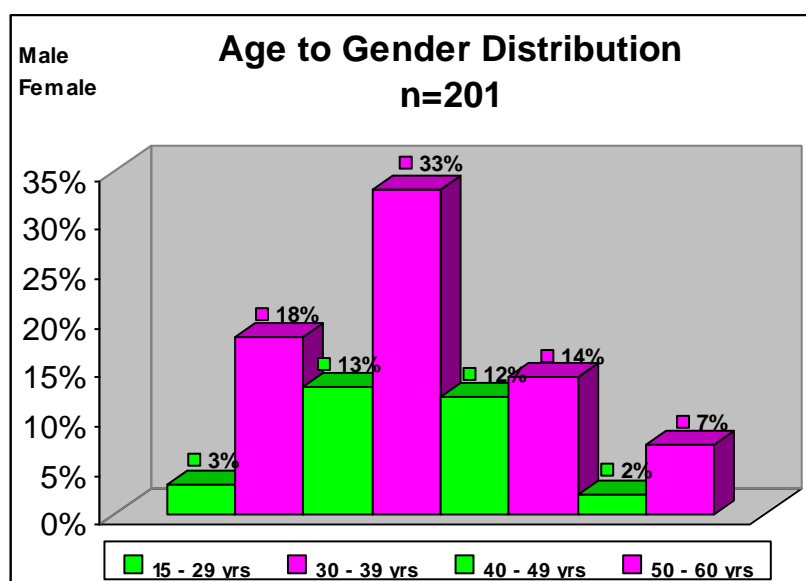
44 (22%) of the respondents were between 15-29 years

93 (46%) of the respondents were between 30-39

46 (23%) of the respondents were between 40-49

18 (9%) of the respondents were between 50-60

Figure 7: Age to gender distribution



The above graph illustrated the following:



(3%) of the male respondents were between 15-29
(18%) of the female respondents were between 15-29
(13%) of the male respondents were between 30-39
(33%) of the female respondents were between 30-39
(12%) of the male respondents were between 40- 49
(14%) of the female respondents were between 40-49
(2%) of the male respondents were between 50-60
(7%) of the female respondents were between 50-60

It is evident from this research that the majority of respondents, 137 (68%), fall in the age group of under 40 years. Of these, 137 (69%) respondents were single women. This research has further revealed that 44 (22%) of respondents were under the age of 30.

The data collected from the qualitative part of the study with regards to age: correlates with the findings from the quantitative part of the study. Thus the theme of age and adherence was prevalent under the category of biographical data, with interesting contradictory findings.

One main theme emerged from the responses to the semi-structured interview schedule: Age plays a role in adherence; with the following extremes: the youth are more adherent due to better insight and the elderly are more responsible and thus more adherent.

Theme:

- Age plays a role in adherence to ART.

Sub-themes:

- Younger people, show more insight, and are motivated to live longer and tend to be more adherent.
- Young adults have further other issues (psychological changes and psychosocial challenges) to deal with, other than adherence to ART.

- Older people are more reliable and responsible, but they do not show a lot evidence much of insight and is often supported by younger family members.

Table 10: Theme: Age plays a role in adherence to ART.

Respondent	Verbatim interview quote from the research interview
Medical doctor	“Age plays no role in adherence.”
Counsellor 1	“The young are better adherent, they understand better and they want to live longer.”
Counsellor 2	“The older are not so educated and they don’t understand, but older people can be reliable. Older people ask their children and grandchildren to help them.”

The above research findings are supported by the following literature:

These findings correlate with the National HIV and Syphilis antenatal seroprevalence survey in South Africa (2004:1), where the number of women with HIV infection attending the antenatal clinics is greater among women in their late twenties and early thirties and lower among teenagers (22% being between 15 and 29). The risk of HIV infection increases with age, indicating a higher risk among the older teenagers and women in their early twenties. This age group (25 to 34) is also associated with higher fertility and sexual activity.

Regarding adherence and age, Friedland (2003:35-40) comments: “With regard to patient related characteristics, the literature in the developed world indicates that age and race consistently predict adherence. Older adults are likely to be more adherent, and in the USA studies have found that the African Americans and people with low literacy levels are associated with poorer adherence.” Whether this finding will hold in Africa remains undetermined.

The researcher is of the opinion that younger people will most probably be more adherent, since they are usually better informed. She set out to establish whether this allegation holds true in South Africa, in contrast to Friedland’s



(2003:35-40) statement that older adults are likely to be more adherent in USA studies.

The above research findings also correlate with those of Venter (2005:23) where limited data indicates the average age of ARV access to be in the late 30s, while epidemiological data suggests a high death rate in the late 20s. He suggests that attempts should be made to make clinics more accessible and youth-friendly.

Furthermore, the present research also indicates that the majority of people are infected during late adolescence and their early twenties. It is only when they start developing AIDS-related symptoms and are confronted with the reality, severe symptoms and death, that they are forced to seek medical treatment.

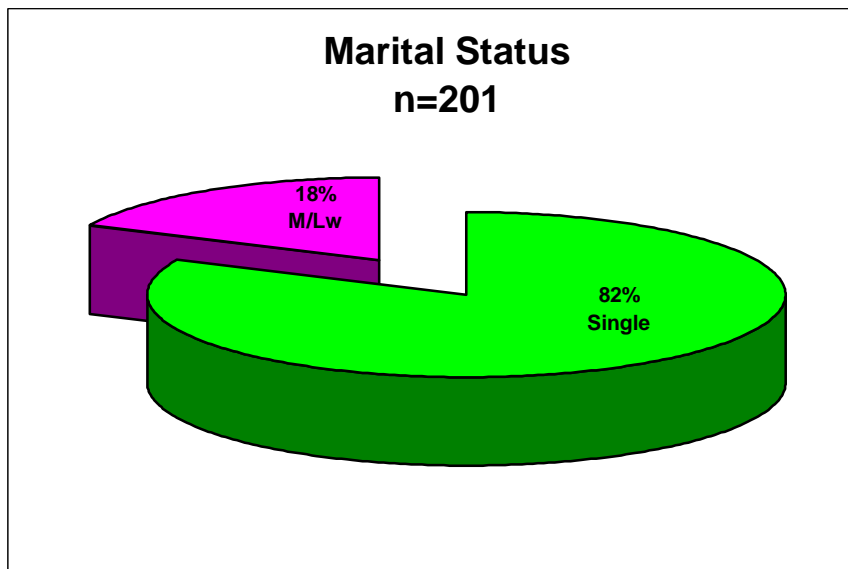
The researcher is further of the opinion that adolescents and young adults, who are generally associated with psychological changes and psychosocial challenges, are currently also confronted with the specific challenges of HIV/AIDS and issues regarding illness and death. It is here that the specific role of the social worker in the HIV/AIDS field is indicated regarding earlier education and training and access to VCT. Quicker and better access to ART and counselling is also indicated, especially in the late adolescent and early twenties age group.

The researcher confirms Venter's (2005:23) view that there have been several reports of the high expectations with regards to adherence "overkill" for example, the demands for multiple visits, "buddy" support, inexperienced and inflexible staff, and exposure of the patient to unnecessary morbidity and mortality risks. The said researcher supports Venter in that patients should be targeted earlier for ART. Most patients visiting the clinics are already very weak. Long waiting lists, multiple visits, and the need for a "buddy", discourage patients who often do not have the strength to return for follow-up visits.

6.3.1.3 Marital Status of Respondents

The researcher intended to establish the marital status of respondents since it is generally accepted that social support is associated with better adherence.

Figure 8: Marital status



The above graph illustrates the following:

165 (82%) of the respondents were single

36 (18%) of the respondents were in a relationship, (including those married by civil rights (m), customarily married (lw) and living in cohabitation.)

This research indicates that most of the respondents, 165 (82%) were single. Of these respondents, more than half, 147(73%), were women. These results explain the dilemma of why patients are reluctant to disclose their HIV status, since people who are not in stable relationships will have difficulties disclosing their status.

The data collected from the qualitative part of the study with regards to the influence of marital status on adherence to ART, correlate with the findings of the quantitative part of the study and literature. The data reveal the following:

Theme:

- Marital status influence adherence to ART.

Sub-themes:

- Marriage, specifically supportive relationships, influence adherence to ART positively.
- Disclosure of HIV status to the partner is indicated for adherence to ART.
- Marriage, if not a supportive relationship, coupled with non-disclosure to the partner, influences adherences to ART negatively.

Table 11: Theme: Marital status influence adherence to ART

Respondent	Verbatim quotes from the research interview
Social Worker	"If they have not disclosed their status to their partner, taking medication in secrecy could influence adherence negatively."
Counsellor	"Marriage could influence adherence both ways: if people disclosed their status to their partner, it has a positive influence on adherence, if they didn't, it could influence adherence negatively."
Medical doctor	"Supportive relationships influence adherence positively."

The above research findings are supported by the following literature:

Friedland (2003:37) postulates that social isolation predicts poor adherence levels and encourages patients to bring supportive family members with them to clinic visits. Literature further indicates better adherence among patients with families, including children, than among young, unmarried patients, as stated by O'Brien (1990:209) with reference to adherence by dialysis patients.

As indicated in the quantitative part of the study, most of the respondents 137(69%) are single women and this could further indicate that they are solely responsible for the upbringing of the children and that this motivates them to seek treatment. One main theme emerged from the responses to the semi-structured interview schedule. In the sub-theme that emerged it was reported that marital status as such, does not influence adherence, but rather, whether



the patient discloses his/her status to the partner. The issue of disclosure, and subsequently, receiving support emerged strongly.

The researcher considers that these findings, confirm the relationship between marital status, support and disclosure of the HIV/AIDS status of the patient. This is of particular significance, since a correlation between age, gender and marital status is indicated, considering that the majority of respondents were women, 147 (73%), less than 40 years of age 137(68%) and in no stable relationship 165 (82%).

This further indicates why patients are reluctant to disclose and/or find it difficult to adhere to The National Antiretroviral Treatment Guidelines (2003:4) which recommends that patients should be encouraged to disclose their HIV status to at least one friend or family member (buddy), or join a support group before ARV medication can be initiated.

The researcher is of the opinion that it is not always possible for patients to disclose their status, since the present research indicates that many patients are not in a supportive relationship.

The social worker, with her specialized skills in counselling, can assist patients with respect to disclosure and network regarding support structures. The researcher is further of the opinion that this situation is one where the skills of the social work profession can be utilized in motivating patients to disclose their status and also to explore alternative support systems by means of networking.

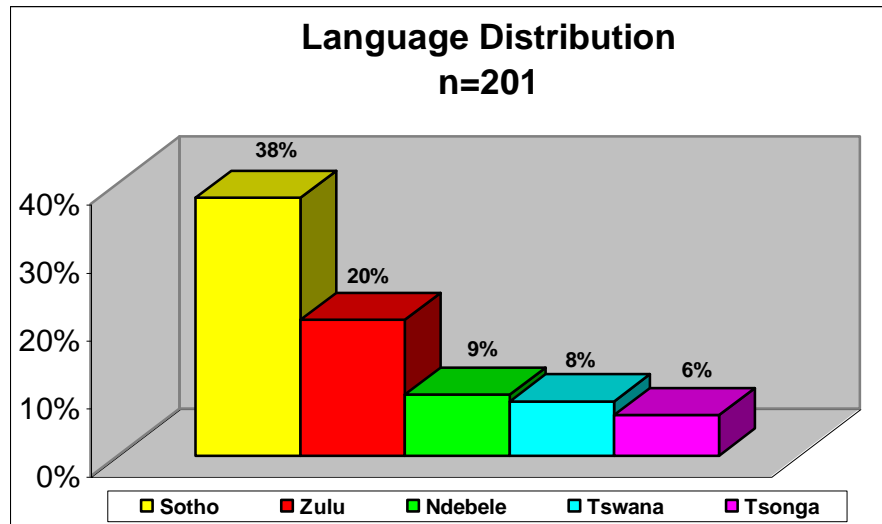
6.3.1.4 Home Language

The researcher did not ask any direct questions regarding race but included this question regarding home language since this could provide an indication of the language spoken, and thus, the ethnic groups represented by the respondents.

In South Africa specifically there is sensitivity when probing into racial matters due to the history of apartheid that is why the researcher asks specifically this

question related to language as each language is an indication of a racial group, and this is certainly influenced by a specific culture and traditions.

Figure 9: Home language



The above graph illustrates the following:

76 (38%) of the respondents spoke Northern Sotho

40 (20%) of the respondents spoke Zulu

18 (9%) of the respondents spoke Ndebele

17 (8%) of the respondents spoke Tswana

13 (6%) of the respondents spoke Tsonga

In the table above respondents indicated that they spoke Sotho 76 (38%), the most predominant language. The languages spoken by the respondents indicate that they belong to various African ethnic groups. The ART clinic is situated in Gauteng and the above findings correlate with the language of prevalence, Northern Sotho, spoken in this area. This could also be an indication that the majority of patients are from the Gauteng area, since this is the local clinic and language.

From the data collected for the qualitative part of the study with regards to the influence of language on adherence to ART one main theme emerged.

Theme:

- Language, culture and traditions influence adherence to ART.

Sub-Themes:

- Different ethnic groups have hold to different traditions, values and believes that influence adherence.
- Certain cultures do influence adherence through myths and certain traditional beliefs and values.
- Certain traditional healing methods and certain cultures (language) can jeopardize adherence to ART.

Table 12: Theme: Language, culture and traditions influence adherence to ART.

Respondent	Verbatim quotes from the research interview
Nursing sister	“Traditional healers want to clean the body from evil through vomit/enemas; this is a problem when taken with ART medicine.”
Dietician	“Certain cultural groups are more susceptible to influence.”
Medical doctor	“Certain cultural groups are more traditional.”
Counsellor	“Culture definitely influences adherence like visiting traditional healers. Some cultures have certain beliefs and rules regarding medicine. Family pressure on patients to adhere to their beliefs influence adherence.”
Counsellor	“Some cultures can be difficult especially, Zulus - it is their tradition.”
Counsellor	“Yes, it depends on the background of the patient. For example people from Kwazulu Natal must discuss medication, treatment first with elderly.”
Counsellor	“Ikilele”, is a Setswane tradition, where a woman whose husband passed away must stay at home except for work or funerals. They drink “muti” that the family gets from “inyanga”/ traditional healers for 6 months to 1 year to clean themselves.”

The above research findings are supported by the following literature:

From the above data regarding the theme of language, the following sub-themes emerged – that culture, myths, and ethnic groups influence adherence. The researcher holds the view that this again strongly indicates that the influence of culture should not be underestimated where ART is concerned.



She concurs with Cockerham (2001:54) in that the time is rapidly approaching when racial/ethnic HIV/AIDS differences will no longer be based primarily on comparisons between whites and blacks, but will, rather, be determined by socio-economic status and, specifically, poverty, knowledge, education, culture and the access to medical treatment, since the living conditions associated with poverty influence the onset and cause of most health problems.

The above research results show that it is important to note that the majority of respondents are black and stem from various ethnic groups who experience varying cultural influences. These influences should not be underestimated since they can have a major impact on ART and adherence. The researcher opines that this also indicates the language that should be employed for educational and adherence material.

Furthermore, the said researcher believes that traditional beliefs and values should be taken into account regarding adherence since culture has been identified by various sources as one of the primary barriers to preventing the spread of HIV/AIDS. Culture and specific cultural beliefs, values and traditions could also influence treatment and adherence to therapy (Friedland, 2002:35-40). Ross and Deverell (2004:16) are of the opinion that cultural considerations definitely affect whether members of a population choose to participate in prevention campaigns and whether they choose to believe, internalise and accept the messages propagated by such campaigns, such as adhering to ART.

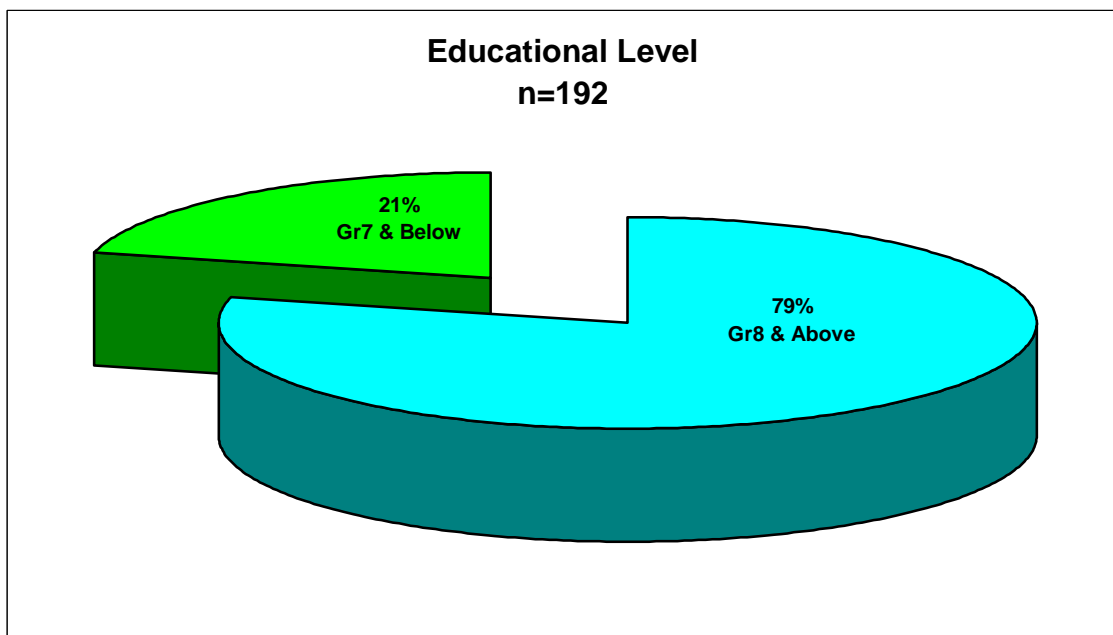
If Friedland's (2002:35-40) remark that USA studies have found that the African American are associated with poorer adherence holds true, the results with regards to adherence would be significant, since the present research indicates that the majority of respondents belong to the African ethnic groups (Northern Sotho, 76 (38%) and Zulu 40 (19%). It is further noted that 6% of the respondents are Afrikaans speaking. This could be an indication that they belong to the White or coloured racial groups. The research was conducted at a state clinic, where the majority of patients belong to various black ethnic groups.

They are dependent on state hospitals and clinics, since they are not members of a private medical aid, owing to their socio-economic status.

6.3.1.5 Educational level of respondents

Education and knowledge, or rather the lack thereof, have been identified as important factors in HIV/AIDS education. The researcher has also identified educational level as an important factor for adherence to ARV medication. Thus the intention was to establish the educational level of the respondents, because insight into this complicated disease and treatment regimen is the key to adherence. Since South Africa is a developing country, the assumption exists that the profile of people with HIV/AIDS is linked to low education or lack of literacy.

Figure 10: Educational level of respondents



The above graph illustrated the following:

71(37%) of the respondents have completed Gr. 12

46 (24%) of the respondents have completed Gr. 8 – Gr. 10

39 (20%) of the respondents have completed Gr. 1 – Gr. 7

30 (16%) of the respondents have completed Gr. 11

4 (2%) of the respondents have received tertiary education

2 (1%) of the respondents have had no schooling

The above research results reveal that the majority of patients in the sample could be regarded as educated and literate, since 119 (79%) of respondents reported an educational level of Gr. 8 (secondary school level) and higher.

The data collected for the qualitative part of the study with regards to the influence of education on adherence to ART, reveal interesting contradictory findings. One main theme emerged.

Theme:

- Education influences adherence to ART.

The sub-themes:

- Better educated people demonstrate better greater insight regarding adherence to ART.
- Better educated people are more open to training.
- Formal education should not play a role in adherence issues.
- People can be educated by means of counselling and training to help improve adherence.

Table 13: Education influences adherence to ART

Respondent	Verbatim quotes from the research interview
Social Worker	“Education seems to play a role in adherence: people show more insight if they are better informed which comes from education.”
Medical doctor	“Education should not play a role if people are adequately counselled.”
Counsellor	“People know how to drink tablets, even if they can’t read.”
Medical doctor	“Definitely, educated people understand better – especially if they can read.”

The above research findings are supported by the following literature:

The above findings from the qualitative and quantitative research indicate that respondents were subjected to HIV/AIDS education and training, especially since this forms part of the curriculum of the Department of Education in all



South African schools. Abdool Karim & Abdool Karim (2005:268) corroborate this view on HIV/AIDS and education: “Widespread education and associated high levels of knowledge have done little so far to contribute to a decline in HIV prevalence.” The general assumption that illiterate people are ignorant and more susceptible to HIV infection thus does not hold true since, in this study 119 (79%) of respondents reported an educational level of Gr. 8 (secondary school level) and higher.

The WHO (2004:39) states that good adherence in settings with few resources can be achieved if the programme combines patient-centred education with individual, peer and practical support. A study done by O’Brien (1990:212) with regards to dialysis patients shows that people tend to cope with health and illness-related problems according to the knowledge they possess in the area.

The view of the present researcher is that it is not the level of literacy, but rather, the lack of HIV education, training, and counselling by experienced counsellors, as well as the attitudes and motivation of the patient, that, are the predicting factors in adherence.

The present researcher adds that the respondents were already receiving ART and is of the opinion that the research results could further indicate that education and literacy specific play a role in motivating patients to seek medical treatment. It is easier to provide information and education and to develop insight into cultural beliefs and norms when people are well informed and literate.

As noted above, Friedland (2002:370) claims that in the USA, studies have found that low literacy levels are associated with poorer adherence. The researcher is of the opinion that literacy should not be a factor excluding the assessment of patients for adherence to ART, but that education and knowledge regarding HIV/AIDS and ART should rather receive priority. Abigail Harrison in Abdool Karim and Abdool Karim, (2005:277) has observed that there is a link between education and improved sexual health outcomes, such as a reduced incidence of teen pregnancy in South Africa and globally.”



6.3.1.6 Areas where respondents were staying.

The intention of the researcher was to establish whether respondents were living in rural or urban areas. As already mentioned, the clinic, where the research was conducted, forms part of the Comprehensive HIV/AIDS Treatment Clinic of the Gauteng Provincial Government at the Pretoria Academic Hospital. This clinic is in the Tshwane/Metsweding Region, of the Gauteng Department of Health. Geographically, this is an urban treatment centre attached to an academic hospital.

Table 14: Distribution regarding urban and rural area

Rural	Urban
15(8%)	186(92%)

n=201

The above table indicates that the majority of respondents reside in an urban area, 186 (92%). These results could be explained by the fact that the clinic where the study was conducted, serves patients mainly from the urban area, as stated above. The researcher is of the opinion that a factor contributing to good adherence could be the fact that the respondents were residing in an urban area, close to the facility, and that this limited their travelling costs.

From the data collected from the qualitative part of the study with regards to the influence of living conditions on adherence to ART emerged the following theme.

Theme:

- Residential area influences adherence to ART.

Sub-themes:

- Rural people prefer to travel to urban clinics; they perceive the clinics to offer better treatment.
- Urban clinics are valued more by patients than rural clinics.
- Patients still fear discrimination and prefer to attend clinics far away from home.



- Easy access to a clinics influences adherence positively, due to transport costs.

The above research findings are supported by the following literature:

A matter of concern, as indicated by the above sub-themes that emerged from the findings, is that patients show an unwillingness to attend rural local clinics in their own area, because they are afraid of being identified in their communities. These patients use a local address in urban areas to be able to attend clinics in urban areas. Some patients also assume that urban clinics attached to a provincial/tertiary hospital, offer better services than the local, rural clinics.

The researcher concurs with Frohlich in Abdool Karim (2005:351) that HIV/AIDS, coupled with urbanization, has a major impact on individuals and community structures, such as the family. Traditionally, the family has been the fundamental unit of any society, but as the epidemic progresses, this structure is steadily being eroded. One of the most obvious changes has been the increase in single-parent households. The present researcher has experienced, within her working environment that HIV infection presents a medical and psychosocial crisis of unparalleled proportions for the majority of infected and affected.

If the number of unemployed respondents (72%), as shown in this research is taken into account and compared to the number of respondents 186 (92%) living in an urban area, it can be assumed that most people in the urban area are seeking employment or medical treatment. In addition to this, judging by the 151 (79%) respondents who reported an educational level of Gr. 8 and higher, a further assumption can be made that respondents live in the urban area, and are seeking better opportunities.

Table 15: Theme: The influence of living area on adherence

Respondent	Interview quote
Social Worker	“Patients prefer to attend urban clinics, as they perceive the urban clinics to be better and they fear discrimination at their local clinics.”
Counsellor	“Urban versus rural can have an influence: if people have to travel far to attend a clinic it is too costly.”
Medical doctor	“The area where people live could influence the level of understanding – but depends on education and resources.”

6.3.1.7 Living conditions of respondents (Type of accommodation)

The aim of this question was to establish the living conditions of the respondents. The clinic where the study was conducted, as indicated in the previous section, serves patients from the urban area. Urban living conditions tend to comprise more formal structures, and are further characterized by over-sharing due to financial, recreational, educational, employment and medical constraints.

Table 16: Living conditions of respondents

Type of living	Percentage	Frequency
House	62%	125
Shack	20%	41
Flat	16%	8
Room	16%	8
Hut	1%	3

n= 201

The above table illustrates the following:

125 (62%) of the respondents were residing in a house

41(20%) of the respondents were residing in an iron/tin shack

16 (8%) of the respondents were residing in a flat

16 (8%) of the respondents were residing in a room

3 (1%) of the respondents were residing in a hut

As indicated in the above table, the majority of patients, 157 (78%), reported that they were staying in what can be described as proper well-constructed accommodation, e.g. either a house, 125 (62%), flat, 16 (8%), or room 16(8%).

From the data collected for qualitative element of the study regarding the influence of living conditions the following themes and sub-themes emerge:

Theme:

- Living conditions influence adherence to ART. .

Sub-themes:

- Overcrowded living conditions influence adherence negatively.
- Chaotic living conditions are contraindicated for adherence.
- The type of house (shack or house) does not influence adherence.
- Homeless people have difficulty in adhering.

Table 17: Theme: Living conditions influence adherence to ART.

Respondents	Verbatim quotes from the research interview
Social Worker	“If their living conditions are overcrowded people could miss medication because their environment is chaotic and they do not have any routine, medication does get lost.”
Counsellor	“Type of housing does not play a role.”
Medical doctor	“Crowded living conditions in urban areas/or lack of sanitary or clean water in rural areas plays a role.”

The above research findings are supported by the following literature:

The researcher suggests a link between the accommodation or living conditions of patients, urban living 186 (92%) and high educational levels that were reported. The myth that lower-educated, homeless people are more likely to suffer from HIV/AIDS, does not hold true.



The researcher supports the National Antiretroviral Treatment Guidelines (2003:4) in that taking ART medication in secrecy in crowded and chaotic living conditions could be a factor contributing to non-adherence for the following reasons.

- Patients who have not disclosed their status might experience problems with storing and or transporting medication;
- It will be difficult to use reminders to remember to take medication at specific times;
- Side-effects and adverse reactions to medication cannot be reported or monitored by family members; and
- Family members could not take medication to the patient in the case of hospitalisation or family responsibilities such as funerals.

The sub-themes that emerge from the above findings indicate that overcrowded, chaotic living conditions influence adherence more negatively than the type of housing

6.3.2 Clinical factors and adherence detail

The next phase of the questionnaire was aimed at exploring the biological, medical or clinical factors that could possibly influence adherence (negatively and positively), to ART as experienced by HIV/AIDS patients receiving it.

The biopsychosocial model as constructed by Engel (1980:535) is in the researcher's view a scientific model, which takes into account the missing dimensions of the biomedical model. Assessing the patient as a whole is relevant, particularly with regards to the delivery of service to the HIV/AIDS patient, and thus, to the present study.

According to Kaplan, *et al.*, (1994:1), this model stresses an integrated systems approach to human behaviour and disease; because of the continuous interaction between the individual's body, mind and social context. Karoly (1985:434) argues further that the biopsychosocial orientation involves an



interdisciplinary systems-orientation towards healthcare. This orientation enables the service providers to consider the biological, psychological and environmental information concerning a patient, in order to make an appropriate diagnosis and develop a treatment programme that encompasses all three of these areas. Green and Shellenberger (1991:19) postulate that, the biopsychosocial approach to health and wellness, views these states as the result of the interaction of biological, psychological and social factors. The psychosocial aspects will be discussed in the next phase of the questionnaire.

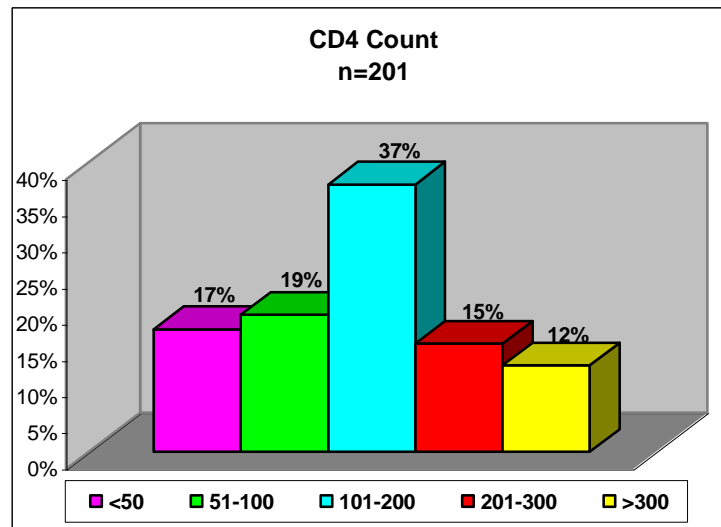
As indicated earlier on, the biopsychosocial model is based on the systems approach, which stresses an integrated systems approach to human behaviour and disease. The assessment of the biopsychosocial factors, in the view of the present researcher, will enable the health team to provide a treatment programme that is responsive to the needs of individuals. Without this holistic approach, the patient will be provided with an incomplete assessment when all the aspects, specifically the psychosocial, are not attended to, which could lead to non-adherence and treatment failure. The researcher strongly believes that the biopsychosocial model is the relevant model to be used at the ARV Clinic.

The questions in this section of the research, give consideration to the CD4 count of the respondents, the WHO stage and performance status, and also concentrate on ART matters. The researcher further explores the period for which the respondents have been on ART, the factors enhancing the adherence of the respondents to ART, and the difficulties respondents have experienced since commencing ART. The person (if any) who assists the respondents with their ART, as well as alternative healing, were also explored.

6.3.2.1 CD4 counts of respondents

Using this question the researcher intended to explore the CD4 cell counts of respondents, because it is an important method employed in assessing the effectiveness of ART.

Figure 11: CD4 Counts



The above graph illustrates the following:

- 35 (17%) of the respondents reported a CD4 count of <50
- 39 (19%) of the respondents reported a CD4 count of 51 - 100
- 75 (37%) of the respondents reported a CD4 count of 101 - 200
- 30 (15%) of the respondents reported a CD4 count of 201 - 300
- 22 (12%) of the respondents reported a CD4 count > 300

The above research findings indicated that the CD4 count of most respondents 149 (73%), was below 200. The majority of patients 75(37%), reported a CD4 count of between 101 - 200. In this respect, the criterion for initiating patients to receive ART, according to the National Antiretroviral Treatment Guidelines of South Africa's (2003:4), is a CD4 count of <200 or an AIDS-defining disease as discussed in the above phase.

The data collected from the qualitative element of the study regarding the influence of knowledge of the CD 4 count on influencing adherence to ART reveals the following:

Theme:

- Knowledge of the CD 4 count, could influence adherence to ART.

Sub-themes:

- The CD4 count is a reflection of the improvement of the immune system and tends to serve as a motivation.
- The CD4 count can also influence adherence negatively in some circumstances, e.g. the CD 4 count might not improve and patients may tend to get become disillusioned.
- If the CD 4 count increases, some patients do not adhere for fear of losing their disability grant. W, which requires the patient to be in stage IV or CD 4 count under 200.
- The CD4 count is a difficult concept to try and explain in counselling.

Table 18: Knowledge of the CD 4 count could influence adherence to ART

Respondent	Interview quote
Social Worker	"The CD4 count has a definite influence on adherence; it seems to motivate patients once they understand it. The results are shown and explained to them."
Pharmacist	"CD4 count can also influence adherence negatively, as patients tend to not understand why they have to still take antiretroviral when their CD4 is high."
Medical doctor	"CD4 count does not influence adherence, but pill fatigue does influence adherence."
Counsellor	"CD4 count does not make sense to most people, you can try and explain but they do not understand it. If they understand it, it motivates them when it goes up."

The above research findings are supported by the following literature:

From the above findings, the sub-theme, CD4 count and its link to motivation, has emerged. It is indicated that the CD4 count can be utilized to indicate to patients the restoration of their immune system and thus motivate them to continue with ARV medication.

The R.S.A. Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment (2003:4) criteria for ARV initiation is the following:



- CD4 <200 or
- AIDS defining diseases regardless of CD4 count.

In other words, only patients who are diagnosed with AIDS can be initiated. For example a patient whose CD4 count is >200 but suffers from cancer and possibly needs chemo- or radiation therapy, also qualifies for ART.

The respondents participating in this research had received ART for less than a year, which could explain the above findings if it is taken into account that the CD4 response is generally a mirror image of the HIV/RNA decay curve, with increases that average 50-60 cells/mm³ in the first 4 months, with subsequent increases at a rate of 8-10 cells mm³/month or 100-150 cells/mm³/ per year with good viral suppression. It is reported in Bartlett, Gallant & Joel (2005:3) that a CD4 count should increase by 50% after 8 months of treatment.

One of the goals of ART is that the CD4 count of the patient should rise and remain above the baseline count. The CD4 count of a patient is highly variable and dependent on the individual immune system, the general state of health and the presence of concurrent diseases (S.A., 2004:2). According to the selection criteria of the National Antiretroviral Treatment Guidelines (2003:4), patients must have a CD4 count <200 cell/mm³, irrespective of the WHO stage or WHO stage IV disease, and irrespective of the CD4 count, in order to be initiated on ART.

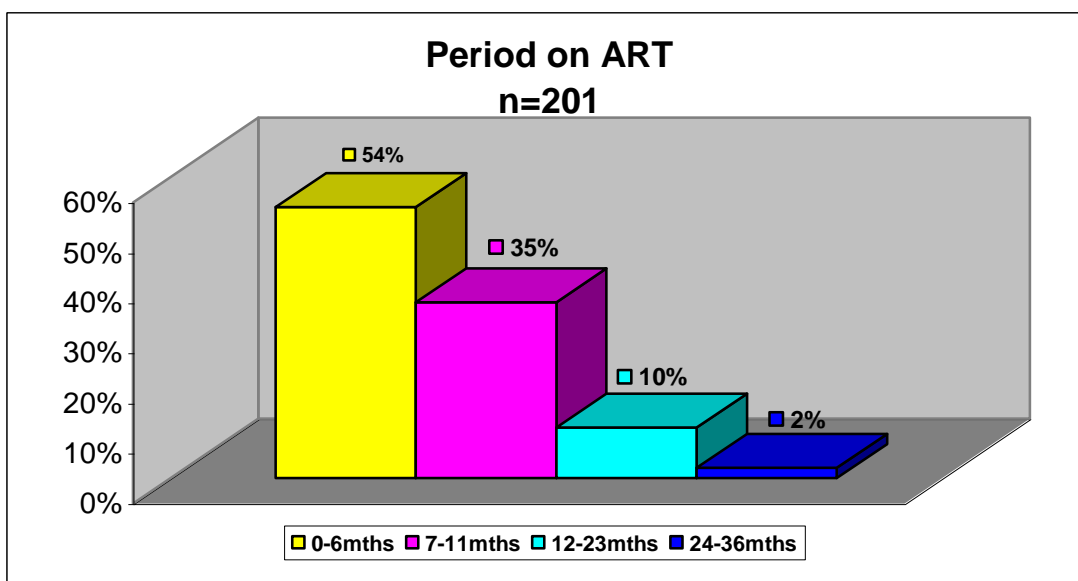
Furthermore, therapeutic decisions are usually based on viral load data. Virological failure is ascribed either to resistance or failure of the drugs to reach the virus, owing to inadequate adherence, altered metabolism or drug interaction (Bartlett, Gallant & Joel, 2005.4).

6.3.2.2 Period on ART

The present researcher included this question regarding the respondent's period on ART, to explore issues such as pill fatigue and monitoring of treatment.

The research was conducted at the Tshwane District Hospital, one of the Government's sites for Comprehensive Care and Treatment of HIV/AIDS and TB between October and November 2005. This ART site only initiated treatment of its first patients during June 2004. The respondents participating in the present research would thus have been on ART for approximately 1 year.

Figure 12: Period on ART



From the above graph the following information was captured:

109 (54%) of the respondents were on ART for 0 - 6 months,
71 (35%) of the respondents were on ART for 7 – 11 months,
2 (10%) of the respondents were on ART for 12-24 months, and
1 respondent was on ART for >24 months.

The majority of respondents, 180 (90%) reported to have been on ART for less than a year. This correlates with the period mentioned above that they were on ART, reflecting a reliable response as expected.

The data collected from the qualitative element of the study regarding adherence and the length of the period on ART reflects the comments of the team members.

Theme:

- The period a patient has been on ART influences adherence.



Sub-themes:

- The period on ART does not indicate non-adherence, but patients tend to stop ART once they feel better.
- After a lengthy period on ART some patients tend to get tired of pill taking (pill fatigue).
- Patients are not always aware that ARV medication is for life.
- Monitoring and motivating adherence throughout ART treatment is indicated

Table 19: Theme: The period a patient has been on ART influences adherence

Respondents	Verbatim quotes from the research interview
Social Worker	“Patients tend to stop medication once they are feeling better.”
Medical doctor	“Pill fatigue, which is coupled to period on ART influences adherence. The late Peter Bussie, an AIDS activist reported publicly, shortly before his death in 2003, at an adherence seminar, that he is suffering from pill fatigue and that he is taking a break from it”.
Counsellor	“Patients must be made aware that AIDS is a chronic disease, like high blood pressure.”

The above research findings are supported by the following literature:

The above findings, regarding the influence of period on ART on adherence, the multidisciplinary team acknowledged the correlation between the period on ART and pill fatigue, emerged strongly. The researcher considers that this is an indication of the need to educate patients regarding chronic illness and their responsibility for taking life-long medication in order to maintain their health. The following theme and sub-theme emerged.

A strong correlation exists between virological response and adherence and the need for >95% adherence is reported (John G. Bartlett, 2005:68). Regarding adherence in general, Kaplan & Sadock (1994:11) postulate that, in general, about one third of all patients comply with treatment, one third sometimes comply with certain aspects of treatment and one third never comply with treatment.



The researcher is of the opinion that if patients are assessed, trained, counselled and supported, it will make a dramatic difference to adherence.

6.3.2.3 Current performance status of respondents according to the Karnofsky Scale

With this question, the intention was to establish the physical wellness or performance status of respondents. For this, the researcher has found the Karnofsky's Scale, which is widely accepted as a measuring tool for performance, to be the most appropriate, as previously discussed in chapter 3:

http://www.cancerbacup.org.uk/Qas/AboutcancerQAs/AllQAs/related_faqs/Qas/993:28.02.2006

Respondents reported the following performance status, according to the Karnofsky scale (N 201).

72 (36%) of the respondents reported normal health

84 (42%) of the respondents reported minor symptoms

25 (12%) of the respondents reported normal activity but with some effort

20 (10%) of the respondents reported less than 80% performance status

The research findings regarding the performance status of the respondents indicate that most of the respondents 156 (78%) reported normal health or suffering from minor symptoms.

The data collected from the qualitative element of the study regarding the influence of patients performance status, reveals that the team members do not seem to make use of the Karnofsky scale in practice. The following themes and sub-theme emerged.

Theme:

- Performance status (Karnofsky) of patients influences adherence to ART indirectly.

Sub-themes:

- The performance status is not used directly in counselling patients at clinics.

- It is a difficult concept to try and explain to patients.
- The performance status is a confirmation, of the improvement of the physical functioning and could serves as a motivation to adhere to ART.

Table 20: Performance status (Karnofsky) of patients influences adherence to ART indirectly

Respondent	Verbatim quotes from the research interview
Medical doctor	“The performance status is not utilized at the clinics by counsellors.”
Counsellor	“The performance status is not something we use a lot in explaining to patients. It plays no role in adherence.”

The above research findings are supported by the following literature:

The findings regarding the performance status of patients revealed that the performance scale is not utilized in clinics, the reason being that counsellors are not specifically trained regarding the Karnofsky Scale. The use of an increasing CD4 count or viral load is preferred in motivating patients regarding ART.

The above results can be explained by the fact that, according to the R.S.A. Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment (2003:4), and in terms of the clinical selection criteria, the symptoms of the patient must be treated prior to initiating ART, and active TB must be excluded. One of the goals of ART is that patients should experience fewer HIV-related illnesses (S.A., 2004:2).

In conclusion, it is evident that respondents reported high scores according to the Karnofsky scale, since the majority reported normal functioning. This could be an indication of good adherence and the subsequent success of ART.

6.3.2.4 The WHO staging before initiation of treatment

The immunodeficiency that develops during HIV infection is a continuum, but several discrete clinical phases can be identified. The researcher included this



question because the CDC staging of AIDS Surveillance Case Definition for Adolescents and Adults (Centers for Disease Control and Prevention, 1993) includes all HIV-infected individuals with either a CD4 count $<200\text{cell}/\text{mm}^3$ or an AIDS indicator condition.

The quantitative part of the study indicates the following regarding staging:

n=201

(27) 13 % of the respondents reported WHO stage 1

(27) 13 % of the respondents reported being in the WHO stage 2,

(104) 52 % of the respondents reported being in the WHO stage 3

(43) 21% of the respondents reported being in the WHO stage 4.

The majority of respondents 147(73%) reported to be in between stage 3 and 4. One hundred and four (52%) reported to be in stage 3, and 43 (21%) reported to be in stage 4. These research results should be seen in the light of the R.S.A. Comprehensive Care and Treatment of HIV/AIDS Antiretroviral Treatment guidelines (2003:4). Once a patient has been “staged”, he/she remains in that stage with or without symptoms (HIV/AIDS management for Professional Nurses Manual, FPD: 2004:90).

Similarly to the above question regarding the Karnofsky scale, the qualitative aspect of the study reported the following regarding the WHO staging:

The following themes and sub-theme were revealed:

Theme:

- WHO staging does not influence adherence to ART directly.

Sub-themes:

- WHO staging is only used by clinicians prior to initiation in clinics and is not used by counsellors.
- It is also a difficult concept to try and explain to patients.



- WHO staging is an indication of the improvement of the medical condition and could likewise serves as a motivation.
- WHO staging does not influence adherence, since patients just see an improvement physically and the regaining of lost roles.

Table 21: Theme: WHO staging does not influence adherence to ART directly

Respondent	Verbatim quotes from the research
Medical doctor	“The WHO staging is only used in clinical diagnoses, not in adherence issues as a person once staged does not go back to.”
Counsellor	“The WHO status is not used in counselling as is just too difficult to explain.”

The above research findings are supported by the following literature:

The World Health Organization (WHO) utilizes standardised criteria to clinically stage HIV infection. This staging accommodates facilities where CD4 testing is not freely available and thus only uses patient clinical determinants (Botes and Levay 2004:13).

The above findings indicated that the WHO staging is not utilized by counsellors in adherence issues. WHO staging could be linked to quality of life issues, for example, a person with WHO stage 4, would suffer from severe AIDS-related symptoms, which will impair his/her, quality of life severely.

After initiation of ARVs, a person’s WHO staging might improve to stage 1 or 2, with a concurrent improvement in her/his quality of life. This, according to the present researcher, is the most important goal of ARV therapy. These clinical facts could be used to motivate people regarding adherence to ART.

6.3.2.5 Factors that enhance adherence to ART

This question has been included because, as indicated by most of the literature, adherence is a very important aspect in ART. Adherence was defined and discussed in chapter one.

Table 22: Adherence enhancement to ART by respondents as indicated across the nine individual aspects measured

Adherence enhancement to ART	Frequency	Percent
No support	123	17
Diary chart	139	19
Family / “buddy”	168	23
Pill-count	143	19
Electronic device	1	0.13
Pillbox	10	1
Support group	21	3
Cell phone	93	12
Clock/watch	47	6

The above table illustrates the following:

The above data were obtained from a multi-answer questionnaire, where the respondent could indicate more than one method of support concerning adherence. The respondents could indicate more than one method used to enhance their adherence. With the assistance of the Department of Statistics, University of Pretoria, the data was processed and programmed using the SAS, version 8.2, statistical software. It is illustrated in one graph for practical and comparative reasons.

The data collected from the qualitative element of the study regarding methods use to support and enhance adherence reveals the following:

Theme 1:

- Various forms of support and aids are necessary to enhance, adherence to ART.

Sub-themes:

- Family support, especially mothers appear to be the most common form of support to patients.
- Patients use mainly cell phones as reminders.
- Some patients plan pill-taking around TV or radio programs.

- Patients do not use aids, like pillboxes, to support adherence.
- Some patients can adhere and are responsible on their own.
- Patients do use diary charts if supplied by clinic.
- Pill counts done at clinics are a good form of supporting adherence and detecting up problems.

Theme 2:

- The social worker with her specialized skills is very imported in supporting patients.

Sub-themes:

- Social worker can assess needs and refer to appropriate resources.

Theme 3:

- Support groups are not valued at present.

Table 23: Theme: Various forms of support and aids are necessary to enhance, adherence to ART.

Respondent	Verbatim quotes from the research interview
Medical doctor	“The patients rely a lot on all forms of support, at the ART clinic. Specially the social worker, it seems the only easy access they have to specialized services.”
Social Worker	“The patients to not use aids in supporting adherence. If they are supplied with adherence aids they will use it.”
Social Worker	“In my experience, family shows to be the major form of support to ART patients- especially mothers.”
Counsellor	“Patients do not have confidence in support groups unless they get something out of it.” “ART is a complex issue if support groups are not educated and trained in ART they might do more harm than good.”
Counsellor	“If a support group is well organized by a company, or sponsored, it works, but most people in the community do not have the resources to start and maintain support groups.”
Counsellor	“Patients use mainly cell phones as reminders. Other aids not popular.” they do not want to focus attention on medication.”
Counsellor	“Patients do not use pillboxes. Reminders use are mainly cell phones, TV or radio programmes and clocks are also used by specially older people.”



Medical doctor	“Pill counts and diary charts are good forms of monitoring adherence especially for the older and less literate patients.”
----------------	----------------------------------------------------------------------------------------------------------------------------

The above research findings are supported by the following literature:

In the qualitative part of the study, most of the respondents, multidisciplinary team members, especially the counsellors, who were involved in ART, indicated a need for common standards for support.

Thus, the sub-themes that emerged from the above qualitative findings show the need for support groups that comply with common standards in order to promote credibility. Patients generally do not trust support groups. The support offered by a comprehensive ARV clinic is very important in facilitating the social needs of patients. Often, family support proves to be the only form of support.

From the above data, 68(84%) respondents reported their family as being their major source of support. The family included children, parents and extended families. The present researcher has experienced that the family support usually comprises the elderly. As conveyed by Marais, (2005:82). “The ‘reverse orphans’ who, in the twilight of their lives and in grossly disadvantageous circumstances are transforming themselves again into mothers and fathers”. The pattern of burden-shifting onto the elderly is also clearly evident in the current study and clinic. The present researcher would like to add that the burden of care is also shifting to young and teenage children who care for and support ill parents.

A matter of great concern for the researcher is the fact that 123 (61%) respondents reported no significant support. This can be linked to the 165 (82%) respondents who reported that they are single and not in a significant relationship, bringing the importance of the issue of support structures for patients to the fore.

One hundred and forty three (71%) respondents reported that they make use of daily medication, diary charts or pill-counts at the clinic. The researcher



considers that this indicates that the ARV clinic is a major form of support for most patients, which, again, indicates the importance and comprehensive role of an ARV clinic, where patients on ART are monitored during their routine clinic visits.

The physical decline of patients often forces them to seek medical support. Difficult socio-economic circumstances coupled with physical symptoms aggravate the patient's need for support at a one-stop service centre.

The researcher asserts that people are not naturally adherent and that patients should utilize some kind of reminder or support system to support their adherence. The researcher further confirms the view of Friedlands (2002:45) that behaviour skills, with regards to taking medication, should be developed, not only for HIV/AIDS patients, but that the general public should also be educated regarding the importance of adherence and the development of good medication habits.

Disclosure appears to be viewed as a form of punishment rather than a mechanism in order to provide adherence support (Venter 2005:22). This research further indicates that devices, like pillboxes or electronic devices are not popular aids to support adherence. Regarding this, one could speculate that patients still prefer to keep their status confidential, which will influence their medication routine: using devices (for example pill boxes), could attract attention.

The above findings stemming from both the qualitative and quantitative parts of the study indicate that support groups are not popular. The majority of respondents reported not having access to support groups or not being interested in support groups. The researcher is of the opinion that HIV/AIDS is still a sensitive and traumatic experience for patients, who fear discrimination. Issues regarding HIV/AIDS almost always have a sexual connotation, a sensitive issue in all cultures. Patients perceive their status as confidential and do not want to share it with strangers or the community in general. Confidentiality cannot always be guaranteed in support groups. Furthermore,



support groups are not always easily accessible, which places an extra financial burden on patients. The facilitators of support groups are not always trained in adherence to ART. The researcher is not suggesting that support groups are not an important form of support, but, rather, that patients need professional, non-discriminating support, without an added financial burden, where credibility and confidentiality can be guaranteed.

The researcher further argues that there is no workforce regulatory framework to protect patients and promote high standards of practice or build professional credibility for support groups in general. Support groups and counsellors without professional training should be subjected to some sort of registration or license to practice. The poor public image of some support groups in the HIV/AIDS and ART field has done little to support the majority of patients, as indicated in the study.

The Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment, accepted during November 2003 (2003:4), makes provision for such support systems. It has acknowledged the need for psychosocial support to the patients and makes provision for social workers, dieticians and lay counsellors at each ART site.

Factors promoting adherence include affordability, disclosure of status to partners and family, and regimens with limited numbers of pills. Poor clinical management and side-effects can adversely affect adherence.

6.3.2.6 Difficulties that respondents experience as a result of ART

The researcher is aware of the fact that adherence to chronic medication is a complex issue and is influenced by various factors. The advent of ART, specifically HAART has revolutionised the treatment of HIV, with improvements in both quality and quantity of life.

Table 24: Difficulties experienced with ART as reported by respondents across the ten individual aspects measured

Difficulties experienced regarding ART	Frequency	Percentage
Side Effects	114	57
Clinic Visits	71	36
Nutrition	59	30
Medication	58	29
Financial	52	26
Employment	46	23
Support Group	23	12
Housing	19	8
Red Tape	11	5
Resistance	8	4

The above data was obtained from a multi-answer questionnaire, where the respondent could indicate more than one problem in response to this question. The above table illustrates that the majority 114 (57%) of respondents experienced difficulties with adherence to ART owing to side-effects, while 71 (36%) found that it was difficult to maintain regular clinic visits. Other difficulties that the respondents experienced in this regard were related to nutrition: 59 (30%), financial 52 (26%), medication 58 (29%), employment 46 (23%), support groups 23 (12%), housing 19 (8%), "red-tape" 11 (5%), and resistance 8(4%).

The research findings of the qualitative part of the research indicate, the difficulties experienced with regards to ART. In this qualitative section of the research, the participants also reported adverse reactions and side-effects as a major reason for non-adherence. The data collected from the qualitative element of the study reveals the following:

Theme:

- Patients experience various difficulties regarding adherence to ART.

Sub-themes:

- Patients do experience side-effects and complications of ART.

- These side-effects and complications of ART are contra-indicated for adherence.
- Financial difficulties and material needs do influence adherence to ART.
- Patients are not educated regarding various grants that they qualify for.

Table 25: Patients experience various difficulties regarding adherence to ART

Respondent	Verbatim quotes from the research interview
Pharmacist	“Patients suffer from severe side-effects; they sometimes decide themselves which of the combination pills is the cause of it and then stop taking medicine.”
Medical doctor	“Side-effects are a major problem in ART.”
Counsellor	“Patients are not aware of all the grants they qualify for.”
Social worker	“Material needs feature strongly.”
Medical doctor	“Difficulty to adhere to specific time to take pills.” “Side-effects and complications of treatment.” “Patients do not like routine blood-taking.”

The above research findings are supported by the following literature:

Sub-themes that emerge from the findings of this section of the study are side-effects, indicated to be a major problem in adherence issues, financial problems, and material needs, which suggest socio-economic status also seriously influence adherence.

A wide variety of ART drugs are now available, but antiretroviral drugs, like most chronic medication, do not come without their negative aspects such as drug interactions, pill burden, drug toxicity, adverse events, concomitant illnesses, side effects and contra-indications. All of the above adverse events, coupled with adherence issues and individual factors such as pill fatigue, transport and disclosure, contribute to ART being a very complex issue. The research findings of the qualitative part of the research indicate, the difficulties experienced with regards to ART. In the qualitative section of the research, the



participants also reported adverse reactions and side-effects as a major reason for non-adherence.

Thirty percent of respondents reported nutritional needs. The researcher is of the opinion that this might be due to financial insecurity since 145(72%) of respondents reported unemployment as stated above. Nutrition is a primary need and if not addressed, it will severely affect their adherence and quality of life.

Other problems reported by 71 (36%) of respondents were clinic visits. This is primarily perceived as a financial difficulty and could be seen in the light of the reported unemployment and the socio-economic status of the respondents.

Patients who are employed also perceive clinic visits to be a problem since they are required to take a day's leave or sick leave in order to visit the clinic. Although respondents perceive the clinic as a support, nevertheless, it constitutes an additional burden (transport costs).

Although Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment (2003:4) has made provision for nutritional needs by means of supplements, food parcel projects and, PMTCT programmes, as well as social security and disability grants, a matter of concern is that the food parcels, food supplements and other aids are not easily accessible or always available. The researcher has experienced since the treatment rollout in June 2004, that these programmes are generally not well-administered.

6.3.2.7 Respondents' motivation for ART

The researcher's intention in this question was to establish the motivation of respondents for ART since it is well-known that motivation is a strong determinant of behaviour. She identifies with the view of Bandura (Meyer, Moore and Viljoen, 2003:296) in this respect: "Instead of attributing motivation to specific motives or drives, the social cognitive learning theorist regards

motivation as they do any other aspect of human functioning - as the result of two processes, namely interaction and learning.” The basic idea here is that individuals are not motivated only by specific intrapersonal drives, nor are they motivated only by external stimuli. They are motivated by the interaction between the individual and the situation.

Table 26: Motivation for adherence to ART as indicated by Respondents across the eight individual aspects measured

Respondent's motivation for ART	Frequency	Percent
Survival	197	99
Strength	193	97
Children	175	88
Model	174	87
Doctor	158	79
Family Support	155	78
MPTC	125	63
Encouragement	105	53

The following findings are evident from the above table:

The above data was obtained from a multi-answer question, where the respondent could indicate more than one motivation for ART.

The majority of patients, 197 (99%), reported that their primary motivation for ART is to stay alive and to be physically stronger 193 (97%), without symptoms. The Southern African HIV Clinicians Society (2005:31) postulates, regarding the above motivations, that “patients are frightened by the prospect of losing control and the prospect of disabling symptoms of advanced AIDS”.

The present researcher wishes to explain the motivations of the patients to stay alive, be physically strong and be without pain, according to the basic human needs as identified by Maslow.

Furthermore, 175 (88%) of respondents reported that they want to see their children grow up and need to support their families 155 (79%). Since 165 (89%) respondents of the total sample size are single women, it explains why this is a major motivation (for women) to seek ART. The multidisciplinary team in the qualitative research also reported motivation as a strong force for adherence through the interviews:

The data collected from the qualitative element of the study regarding the motivation for adherence ART indicated the following themes and sub-themes:

Theme:

- The need of patients to stay alive (survival) is featuring features as their strongest motivation to adhere to ART.

Sub-themes:

- Patients are mostly motivated to adhere in order to improve their health in general and to be symptom-free.
- Patients are motivated to adhere so as to be able to care for their families.
- Patients are frequently urged by external pressure to adhere to ART.

Table 27: The need of patients to stay alive (survival) are featuring features as their strongest motivation to adhere to ART

Respondent	Verbatim quotes from the research interview
Social Worker	“Getting better to see progress because they are single parents.”
Counsellor	“The motivation of patients for ART is usually to be healthy and live longer because they want to and care for their families.”
Medical Doctor	“Patients want to be symptom free.” “Patients want to feel healthy, strong and gain weight.” To look after their children if they are primary caregivers.
Medical Doctor	Outside pressure from family or employers.

The above research findings are supported by the following literature:



The sub-theme that emerged strongly from the above findings is that people want to be symptom-free and healthy so as to be able to take up their responsibilities to care for their families.

As stated before, adherence is a complex clinical behaviour with a wide array of determinants. The researcher is of the opinion that motivation is probably the strongest determinant of adherence and therefore, this question regarding motivation for ART was included. In the treatment of an HIV/AIDS patient receiving ART, which requires lifelong behavioural change, motivation plays a very important role, which might include attitude and beliefs, social support, trust in the physician, the psychological status of the patient, and competing priorities.

The present researcher avers that the characteristics or personality of the patient, and his/her readiness to begin and maintain treatment are of the utmost importance in adherence issues. Adherence to therapies has been shown to be influenced by behavioural difficulties such as depression and social isolation (Friedland, 2002:38).

Friedland (2002:35) further broadly defined motivation to include all variables that encourage or discourage adherence. These might include attitudes and beliefs about HIV treatment and a specific medication, social support, trust in the physician, the patient's psychological status, and the presence of competing priorities in the life of the patient. Adherence to therapies has been shown to be influenced by behavioural difficulties such as depression and substance abuse (e.g. alcohol and mood-altering drugs) and social isolation.

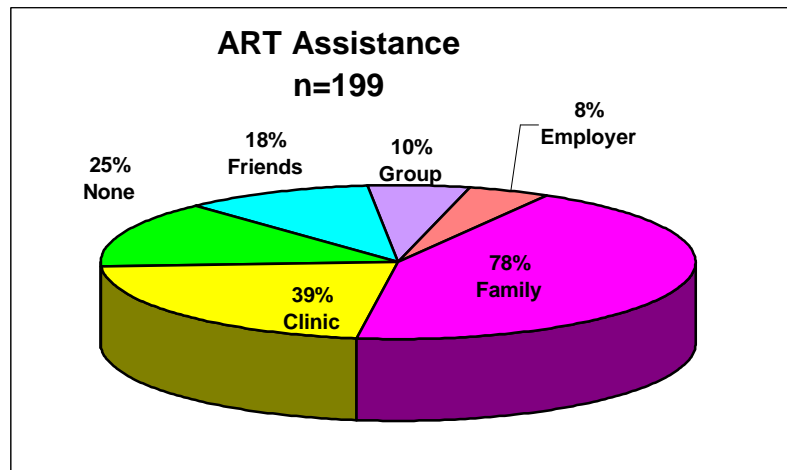
In summary, the researcher supports the socio-cognitive learning view of motivation: "To a great extent individuals, in interaction with the situation, determine their own motivation and that human behaviour is therefore determined by a large variety of different, individual motives." (Meyer, Moore, and Viljoen, 2003:298).

The social worker's role regarding motivation and adherence would be: to assess the patient's circumstances, to develop insight and determine the patient's reason (motivation) for ART.

6.3.2.8 Assisting Respondents with adherence to ART

The intention of this question was to explore the support systems of the respondents. It is generally accepted that HIV/AIDS patients who are isolated and without support do not cope well with ART. The Gauteng Department of Health's Comprehensive HIV/AIDS Guidelines (2004), strongly recommends support structures, including disclosure, before initiating patients for ART.

Figure 13: Assisting with adherence to ART



The above graph illustrates the following:

- 155 (78%) of the respondents report family as a support
- 77 (39%) of the respondents report the clinic staff as their support
- 49 (25%) of the respondents report no assistance with ART
- 36 (18%) of the respondents reported their friends as their support
- 19 (10%) of the respondents reported a support group
- 15 (8%) of the respondents reported their employers as their support

The above research results have indicated, yet again, that patients (155 (78%)) rely heavily on family structures to support them with ART. This pattern of burden-shifting onto the elderly is clearly evident in most highly HIV-prevalent countries (Marais, 2005:82). The pattern of burden-shifting is also clearly



evident in the ARV clinic. The researcher has seen the responsibility of caring being shifted from adult children to, not only the elderly, but also children who support ill parents, men caring for small babies and employers supporting weak employees.

Family support was reported by 168 (84%) respondents as their major source of support. The question was compiled to include children, parents and extended families with reference to family support. This family support, as previously reported usually refers to the elderly (Alpaslan & Mabutho, 2005:276). A further 77 (39%) respondents indicated clinic staff to be their support in ART issues. These findings correlate with the Gauteng Department of Health's Comprehensive HIV/AIDS Guidelines (2004), where support structures at an ART site were implemented in order to assist patients with ART. These results indicate that, besides the family, the clinic is the patient's primary form of support. This further indicates the importance of the role of the comprehensive ART clinic in adherence matters. Routine clinic visits and consultation with professional and trained staff comprise a major means of supporting and monitoring ART. This was also indicated in section 6.3.2.5.

Friends, employers and support groups are not indicated as their major means of support, which could be explained in the light of stigmatisation and fear. Patients do not disclose their status to their friends and employers. They are also reluctant to attend support groups. This correlates with 6.3.2.5 where patients did not indicate the need for support groups.

The data collected for the qualitative element reveals the following from the multidisciplinary team with regards to assistance with ART. The following theme and sub-themes emerged:

Theme:

- Assistance and support regarding adherence of patients on ART is very important for adherence.

Sub-themes:

- Family support features strongly
- Employers play no role in adherence issues
- Medical team is an important form of support

Table 28: Assistance and support regarding adherence of patients on ART is very important for adherence

Respondent	Verbatim quotes from the research interview
Medical doctor	“Employers play a role, usually to complain.”
Counsellor	“Medical team plays a big role.”
Social Worker	“The most significant assistance with ART is family, particularly mothers. Spouses few. Children supporting parents a few. A lot of support from siblings. Boyfriends do not assist a lot, they tend to disappear.”
Medical doctor	“The medical doctor should also take responsibility for counselling and not leave it to counsellors.”
Social Worker	“I do not know what counsellors cover in their counselling. I am not sure of their level of understanding and training.”
Medical doctor	Counselling services are not always comprehensive
Professional nurse	“General practitioners, in private practice are still testing and prescribing ART without sufficient counselling, specifically adherence.”
Professional nurse	“There are a lot of problems at support groups.”
Medical doctor	“Continuing care. Counselling from all team members. Family support.”

The above research findings are supported by the following literature:

Thus, the sub-themes that were found again indicate family support to be very important, while support from the medical or clinic teams was also mentioned. Employers do not feature strongly with respect to supporting patients receiving ART.

Support groups are also not perceived to be a good form of support as indicated by the qualitative and quantitative part of the study. In order to increase



confidence in support groups, the researcher believes that a national body, on government level, is required, to monitor credibility and the overall standards.

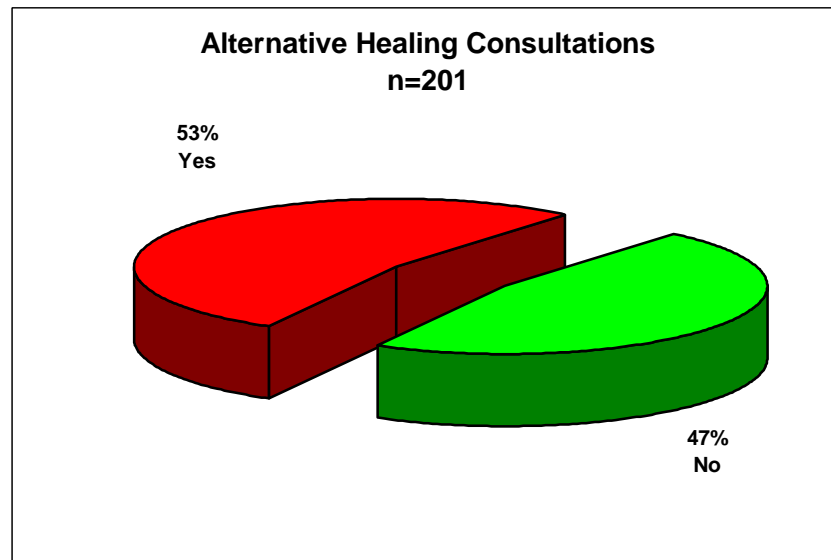
A factor contributing to the difficulties with counsellors is that there are no general or minimum standards. The researcher maintained that people in such a position of responsibility regarding the most intimate circumstances of the patients, should adhere to common standards. No register for either counsellors or support groups is kept where their credibility can be monitored. The standardizing of counselling services would increase confidence in such a service. This would further demonstrate to the general public a commitment to high standards and abilities.

Counsellors have complained that the community does not understand their function, and this, in turn, means that the latter do not sufficiently value counselling. This image has affected morale and recruitment. The Department of Health places a high priority on counselling, but no controlling body specifically monitors, trains and supports counsellors. The public service should start turning this around by being both a guardian of standards and supporter of the committed support structure (General Social Care Council United Kingdom, 2002).

6.3.2.9 Alternative healing methods

This question has been included, since it is a well-known fact that people suffering from chronic, especially life-threatening diseases, will investigate different means of healing. Some alternative healing methods could be a contraindication for ART, but no scientific research has been undertaken in this regard.

Figure 14: Alternative healers consulted



The above graph illustrates that 84 (47%) of the respondents reported not using alternative healing methods, while 117 (53%) reported having used these methods. This includes traditional healers, “sangomas”, witchdoctors, herbalists and faith healers.

In the qualitative part of the study, the following was reported with regards to traditional healing: Similarly to the results of the qabove question regarding the qualitative aspect of the study reported the following. Themes and sub-themes derived from the data:

Theme:

- Traditional healing influences adherence to ART in SA.

Sub-themes:

- Certain traditional beliefs and rituals are contraindicated for adherence to ART.
- Traditional healing does interfere with ART.

Table 29: Traditional healing influences adherence to ART in SA

Respondent	Interview quote
Social Worker	"Traditional healing still plays a big role in healing and we must always remember that."



Counsellor	“I believe that if somebody is on ART they should not take traditional medicine. The ‘muti’ that causes diarrhoea and vomiting to clean the body interferes with the absorption of ART.”
Medical doctor	“Traditional healing influences adherence.”

The above research findings are supported by the following literature:

Both indicate that traditional healing is an important factor concerning adherence issues. Rossouw (2006:18) postulates that the issue of traditional healers and traditional medicine has become one of the most complex to deal with, concerning ART. The WHO estimates that 80% of African populations consult traditional healers.

Anecdotal and early scientific evidence issues a warning of significant interactions between traditional and Western medicine. This has raised the question of whether patients using traditional medicine should be excluded from the ARV programme. Regarding traditional healers, the present researcher is of the opinion that patients will not willingly disclose their participation in traditional medicine, since they know that proponents of western medicine tend to hold negative views towards traditional medicine.

Certain traditional beliefs, such as “makgome” are practiced amongst most South African cultures. “Makgome” is a condition one might contract from having close contact with a person whose partner has died if he/she has been through the expected cleansing process. The surviving partner is compelled to visit a traditional healer (“Inyanga” or “Nyaka”) after the death of the spouse. This cleansing method requires traditional medicine (muti) to be taken for a certain period (3-6 months).

Patients are not eager to take ARV medicine while they are taking traditional medicine, which could also be a contraindication for ART. The family usually insists that the person participate in the above traditions so as not to infect others with “makgome”. The researcher is of the opinion that if a patient were to



take ART against the wishes of their family and the requirements of their traditions and culture, it would complicate adherence. Thus, a consciousness regarding different cultures and traditions is necessary in adherence matters.

The researcher believes that the incidence could be even greater, since most patients could be afraid to report that they also consult traditional healers. She further believes that in Africa, and specifically South Africa, a country rich with cultures, western medicine should meet with traditional medicine. The team at an ARV clinic should be aware of the different beliefs of patients. The role of the social worker could include the development of insight into the different cultures by facilitating / taking part in networking.

6.3.3 Psychosocial needs of respondents

Engel (1980:538) argues that when collecting data regarding the biological aspects of the patient, it is crucial also to explore her/his psychological being, because the course of the illness and the care of the patient may be importantly influenced by processes at the psychological level. Engel (1980:543) further illustrates that by using the biopsychosocial model, the medical practitioner is able to identify and evaluate the stabilising and destabilising potential of events and relationships in the social environment of the patient, while not neglecting the way in which the destabilising effects of the patient's illness on others may feed back as a further destabilising influence on the patient. This argument emphasises the important influence of the patient's social environment on his/her health and illness.

According to Kaplan, *et al.* (1994:1), the psychological dimension emphasises the effects of psychodynamic factors, motivation and personality on the experience of illness and the reaction of the patient. This dimension forms an important component of the biopsychosocial model, in the sense that it helps the medical practitioner to understand the patient's perceptions of his/her condition and the extent to which he/she is motivated towards obtaining help.



In this section of the questionnaire, the psychological needs and circumstances of the respondents are explored. Questions included in this section focus on the psychosocial support – the needs and problems of the respondents, alcohol consumption, drug abuse and criminal records, as well as counselling needs. Questions regarding financial circumstances, religious matters and accommodation issues were also included. Furthermore, the emotions of the respondents, disclosure issues and sexual matters were explored. The last question posed, concerned the quality of life of the respondents.

6.3.3.1 Psychosocial needs/problems that respondents experienced since receiving ART: psychological dimension

It is a well-known fact that the social and psychological issues confronting HIV/AIDS patients are enormous. Patients diagnosed with most life-threatening diseases such as cancer are usually smothered with sympathy and support. The diagnosis of HIV/AIDS is often characterised by stigmatisation, and subsequent social rejection and emotional isolation. The social stigmatisation reminds us of the rejection with which a person suffering from leprosy met in the biblical period. (Holy Bible: Luke 17:11 and Leviticus 13)

Table 30: Psychosocial needs of Respondents as indicated across the eight individual aspects measured

Psychosocial needs of Respondents	Frequency	Percent
Disability Grant	96	48
Counselling	48	24
Emotional Problems	48	24
Sexual Problems	34	17
Relationship Problems	24	12
Alcohol Problems	11	5
Stigmatization	9	4
Terminal Care	4	2

The following findings are emphasised in the above table:



The above data was obtained from a multi-answer questionnaire, where the respondent could indicate more than one psychosocial need.

The above research findings indicated that a need for disability grants (96 (48%)) is the greatest psychosocial need reported by respondents while 48 (24%) indicated needs with respect to emotionally related problems and only 34(17%), sexual matters.

The findings from the qualitative aspect of the study revealed the following regarding psychosocial needs: Similarly to the above question regarding the Karnofsky scale, the qualitative aspect of the study reported the following regarding the WHO staging:

Theme 1:

- Psychosocial needs of patients featured strongly.
- Patients need support structures that are supportive and standardized.
- Patients have a need for maintenance of confidentiality.
- Patients need ongoing motivation and support.
- All patients need a thorough assessment of personal circumstances and needs.
- Financial assistance featured strongly.

Theme 2:

- Psychosocial needs of counsellors featured strongly.
- Lay counsellors in concerning adherence matters need formal training.
- Lay counsellors in general need better working conditions and expect formal employment with benefits.
- Lay counsellors
- The standards governing lay counsellors need to be standardized and uplifted.

Table 31: Psychosocial needs of patients featured strongly

Respondent	Interview quote
Social Worker	“Patients needs presented to me, are always material needs. Need for a disability grant or food. But when I assess the patient I always find more complex issues to attend to.”
Social Worker	‘A thorough assessment is necessary of each patient’s needs.”
Counsellor	“The government is seeing us as the last resort. We are the doormats of the government.”
Counsellor	“Why can’t counsellors be officially employed?”
Counselling	“Motivate counsellors by bursaries and educational and learning programmes to uplift their standards.”
Counsellor	“Nobody represents counsellors and there are no support structures and there are no standard services.”
Medical Doctor	“Support and motivations is one of the major needs.”

The above research findings are supported by the following literature:

The researcher is of the opinion that the hierarchy of needs developed by Maslow, a pioneer in the field of psychology, is very applicable to HIV/AIDS patients. If the basic needs such as hunger, thirst, sex and the maintenance of the internal state of the body are not fulfilled, respondents will not indicate higher psychological needs, such as emotional needs (Maslow, 1954). This paradigm is an indication of the need to belong in a social and familial sense and to be accepted and affiliated to others and could include the need to reach self-fulfilment.

An interesting aspect that emerged during this study in the interviews with lay counsellors, was the needs of these counsellors. The sub-themes that emerged, were focussed on the needs of counsellors and not on the needs of patients. The researcher is of the opinion that the latter’s self-interest and concern with their own personal needs and welfare, rather than those of the patients, features strongly in the above findings, and is contra-indicated for counsellors. These lay counsellors, their skills, training and recruitment should



thus be addressed. The qualitative part of the study, has thus revealed a need for common standards being applied to counselling services in ART.

It seems that “a can of worms” was opened regarding various aspects of lay counselling. Self-interest, often equated with egoism, an exclusive concern with one’s own personal needs and welfare rather than those of others, as discussed by Baran, Byrne & Branscombe (2002:88), featured strongly in the above findings. Baran *et al.* (2002:88) further proclaimed that if lay counsellors are motivated by self-centred needs, such as gaining self-understanding, and self-esteem enhancement, these tend to be stronger predictors of prolonged volunteerism.

The researcher is further of the opinion that in the recruitment of lay counsellors, the motivations for their involvement, specifically in HIV/AIDS matters, should be explored. Baron *et al.* (2002:412) discusses the different theories attempting to explain the reasons for pro-social behaviour as follows:

- Negative-state relief model; proposes that people help other people in order to relieve and make less negative their own emotional discomfort.

The above findings are again an indication of the comprehensive service that is needed at an ART site. Social workers and counsellors should be skilled and trained in the thorough assessment of clients. Some of the roles that are indicated for a social worker in the ART clinic are indicated as being an advocate for the rights of patients, educator, and supervisor for standards in counselling.

6.3.3.2 Alcohol Consumption

This question explores the presence of alcohol use/abuse in respondents, since it is perceived as a contra-indication for adherence.

Only 9 (4%) respondents reported moderate alcohol consumption on Fridays, 16 (8%) on Saturdays, and 11 (5%) on Sundays. The research results indicated that only 35 (17%) respondents reported mild alcohol use over weekends.

In the qualitative part of the study, the multidisciplinary team members reported the following regarding alcohol use:

Theme:

- Alcohol dependency not reported often at ART clinics.

Sub theme:

- Alcohol dependency or abuse does not feature strongly at ART clinics.
- Alcohol abuse is too often or willingly disclosed.

Table 32: Alcohol dependency not reported often at ART clinics

Respondent	Interview quote
Counsellor	“Patients counselled are drinking but they are scared to tell. Patients commonly drink ijuba (zulu beer) as it is cheap.”
Counsellor	“If you ask, they say they drink because of stress.” “If you drink you forget to take the pills.”
Counsellor	“Men drink more because of traditional beliefs and they have more money than women.”
Social worker	“Alcohol does not feature strongly – most people are just too poor or sick to drink.”
Medical Doctor	“Alcohol - cases are isolated.”

The above research findings are supported by the following literature:

The theme that emerged is that alcohol does not feature very strongly in ART matters. The notion of the present researcher is that the above results can be attributed to the fact that the economical and/or physical status of most patients does not allow for alcohol abuse or even its use. Most respondents reported that they were unemployed and dependent on family members for their basic human needs, which certainly does not include alcohol. If a patient should have an alcohol problem this would influence adherence. According to Kaiser (2002:10) many predictors of poor adherence to ART have been identified and

include active drug use and alcohol abuse, active mental illness, in particular, depression.

Furthermore, the reported low consumption of alcohol or its abuse could also be attributed to the fact that the respondents participating in this research have already been initiated on ART. According to the Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout Plan for Antiretroviral Treatment (2003:4), alcohol abuse should be excluded before initiating ART and this could explain the reported low consumption of alcohol.

6.3.3.3 Drug Abuse

Regarding drug abuse, the following was reported in the qualitative part of the study:

Similarly to the above question regarding the alcohol, the qualitative aspect of the study reported the following regarding the WHO staging:

Theme:

- Drug abuse not reported to be prominent at ART clinics.

Sub-themes:

- Drug abuse is not reported by patients. Patients are too poor to afford drugs.
- People do not easily disclose drug abuse.
- Drug abuse is more prominent amongst white or financially stronger patients.

Table 33: Theme: Drug abuse and adherence

Respondent	Interview quote
Counsellor	"I have never seen somebody that takes drugs - maybe they are not telling."
Social worker	"Drug abuse is not a problem. If there is drug abuse - it is usually the white patients."
Medical Doctor	"Isolated cases."

The above research findings are supported by the following literature:



No significant sub-themes emerged from the above question, except the possibility that drug abuse is found more often among white, rather than black patients.

As with alcohol, the abuse of recreational drugs is contraindicated for adherence. The National Antiretroviral Treatment Guidelines (2003) consider drug abuse as an excluding factor before initiation of ART.

Respondents in this research reported no drug abuse, because, the present researcher believes, that since the respondents were already receiving ART, they would have been screened for, drug abuse, an exclusion factor for initiating patients for ART.

The researcher is also of the opinion that another reason why drug abuse is not reported, as discussed in section 6.3.3.2 regarding alcohol, is that the patient's financial circumstances also cannot support the use of recreational drugs. If this research had been conducted in a private facility where the financial circumstances of patients were different, drug abuse might have been mentioned.

6.3.3.4 Criminal Record

By including this question, any criminal record/history of the respondents is investigated, since criminal activity could be an indication of irresponsibility. Prisoners, receiving treatment at the ART clinic, were not included in the research for practical reasons. Less than a third of the respondents 44 (22%) reported some kind of criminal record.

Similarly to the above in the qualitative element of the study, criminal activity was also not reported as an issue in HIV/AIDS and ART. The data collected from the qualitative element of the study reveals the following:

Theme:

- Criminal involvement. Minimum influence on adherence to ART.

Sub-theme:

- Criminal involvement does not feature in adherence to ART.
- Prisoners should receive treatment in prison and not visit local clinics as is the present practice in local clinics.

Thus, the sub-theme that emerges from the above questions regarding criminal involvement indicates that, in general, patients do not break the law. The sub-theme that emerged strongly was that prisoners should be treated in prison and not at ART clinics in the community, for various reasons.

Table 34: Theme: Criminal record and adherence

Respondent	Interview quotes
Counsellor	“Most patients have not been involved with crime.”
Professional Nurse	“Some patients feel uncomfortable with the prisoners and their guards armed.”
Medical doctor	“Prisoners sometimes waste time by faking symptoms to spend time outside. It is a waste of government human resources personnel and transport.”
Medical doctor	“No role.”

6.3.3.5 Need for Counselling

HIV counselling is defined as a confidential dialogue between a client (patient) and a care-provider, aimed at enabling the client to cope with stress and be assisted in taking personal decisions related to HIV/AIDS (WHO Global Programme on AIDS, 2006).

The quantitative research results indicated the following regarding counselling:

123 (61%) of the respondents reported a need for more adherence counselling, 37 (18%) of the respondents reported a need for more post-test counselling, 33 (16%) of the respondent reported a need for counselling regarding death and dying,



20 (10%) of the respondents reported a need for counselling of important others/family, and 16 (8%) of the respondent reported a need for disclosure counselling.

The above research results indicated that the majority of respondents reported the need for adherence counselling 123(61%). This is significant but could also be biased since adherence counselling is indicated as part of the Gauteng Department of Health’s Comprehensive HIV/AIDS Guidelines (2004) before initiating ART. Furthermore, respondents could have felt obliged to indicate adherence counselling, since they are aware of the fact that adherence is important in ART.

In the qualitative part of the study, the following was reported with regards to counselling needs of patients. The data collected from the qualitative element of the study regarding the counselling needs of patients, reveals the following:

Theme:

- Patients do require various or holistic counselling throughout ART treatment.
- Common standards are required in counselling, specifically regarding adherence counselling.
- Patients need holistic help.
- Patients need trained counsellors to support them

Sub-theme:

- Common counselling standards.
- Standards for counselling and adherence specific.
- Holistic help.

Table 35: Theme: Counselling needs

Respondent	Interview quotes
Social Worker	“I do not know what counsellors do cover in their counselling. I am not sure of their level of understanding and training of counsellors.”



Counsellor	“General practitioners, in private practice are still testing and prescribing ART without sufficient counselling, specifically adherence.”
Medical doctor	“Patients do not need specific counselling they need holistic help.”

The above research findings are supported by the following literature:

Much emphasis is placed on counselling in HIV/AIDS. Terms like VCT, PMTCT; pre-test; post-test and adherence counselling are now well known in terms of HIV/AIDS matters. The Department of Health makes special provision for counselling and counsellors (South Africa, 2003). The researcher is of the opinion that counselling should not be labelled and fragmented, for example, adherence counsellors or VCT counsellors. Counsellors should be able to render a holistic and comprehensive service in assessing patients.

The social-work profession, with its specialized skills, could play an important role in assessing the patient and rendering the necessary therapeutic interventions if required. The social worker has knowledge of community resources and will be able to network with organizations. The present researcher, as confirmed in the qualitative study, has experienced, that most often, patients need more than just pre-test and post-test counselling. A comprehensive assessment by an experienced counsellor and knowledge of resources is often required since patients do experience various biopsychosocial needs that should be addressed by a qualified professional.

6.3.3.6 Issues relating to accommodation

By including this question, the normal circumstances of respondents were explored in order to establish the need for alternative care, such as community home-based care, or institutionalisation, such as hospitalisation or care in a hospice.

The research findings indicate that 18 (9%) of the respondents reported a need for alternative accommodation, 15 (3%) for home-based care, none needed hospitalisation, while only one required hospice care, owing to lack of support.

The researcher holds the view that the above figures could be an indication that the patients do adhere to their treatment because a lesser need for hospitalisation or home based care is indicated. This could further be an indication that this goal (reduced hospitalisation) of ART has been met. No terminally-ill patients were included in the study since this would not have been ethically responsible.

Regarding accommodation, the following was reported in the qualitative part of the study: - The data collected from the qualitative element of the study regarding accommodation needs reveals the following:

Theme:

- Accommodation needs is not prominent in adherence matters.

Sub-theme:

- Most people are content with their accommodation.

Table 36: Accommodation needs is not prominent in adherence matters

Respondents	Interview quotes
Counsellor	"Patients are happy where they are – it is home."
Counsellor	"I do not see a lot of homeless people they are few."

The above research findings are supported by the following literature:

One of the secondary aims of ART is to minimize hospitalisation. The researcher also intended to establish the need for community-based care, which is the care provided to individuals in their own homes where they are supported by their families, a multidisciplinary team, and complementary caregivers (Van Dyk, 2006:14). No significant sub-themes emerged from this question regarding accommodation and adherence issues, except that the patients have a place of abode and are relatively happy where they reside.

6.3.3.7 Financially-Related Problems

The researcher considered that the relationship between HIV/AIDS and poverty, which thus far, has been merely alluded to, would also indicate a correlation between adherence to ART and poverty / socio-economic status. By including this question, the researcher intended to establish the respondent's financial circumstances.

Poverty is a key factor contributing to the AIDS epidemic, according to the First full-scale report of the WHO Global Programme on AIDS (GPA, 2002). The researcher believes that financial hardship will be the key factor contributing to non-adherence; people will default and discontinue ART owing to financial issues such as transport and therefore only visit the clinic for treatment when they can afford it or are admitted to hospital owing to AIDS-related symptoms.

According to the research results, the majority of the families in the present study are unemployed and live on child-support grants as a means of coping with their desperate financial situation. This places a huge responsibility on the few who are employed and the self-employed family members who have to shoulder the basic necessities for the entire family.

The researcher also confirms Janet Frolich's opinion in (Abdool, 2005:365), who states that there is still widespread ignorance of the financial support available to communities, families and individuals affected by HIV/AIDS, and that education programmes are urgently needed to make people aware of the grants for which they are legally eligible.

Table 37: Financially-related problems reported by respondents

Financial related problems	n	Percent
Unemployed	145	72
Disability Grant	103	51
Employed	55	27
Productivity	15	7



The above research findings are supported by the following literature:

The above data was obtained from a multi-answer questionnaire, where the respondent could indicate more than one financially-related problem.

The findings, highlighted from the above table, indicate that 72% of respondents reported unemployment and a further 103 (51%) reported the need for a disability grant. This correlates with section 6.3.3.1 where 96 (48%) respondents reported a need for a disability grant with respect to psychosocial needs. The above minor discrepancy can be attributed to the fact that some patients 83 (41%) were already receiving a disability grant, or are in the process of applying for one and thus did not perceive it as a need.

A matter of great concern for the present researcher is that the majority of patients only receive the disability grant for a temporary period of 6 months, where after they need to re-apply for a further period, as the criteria for the grant in SA is a CD4 count of below 200. The researcher has experienced in her work that patients with a CD4 count that rises above 200, fear the discontinuation of their grants, which is their only means of financial support. This could contribute to non-adherence, in an attempt to keep their CD4 cell count at below 200.

The findings of the qualitative element of the study were reported with regards to financial issues. The data collected from the qualitative element of the study regarding the financial needs of respondents. The theme and sub-themes are as following:

Theme:

- Economic factors influence adherence to ART.

Sub-theme:

- Lack of money influences adherence to ART.
- Poverty does not really prevent adherence.
- People need financial support to adhere to ART and to attend clinics.



- Unemployed patients, dependent on disability grants, fear discontinuing of grant, when adhering and the subsequent improvement of CD 4 count.

Table 38: Economic factors influence adherence to ART

Respondents	Interview quote
Counsellor	“People need grants to come to the clinic.”
Counsellor	“If people are really motivated financial issues do not stop them from taking ARV’s.”
Medical Doctors	“They find money to come.”
Social Worker	“Patients are poor and need financial support.”
Medical doctor	“No money for basic needs does influence adherence and pre-planned defaulting to keep CD4 count < 200 to keep disability grant.”

The above research findings are supported by the following literature:

The sub-themes that emerge from the above discussion are that most people need some form of financial support or grants. It has also emerged that people who are really motivated can adhere, in spite of poverty.

The social elaboration of HIV/AIDS and poverty is endorsed by Mashologu-Kuse (2005:378), as well as Strydom, Cronje, Roux, Strydom, and Wessels (2005:68), who confirm that poverty and the high level of unemployment, coupled with families headed by females, and who receive no support from their partners, and are almost totally dependent on child-support grants, are an indication of the plight of disadvantaged families. The researcher asserts that the issue of disability grants for HIV/AIDS patients should receive special attention. Frohlich, as quoted in Abdool Karim & Abdool Karim (2005:351), asserts that legal mechanisms such as wills, foster care and social grants are foreign concepts for many communities, particularly those in rural areas.



6.3.3.8 Financial Support

The intention of this question was to explore the respondents' socio-economic status.

As discussed above in section 6.3.3.7, most HIV/AIDS patients do experience financial difficulties owing to lack of productivity, caused by the AIDS-related symptoms.

Table 39: Financial support of respondents as indicated across seven individual aspects measured

Financial support	Frequency	Percent
Self	109	54
Family	84	42
Disability Grant	83	42
Spouse	31	15
Child	19	10
Friend	13	7
Colleagues	2	1

The following findings are evident from the above table:

The data was obtained from a multi-answer question, where the respondent could indicate more than one form of financial support.

These findings are interesting, since more than half of the respondents 109 (54%) indicated that they support themselves. These findings could include some form of grant or assistance, but are perceived by the respondents as self-support. Forty-two percent 84 (42%) of the respondents reported family financial support and a further 83 (42%), reported a disability grant as their form of financial support.

The researcher believes that section 6.3.3.7, where 145 (72%) of respondents reported unemployment and financially-related problems, correlates with section

6.3.3.8, where 149 (75%) respondents reported that they are financially dependent on someone. The 134 (67%) respondents, who reported financial support from their families, include: extended family 84 (42%), spouses 31 (15%), spouses and children 19 (10%). It is important to note that 83 (42%) respondents reported that they already receive a disability grant. The data indicates that almost all the respondents experience some form of financial need.

Regarding financial issues and adherence, the respondents reported the following in the qualitative part of the study: - The findings of the qualitative element of the study are: Regarding accommodation, the following was reported in the qualitative part of the study:

Theme:

- Financial difficulties are reported by respondents as to influence adherence to ART.

Sub-themes:

- Supporting patients financially is important for adherence.
- Unemployed patients need disability grants to support adherence.
- Patients rely mainly on financial support from families.

Table 40: Financial difficulties are reported by respondents as to influence adherence to ART

Respondents	Interview quote
Medical doctor 1	"Patients are sick and want to come for follow-ups but due to non-disclosure to employers they cannot keep medical appointments."
Medical doctor 2	"Transport fees v/s basic human needs are a problem specially patients outside the service areas."
Counsellor 1	"Patients are supported mainly by mothers."
Counsellor 2	"Patients need grants the most."
Social Worker 1	"Patients needs presented to me, are always material needs."
Social Worker 2	"Need for a disability grant or food."



The above research findings are supported by the following literature:

The most notable sub-theme that emerges from these data is that patients do need financial support in order to sustain adherence. Often the needs being presented are material in nature, but once they have been assessed, further problems emerge.

HIV usually affects more than one in the household (husband and wife or mother and child). The financial burden is usually borne by the household, e.g. a grandmother who only receives an old-age pension or child-support grant. Whilst a general relationship exists between poverty and poor health, this is particularly so between HIV and poverty (Abdool Karim & Abdool Karim, 2005:381).

The researcher asserts that the above research results confirm, yet again, the need for financial assistance for HIV/AIDS patients who receive ART. The role of the social worker is to assess the patient biopsychosocially. The criteria for disability grants cannot not only rely on the medical report if adherence issues regarding ART are taken into account. The social worker has a role to play in bringing cases with special needs to the forefront.

6.3.3.9 Emotions

By exploring the emotions of respondents, the intention was to establish the feelings of the respondent with regards to their experience of illness and their reaction to it.

According to Kaplan, *et al.* (1994:1), the psychological dimension of the biopsychosocial model, emphasises the effects of psychodynamic factors. This dimension forms an important component of the biopsychosocial model. It assists the medical practitioner to understand the patient's perceptions of his/her condition and the extent to which he/she is motivated to obtaining help. When using the biomedical model on its own, these aspects are neglected, resulting in a negative impact on the patient.

Kerns and Curley (1985:150) add that the individual's cognitive, affective and behavioural functioning greatly influences the extent and meaning of perceived psychological and social losses, as well as their coping with or adapting to these.

Table 41: Emotions as indicated by Respondents across the five individual aspects measured

Emotional	Frequency	Percent
Acceptance	192	96
Positive	187	93
Gratefulness	172	86
Mixed Feelings	72	36
Depression	49	24

The following findings are illustrated in the above table:

The above data was obtained from a multi-answer questionnaire, where the respondent could indicate more than one form of emotional need.

Most respondents reported positive feelings. Regarding this, the researcher confirms that the majority of patients on ART are positive and grateful. These positive feelings can be contributed to the fact that they do experience a sense of control. The patients have accepted their status and are willing to take responsibility in controlling the disease. It has been reported that if a patient experienced greater control, he/she would show stronger feelings of being contented and positive.

In the qualitative part of the study the following was reported regarding emotions: The data collected from the qualitative element of the study regarding the emotions presented by patients, reveals the following:

Theme:

- Patients reported in general positive feelings and feelings of optimism, hope and to be grateful gratitude.

Sub-themes

- Feelings of anxiety were reported regarding disclosure of status.
- Complications, treatment failure and side-effects lead to feelings of despondency and depression.

Table 42: Patients reported in general positive feelings and feelings of optimism, hope and to be grateful gratitude.

Respondents	Interview quotes
Social Worker	“Patients tend to be positive in general.”
Social Worker	“Matters regarding disclosure and confidential issues still cause the most anxiety in patients.”
Counsellor	“We do not see a lot of seriously depressed patients.”
Medical doctor	“When a patient is initiated on ART and experience complications they do tend to be depressed and default.” “Emotional immaturity or lack of insight – they do not understand the importance of adherence.”

The above research findings are supported by the following literature:

From the above data regarding the theme of emotional needs and adherence, the sub-theme that emerged is that people on ART demonstrate positive feelings.

The present researcher has experienced that when a person is diagnosed with a life-threatening or chronic illness, like HIV/AIDS, they tend to go through certain of the stages identified by Kubler-Ross (Taylor; 2003:400). In general, the HIV/AIDS patients also experience feelings of fear, anger, anxiety and guilt. The said researcher has experienced that most patients express feelings of guilt, often feeling ashamed and afraid of being questioned concerning infidelity or homosexuality. The stages do not occur in a predetermined order. Most patients experience some of the stages more than once: for example they might experience depression each time they develop new symptoms, or their CD4 count drops.



The present researcher proposes that the emotional phases that patients with HIV/AIDS experience are: anger, shock, denial, anxiety, guilt, fear, bargaining, depression and acceptance. In previous research carried out by the said researcher (Spies, 1999:88) the respondents reported shock, depression and fear as their primary emotions. After initiation on ART patients do tend to express anxiety, excitement, anticipation, bargaining, and happiness.

6.3.3.10 Treatment for depression

In including this question, the intention was to explore the feelings of respondents, particularly depression.

Only one respondent reported depression. The researcher explains this, in that the respondents already receive ART and generally feel very optimistic. The respondent is also aware that untreated depression is an exclusion criterion for initiating ART. These results correlate with the results in subsection 6.3.2.9 where patients reported their feelings as being happy, grateful and positive.

Regarding this question on depression, the qualitative part of the study reveals the following: - The data collected from the qualitative element of the study regarding depression specific, reveals the following:

Theme:

- Depression is often contraindicated for adherence to ART.

Sub-themes:

- Depression is more often reported in white patients.
- Depression did not feature frequently in patients attending the clinics where research was conducted.

Table 43: Theme: Depression is often contraindicated for adherence to ART

Respondents	Interview quotes
Counsellor	“Patients on antidepressants are usually the white patients; they have a lot of issues.”
Counsellor	“We do not see too many depressed patients.”



Medical doctor

“Depression goes hand in hand with feelings of futility - If a patient experiences this they might decide to give up treatment – they lost hope.”

The above research findings are supported by the following literature:

The most important sub-theme which emerged from this question regarding depression is that the members of the multidisciplinary team involved in ART do not perceive depression to play an important role in HIV/AIDS patients on ART. Depression is also reported to be more prevalent in white patients. Co-morbid depression, or alcoholism and drug dependency, negatively impacts on adherence, whereas disclosure and social support may impact positively (Abdool, 2005:514).

6.3.3.11 Religions

As values and beliefs are integrated with sexual behaviour, the researcher wanted to establish the influence of religion.

Respondents reported the following about the Christian denominations they belong to:

38 (20%) Apostolic

31 (17%) ZCC

22 (12%) Roman Catholic

10 (5%) Lutheran

8 (4%) Methodist

The above research results indicated that respondents represent Christians from different denominations, the highest percentage being Apostolic 38 (20 %), and Zionist Christian Church (ZCC) 31 (17%). Most respondents indicated that they participated in religious activities. This could be another indication for churches to become actively involved in HIV/AIDS/ART training, education and prevention programmes.

The data collected from the qualitative element of the study regarding religion revealed the following:

Theme:

- Religion can influence adherence to ART.

Sub-themes

- If patients are religious, the church and spirituality will convey hope and motivate patients to adhere.
- Some churches have special rituals or prescriptions regarding treatment (faith-healing, cleaning of body and other rituals) which could contra-indicate adherence.
- The concept of faith healing and patients believing that they are cured can result in non-adherence to ART.

Table 44: Theme: Religion and adherence

Respondent	Interview quotes
Social Worker	“Certain churches have special instructions regarding illness and or medication and this can influence adherence.”
Counsellors	“Religions play a role in adherence. Special instructions from certain churches might cause non-adherence.”
Medical doctor	“If patients belong to a religion they feel that there is a purpose to life and tend to be adherent.” “Religious leaders might influence patients to believe in faith-healing – which can cause them to default.”

The above research findings are supported by the following literature:

The sub-theme which emerged from the research regarding religion is that religion and spiritual issues play a role in adherence matters. All individuals possess some kind of belief and some set of values about other people, groups, objects or ideologies. Religion may be described broadly as a system of beliefs and practices which are usually considered to be directed towards the “ultimate concern” of a particular society (Jones, 1991:355).

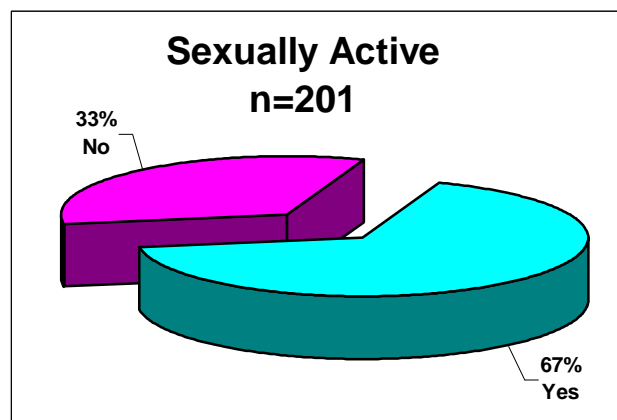
The present researcher is of the opinion that the role of religion should not be underestimated in the treatment of HIV/AIDS patients. Often patients hold quite specific beliefs about the nature of disease (witchcraft) which might be in direct conflict with those held by medical professionals.

6.3.3.12 Sexual activity of the respondent

The present researcher is of the opinion that the co-existence of sexual behaviour and HIV, coupled with the conspiracy of silence and shame surrounding these, are at the core of the pandemic. The results of the questions regarding sexual activity, practicing safe sex and methods of safe sex or contraception are presented together. These questions are all linked, which provides a good indication of the sexual behaviour and circumstances of the respondents.

Figure 15: Sexually Active

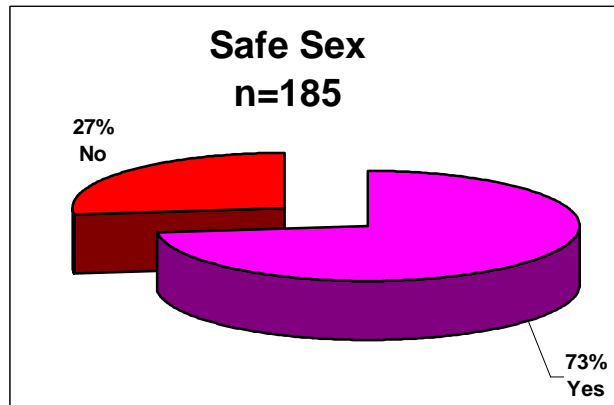
The intention was to establish whether patients are sexually active.



The above graph illustrates that more than half of the respondents, 135 (67%), were sexually active. If these results are compared to the 165 (82%) respondents who reported being single in Figure 8, this could indicate that patients are still sexually active, even without being in a supportive relationship.

Figure 16: Practising safe sex

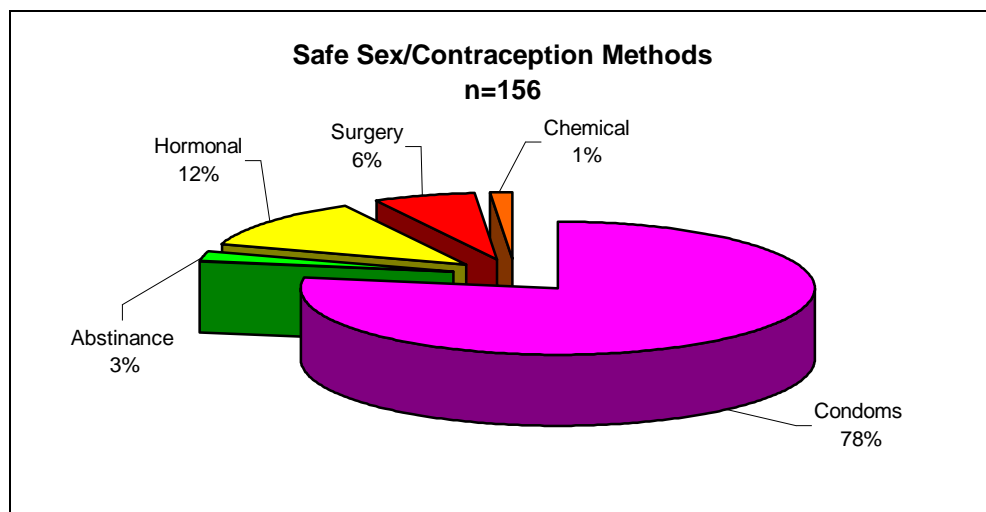
In this question, the intention was to establish whether the patients who are sexually active practise safe sex.



The above graph illustrates: that the large majority, 135 (73%), of respondents reported that they practise safe sex, while 50 (27%) responded negatively.

Figure 17: Safe Sex/Contraception Methods

The views of the respondents with regards to safe sex were explored. In this question the respondents were asked to indicate what they perceive safe sex to be. Contraception was included, because there is a belief that being on contraception such as the pill, is practising safe sex.



The following findings are illustrated in the above table:

The above data was obtained from a multi-answer question, where the respondent could indicate more than one form of safe sex and to explore what they understand under "safe sex."

121 (78%) of the respondents reported the use of condoms (male and female)

19 (12%) reported hormonal methods

10 (6%) reported surgery (hysterectomy/vasectomy)

5 (3%) reported abstinence and



2 (1 %) reported the use of chemicals.

More than half of respondents 125 (67%) reported that they were sexually active, compared to 135 (73%) of respondents who indicated that they practise safe sex and a further 121 (78%) of respondents who indicated the use of condoms as the primary method of safe sex. These results indicated an alarming number of patients who still do not use condoms 36 (22%), which presently is the only safe method except for abstinence (2.56%). Hormonal contraception was included as an option in order to establish whether patients perceive contraception methods to be safe sex: a total of 19 (12%) of respondents responded affirmatively. This is an indication that education should focus on the difference between contraception and HIV positive safe-sex methods.

The data collected from the qualitative element of the study regarding the influence of patients performance status, reveals the following living conditions, and the sub-themes reveal the following:

Theme:

- Sexual activities do influence adherence to ART.

Sub-themes

- Disclosure in sexual matters influence adherence to ART
- Non disclosure in sexual relationships, negatively influence adherence to ART.

Theme:

- People do not practise safe sex.

Sub-themes

- Patients on ART fall pregnant.
- Patients report a lot of STD's at clinics.

Table 45: Sexual activities do influence adherence to ART

Respondent	Interview quotes
------------	------------------



Medical doctor	"I see a lot of STI and pregnancies on ART – which can only be caused by unprotected sex." "Reason nondisclosure, unwillingness of partners and need of partner for children."
Pharmacist	"Sexual relationships will influence adherence especially if they did not disclose to partner."
Professional nurse	"A lot of patients on ART fall pregnant while on ART. They start feeling better. Their blood is warming."
Counsellor	"It seems that the patients do not use condoms."
Counsellor	"People do not use condoms especially if they did not disclose."
Medical doctor	"Patients who have not disclosed to partners will have to take treatment in secrecy and this might lead to non-adherence."
Social Work	"A lot of patients are falling pregnant – this shows that they do not practice safe sex."

The above research findings are supported by the following literature:

The sub-theme that emerges from the research regarding sexual matters is that people do not practise safe sex.

In South Africa, gender role norms contribute to the pronounced gap between HIV awareness and practices and the social processes that influence the disproportionate risk for contracting HIV among young women. There is an increasing recognition that public health approaches which promote abstinence, fidelity and the use of condoms in the absence of wider societal changes are not effective. Unequal power in relationships prevents the negotiation of safe sexual practices in order to reduce the impact of HIV infection and re-infection. Young women have difficulty overcoming existing gender inequalities. A distinct gap exists between cognitive knowledge (knowledge of safe sex and risky sexual behaviour) and behavioural outcome (actual refraining from risky behaviour) (Kasiram; Dano; & Partab, 2006:54-55). As previously mentioned the present researcher is of the opinion that there is little correlation between knowledge and refraining from unprotected sexual encounters, since knowledge



is cognitive and sexual behaviour is usually an emotional act as well as a basic human need.

Whiteside & Sunter (2002:71) postulate that the nature of a person's sexual behaviour is determined by the number and type of sexual encounters he will have. Since sexual behaviour is one of the basic human needs, it renders serious challenges to the health care professions. Sexual behaviour describes the set of behaviours and practices that define sexual activities, and is, in turn, determined by economical, social and cultural factors.

With regards to the risk for HIV, cross-national studies of sexual behaviour across age groups, marital status, gender and age are the strongest determinants of sexual networking patterns (Abdool Karim & Abdool Karim 2005:268). The present researcher believes that sexual behaviour is part of human nature and is very strongly related to cultural beliefs.

Until alternative methods become available, male and female condoms will remain the principal technology for preventing the sexual transmission of HIV in South Africa. A large efficacy trial is planned in South Africa in order to assess the effectiveness of the vaginal diaphragm or gel in preventing HIV infection.

Abstinence, or refraining from sexual activity, is an often-cited prevention strategy among young people, especially women. Abstaining from sex is obviously an important prevention strategy. Secondary abstinence refers to a prolonged periods without sexual activity among those who have already been sexually active (Abdool Karim and Abdool Karim, 2005:277). The said researcher asserts that to promote abstinence is a difficult but long-term possibility, which could work, especially for the youth. This is however, against a basic human need.

6.3.3.13 Other sexual matters

The researcher is of the opinion that sexual matters and HIV/AIDS are connected and at the core of the HIV/AIDS pandemic.



The qualitative element of the study revealed the following regarding sexual matters: The data collected from the qualitative element of the study regarding the influence of patients sexual matter, reveals the following:

Theme:

- Sexual relationships do influence adherence to ART.
- Sexual matters are not specifically discussed in counselling.
- Disclosure of HIV status influences sexual relationships as well as adherence to ART.
- Non-disclosure of status to sexual partners influences adherence to ART negatively, specifically if patients must visit clinics for follow-up appointments and take medication in secrecy. Patients also experience problems when developing side-effects from ART.

Theme:

- People do not practice safe sex.
- Female patients increasingly report being pregnant on ART.
- Patients moreover report STI's at clinics.

Theme:

- Sexual matters are reported to be associated with ART.

Sub-themes

- Patients (both sexes) report an increase of libido on ART.
- Sexual dysfunction is reported by males, specifically erectile dysfunction while on ART.
- Sexual matters not specifically discussed in ART matters.

Table 46: Theme: Sexual problems and adherence

Respondent	Interview quotes
Social Worker	"Physically stronger and without symptoms patients can participate in sexual activities. One of ART side effects is an increase in sexual drive."
Professional nurse	"On ARV the libido comes back. The blood is not cold anymore. They start again with sex."
Medical doctor	"Some patients complain of sexual dysfunctions on ART, this is more white patients." And specifically erectile dysfunction problem in men



Medical doctor	“This is not a subject discussed often. We focus so much on getting patients better; sexual matters are not really discussed. Patients shrink away from discussion of sexual matters.”
-------------------	----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

The above research findings are supported by the following literature:

Thus the sub-theme that emerges in exploring sexual matters is that ART has an effect on sexual behaviour, particularly, an increase in libido.

Sexual dysfunction/disorders are frequently characteristic of HIV/AIDS relationships, and include inhibited sexual desire, sexual aversion disorder, sexual arousal disorder, male erectile disorder, male/female orgasmic disorder, sexual pain disorder, premature ejaculation and vaginismus (Kasiram, M *et al.*, 2006:54).

These sexual dysfunctions are often of psychosocial origin, such as guilt and fear, which, coupled with the complicated and sensitive communication surrounding sexual activity, misconceptions and cultural issues present a challenge for the social workers who should possess the necessary experience, knowledge and skills to probe into sexual matters.

The present researcher speculates that where respondents indicated an increase in their sexual drive this could be attributed to their improvement while receiving ART, so that they are physically stronger and have more energy to indulge in sexual activities. The research also confirms this since 49 (25%) of the respondents reported an increase in their sexual drive.

The researcher is of the opinion that people begin to experience a better quality of life as a result of ARV medication, and therefore could establish new relationships owing to their renewed hope for the future. An increase in sexual drive could also be a side-effect of ART, which has not yet been researched. It is reiterated that the role of the social worker or counsellor is also to educate and develop insight into sexual matters.

Sexual behaviour is the main driver of the South African HIV epidemic. Sexual behaviour is part of the basic human need shaped by various factors: including personal, interpersonal and those related to the immediate living environment and the distal context, as well as structural and cultural issues (Eaton, Flisher and Aard as quoted by Mathews in Abdool Karim and Abdool Karim (2005:146).

6.3.3.14 Disclosure

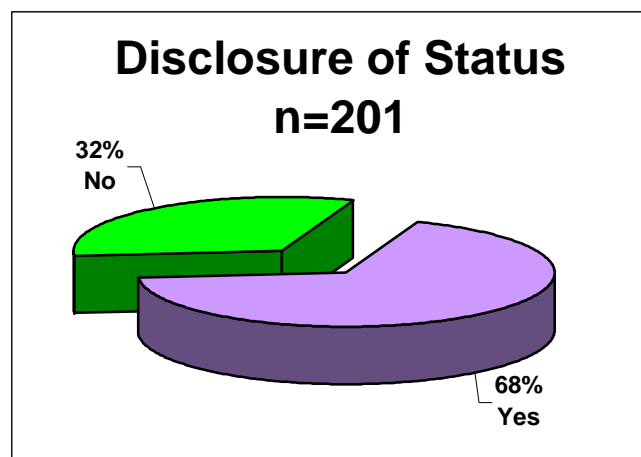
The low percentage ((25%) 50) of respondents who disclosed their HIV/AIDS status to their spouses could be explained by comparing this to the results of 6.3.1.3 where 165 (82%) respondents indicated that they are single and not in a formal relationship. This could explain why patients are reluctant to disclose their HIV status to their spouses and would rather disclose to significant others 80 (40%).

The questions 6.3.3.15 regarding disclosure and 6.3.2.16 with regards to whom they disclosed will be discussed together.

6.3.3.15 Disclosure

In this question the intention was to explore disclosure of HIV status.

Figure 18: Disclosure of Status



The following findings are highlighted from the above graph:



137 (68%) of the respondents disclosed their status while 64 (32%) did not do so. The results indicated that more than half of the respondents disclosed their status to at least one person.

6.3.3.16 Disclosure to whom

Table 47: Disclosure as indicated by respondents across seven individual aspects measured

Disclosed to Whom	n	Percent
Family	129	65
Parents	116	58
Significant (Buddy)	80	40
Spouse	50	25
Children	49	25
Employer	17	9
Colleagues	7	4

The above data was obtained from a multi-answer questionnaire, where the respondent could indicate one or more persons to whom they disclosed their status.

The researcher is of the opinion that these results are an indication of the important role that the family plays in supporting the HIV/AIDS patient. The respondents reported family to be their major form of support: parents 116 (58%), spouses 50 (25%) and children supporting their parents 49 (25%).

HIV/AIDS carries with it a discreditable stigma and disclosure is often avoided as a result of both felt and enacted stigmas. Historically, in South Africa, disclosure is still linked to job loss, partner abandonment, social ostracism, personal injury, refusal of medical treatment, refusal of insurance, and death. (Ross & Deverell, 2004:206). A further task of the social worker would be to identify and address these fears and network with the patient's social structure. The qualitative element of the study revealed the following regarding disclosure:

Theme:

- Disclosure influence adherence to ART.

Sub-themes:

- Disclosure of HIV status features as a major issue in adherence to ART.
- Disclosure of HIV status causes anxiety and influences adherence to ART.
- Patients tend to disclose mainly to immediate family for support.
- Patients try to avoid disclosing to employers and strangers.

Table 48: Theme: Disclosure influence adherence to ART

Respondent	Interview quotes
Social Worker	“Patients especially women still have a problem with disclosure to their partners. They fear the loss of financial support.”
Medical Doctor	“Most of the time disclosure is to immediate family – they have problems in disclosing to partners, employers and elderly parents.”
Social Worker	“Disclosing issues is causing the most anxiety in patients and could also be the reason of a lot of adherence issues.”
Counsellor	“Most patients are supported by their families.”
Counsellor	“In general patients will avoid disclosing to employers.”

The above research findings are supported by the following literature:

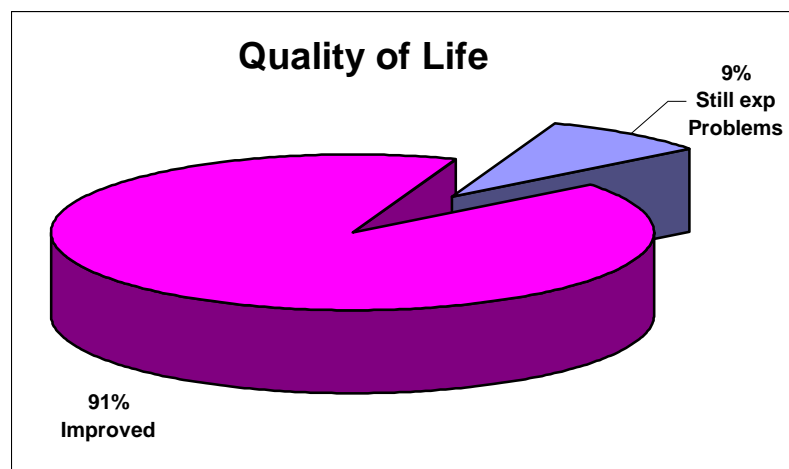
Thus the sub-theme that emerges from the above investigation is that disclosure remains a major issue in adherence matters and causes much anxiety in patients.

The present researcher is of the opinion that a question regarding disclosure is important, since this could also be an indication of the nature of the respondent’s support system. Furthermore, it is difficult to take medication in secrecy, as previously discussed. Patients suffering from AIDS-related symptoms usually need the support of their family to care for them.

While the present researcher identifies with the need for disclosure, reports that patients are not being initiated on ARV's due to non-disclosure (even where this is justified) continue. Disclosure thus appears to be used as a form of punishment rather than a mechanism to provide adherence support (Venter, 2005:22).

6.3.3.17 Experience regarding quality of life

Figure 23: Quality of life



The above graph illustrates that the majority of respondents reported an improvement in quality of life.

The improvements vary between an increase in physical strength and wellbeing 196 (98%), regaining lost roles 195 (98%), and taking control 198 (99%). A small percentage reported continuing to experience problems in their daily functioning.

28 (14%) respondents report rejection or loss, 6 (3%) report physical abuse, 12 (6%) report emotional abuse, 12(6%) report stigmatisation, and 42 (21%) report that they continue to experience AIDS- related symptoms.

As indicated in the above research results, the majority of patients report a general increase in their quality of life in that they experience increased physical

strength, regained independence and lost roles, and are able to take control of their lives.

This is a major indication that ART improves the biopsychosocial functioning of patients in general.

The results of the qualitative part of the study show a very positive response from team members towards an improved quality of life on ART. The data collected from the qualitative element of the study regarding the patients quality of life reveals the following:

Theme:

- The quality of life of most patients had improved on ART.

Sub-themes

- Drastic improvement on ART if adherent and no complications.
- Patients can assume lost roles.”

Table 49: Theme: The quality of life of most patients had improved on ART

Respondent	Interview quotes
Social Worker	“Patients can assume lost roles.”
Medical doctor	“Patients become more functional they start feeling better about themselves and it improves self esteem. It is self motivating if you feel better and that will let them adhere better.”
Counsellor	“Patients not only look much better but function better since on ART.”
Medical doctor	“I see a definite improvement of quality of life, patients can assume their positions in life e.g go back to work and feel better about themselves.”

The above research findings are supported by the following literature:

The most important sub-theme that emerges from this theme is that patients demonstrate an increase in their quality of life when on ART.



The researcher is of the opinion that the most important goal of ART should be to enhance quality of life. Quality of life and the psychosocial consequences of illness and treatment were not always considered a psychological issue of importance. The researcher contends that quality of life is significant among respondents in that by measuring the impact of treatment in this respect, one can assess their treatment is more harmful than the disease itself. (Taylor, 2003:356)

The present researcher suggests that, respondents reported overall positive feelings due to the fact that they believe that they can control their illness/disease by complying with treatments in that they personally have direct control over the illness by means of self-administration of the treatment regimen. According to Taylor (1993:362) evidence suggests that the experience of control and self-efficacy may prolong life. Control appears to be helpful not only in coping with acute disorders and treatments, but also with the long-term debilitation that may result from chronic illness. The said researcher believes that this is specifically relevant for HIV/AIDS.

HIV/AIDS, like many chronic diseases, affects all aspects of a patient's life. Those who live with chronic illnesses need to make intermittent or permanent changes in their physical and social activities. Chronic illness can produce drastic changes in self-concept and self-esteem, including one's body image and social functioning (Taylor 2003:356). In the case of HIV/AIDS, one's physical appearance can be very degrading.

The social worker's role is to motivate patients to adapt to the psychological and physical effects of living with a chronic illness.

6.4. Summary

The research has revealed the following tendencies with regards to the profile of AIDS patients with respect to their age and gender.



6.4.1 Biographical

The biographical section of the present study has indicated that the majority of respondents who participated in this research were women, in the age category <40 years. This correlates with literature and other research findings in that women are the more vulnerable group and men are underrepresented in ARV clinics.

The present research has also confirmed that the majority of people suffering from HIV/AIDS are single, which could complicate disclosure. The researcher is of the opinion, and this was confirmed by the qualitative phase of the study that people are still practising unprotected sex whilst not in a stable relationship.

The research further indicated that, the general assumption that mainly the lower-educated patients suffer from HIV/AIDS, does not hold the truth as respondents indicated higher educational levels and literacy. She has further found in practice that the better educated seek treatment sooner. Thus literacy seems to play a role in seeking medical treatment.

The majority of respondents, as could be expected, spoke North Sotho since the research was conducted in the ART clinic at Pretoria Academic Hospital, of the Gauteng Provincial Government. Regarding accommodation, the research has indicated that the majority of patients resided in an urban area, and lived in properly constructed accommodation.

6.4.2 Medical

Regarding medical and adherence issues, respondents reported that family support is the main factor enhancing adherence to ART. More than half of the respondents reported no support at all; this is alarming. The lack of interest in support groups requires attention. Respondents regard the assistance with ART received from the ART clinic as very important and, sometimes, the only form of support. In the light of the results that most patients are mainly single, unemployed women, this answers the query why patients are reluctant to disclose their status to their sexual partners.



The CD4 counts of the respondents were mostly < 200 , which could be an indication that patients are still suffering from minor AIDS-related symptoms. It could also be an indication that they are adhering to ART, since the researcher has experience that most patients initiated on ART, reported very low CD 4 counts (< 50) and even reported CD 4 counts of nil values. Most respondents had been receiving ART for a period of 6-12 months at the time of their response to the questionnaire; this could be explained in that the given ART Clinic only opened during July 2004. Respondents could thus be seen to be adherent. The current performance status of the respondents, according to Karnofsky's scale, is that of experiencing mostly normal health. Side-effects of ART are reported by more than half of the respondents as being a perceived problem.

6.4.3 Social matters

With regards to the psychosocial circumstances, this research revealed that financial needs are a priority. Most of the respondents were unemployed and thus economically dependent on either a disability grant or family support.

Difficulties relating to alcohol, drugs, and accommodation or criminal records were not significantly reported. No report of significance regarding depression arose.

Regarding sexuality, more than half of the respondents indicated that they are sexually active, but practise safe sex. Respondents reported the use of condoms as the major means of practising safe sex.

Due to the sensitive matters surrounding HIV/AIDS/ART, respondents reported disclosure to family in preference to others. Among HIV/AIDS patients, their needs comprise socio-environmental problems as being the most prevalent. The majority of patients require assistance in applying or reapplying for disability or foster grants. Deficits in external systems, such as the bureaucratic delays in the approval of grants, are primary barriers.



Disclosure was reported as a continuing issue. This could also be attributed to the fact that respondents are single. The lack of available or intact social support systems was also reported.

The majority of respondents do not show a particular need for counselling. It is evident from the research that the emphasis placed on counselling should focus on trained, skilled and experienced counsellors who can deliver a comprehensive service. The specific counselling needs reported was for adherence counselling.

Regarding quality of life, a large number of respondents expressed satisfaction with their current quality of life, and reported positive feelings and hope.

6.4.4 Psychological matters

Motivation for ART is discussed as an important determinant for adherence. Respondents reported their motivations to be to care for their families, stay alive, be physically stronger, be symptom free, and the fear of losing control. Alternative healing methods and the influence of culture should not be underestimated, since these were reported to be significant by more than half of the patients.

The researcher is of the opinion that these findings indicate that the social work profession could focus on education and information, particularly with respect to women concerning their responsibility for their own health regarding safe sex.

These findings further call for education and information programmes regarding ART, in particular, those that target men, since a contributing factor to this could be that there is no active case finding programmes for men, such as the PMTCT programmes for women. Since the current research indicates a need for active programmes that specifically focus on men, such as workplace programmes or, male wellness clinics, such a clinic could possibly be attached to an antenatal clinic, especially when one considers that for every pregnant



woman there must be a sexually active man that could be actively involved in or enrolled at such a clinic.

The researcher believes that with the adoption of the biopsychosocial model at the ARV Clinic, it will be possible to attend to the above findings, improve service delivery and in so doing enhance adherence to ART.

6.5 Final remark

In this chapter the findings from the quantitative, as well as the qualitative, part of the research were presented and discussed. In the following chapter the researcher will summarize the research process and the findings, draw conclusions and make recommendations.



CHAPTER 7: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

7.1. Introduction

The purpose of this chapter is firstly to summarize the content of the preceding thesis and secondly to provide conclusions and recommendations derived from these chapters. The overall goal of the study formulated will be evaluated as well as each objective, and the research question will be addressed.

As mentioned earlier, AIDS has shattered the false sense of security that arrived with the conquest of infectious diseases, like polio. HIV/AIDS, with its far-reaching effect on various aspects of human functioning, is the worst infectious disease in recorded history.

The findings of this research demonstrate that since the advent of HAART, HIV/AIDS has now been transformed into a manageable and chronic condition. Patients receiving ART develop less opportunistic infection, requiring less hospitalization, and show a decrease in viral load and rise in CD4, with at least partial restoration of immune function. The lower viral load slows the progression of HIV-1 disease and subsequently the risk of heterosexual and perinatal transmission is lowered.

The worldwide increase in the prevalence of antiretroviral resistance is of particular concern to all involved in HIV/AIDS matters: as mentioned, one of the greatest challenges is the high adherence rate required. This indicates the need for highly effective social work intervention to address the psychosocial needs of patients referred for HAART.

Not only must the medical perspective be considered in ART matters, but also the psychosocial and social perspectives. ARV treatment is a complex procedure, which is accompanied by severe and wide-ranging biopsychosocial implications. As a result of this there is a need for a comprehensive service



which would ensure that the patients are able to adhere to ART for life. Literature has shown that specifically in the field of HIV/AIDS, without accompanying social support and counselling services, any treatment will not be complete and may fail.

The researcher proposed the biopsychosocial model for use in assessing HIV/AIDS patients for ART. This orientation enables the service providers to consider the biological, psychological and environmental information about a patient, to make an appropriate diagnosis and develop a treatment programme that encompasses all these three areas.

The impact of the various psychosocial needs of millions of HIV/AIDS people, living on ART, on current social structures and services, will place stress on the available professional social services. The importance of having the social worker involved in HIV/AIDS and ARV matters, where all the team members will provide the patients with a comprehensive service, cannot be underestimated. No other team member will be able to meet the patient's comprehensive, psychosocial needs. As Saloner (2002:155), in discussing the critical role of the social work profession in HIV/AIDS matters, has asserted: "even though some social workers may not choose to work directly in the field of HIV/AIDS, there is now no way of avoiding the epidemic". The researcher identifies with the above in that the social work profession should facilitate the optimal functioning of people, which includes education regarding morals, values and ethical issues.

7.2 Summary of Research Methodology

The research process utilized in this study was derived from the 5 phases of the qualitative research framework as outlined by Fouche and Delport (in De Vos, 2002:84-85). The researcher will discuss the research process according to the phases proposed above, in the table to follow.

7.2.1 Illustrated Research

Table 50: Illustrated Research

Type of research: Applied		
	Qualitative	Quantitative
Approach	Creswell's: dominant-less-dominant design/triangulation Qualitative – (Less-dominant)	Quantitative (Dominant)
Design/strategy	Case study Collective case study	Quantitative descriptive (survey) design Randomized cross-sectional survey
Respondents	Multidisciplinary team (20)	Patients on ART (201)
Data collection	Interview Documents	Personal questionnaires
Sampling	Non-probability sampling	Probability sampling
Sampling technique	Purposive sampling	Simple random sampling
Data analysis technique	Transcribed interviews, themes, sub-themes, narrative meanings	Figures, tables, percentages, frequencies

7.2.2 Phase 1: The selection of a researchable topic

The research problem was identified from the literature, personal experience and interest, previous research undertaken by the researcher on HIV/AIDS and her observations within the Department of Health's ARV clinic, Tshwane District Hospital. The researcher is of the opinion that the specific research topic was not only researchable but also necessary, in the light of the current situation.

7.2.3 Phase 2: Formulation of Formal Model

The researcher decided on a combination of qualitative and quantitative approaches, as this could lead to more confidence in the results. Creswell's dominant-less-dominant model was utilized. According to Fouche, in De Vos (2002:365), the two approaches may be used in one study, with one approach being employed more than the other according to the demands of the study.



The researcher believed that comprehensive and rich data could be gathered by the combination of the two approaches to provide further insight into the research topic.

7.2.3.1 Goal of the research

The researcher defined the goal of this study as follows: “To explore the biopsychosocial factors influencing patient adherence to ART, in order to make recommendations and describe relevant factors which could be considered in assessing patients for ART.”

In her opinion this goal was achieved by means of the qualitative and quantitative research undertaken, on the basis of which the researcher did make recommendations and proposed a screening schedule for the assessment of patients.

7.2.3.2 Objectives of the Research

The researcher formulated the following objectives for this study:

Objective 1: “To explore the importance of adherence and the implications of non-adherence, and subsequently, the development of resistance to antiretroviral therapy.”

This objective was addressed by means of an in-depth literature study. Rich knowledge was gained from the literature study regarding adherence, resistance and antiretroviral therapy and presented in Chapters 2, 3, 4 and 5, and will be summarized later in this chapter.

Objective 2: “To conduct qualitative empirical research to explore and describe the biopsychosocial factors that influence adherence to antiretroviral therapy in patients, as perceived by the multidisciplinary team members actually involved in service delivery to HIV/AIDS patients on antiretroviral therapy.”



This objective was achieved in the qualitative aspect of the study where 20 respondents were interviewed. Rich data was gathered from these semi-structured interviews. A detailed picture was gained of the experiences, beliefs and perceptions of the multidisciplinary teams regarding the biopsychosocial factors influencing patients' adherence to ART.

The empirical findings of the qualitative element of the research were presented as direct quotes from the transcribed interviews, and interpreted in the form of themes and sub-themes.

Objective 3: "To conduct a quantitative study to explore the biopsychosocial factors that influence adherence (negative and positive) to antiretroviral therapy as experienced by HIV/AIDS patients on anti retroviral therapy."

Two hundred and one respondents participated in completing a questionnaire as a data collection tool, for the quantitative section of the study. The questions were based on the principles of the biopsychosocial model. This objective was achieved when the empirical findings from the quantitative part of the study were presented, discussed and compared to the relevant literature in chapter 6.

Objective 4: "To explore and analyze patients' circumstances to determine whether the predictive generalization of the theory holds truth, and to make recommendations regarding the biopsychosocial factors that should be considered in screening HIV/AIDS patients for ART that are practical, relevant and appropriate in the African context."

The researcher has explored the circumstances that may impose on adherence to ART and compared these to the literature. The researcher has also proposed an adherence screening schedule, which is attached.

A thorough literature search was carried out regarding the research topic, which was described in Chapters 2 to 5. In both the qualitative and quantitative aspects of the empirical study, the researcher explored the circumstances of HIV/AIDS patients and compared these with the literature. These findings were



presented and discussed in Chapter 6. Conclusions, which have been drawn from these findings, and recommendations, have been made in this chapter, which, it is hoped, could lead to the improvement of services to HIV/AIDS patients, specifically those on ART.

7.2.3.3 Research Questions

In this study the researcher sought to answer the following questions:

Question 1: “What are the biopsychosocial factors that influence adherence to antiretroviral therapy as perceived by multidisciplinary team members involved in the service delivery to HIV/AIDS patients on antiretroviral therapy?”

The researcher desired answers to this question because the multidisciplinary team members involved in ART undergo daily practical experiences with patients on ART. The researcher consequently felt that it would be appropriate to gather their views on the subject. The biopsychosocial factors influencing adherence, as experienced by the multidisciplinary team involved in rendering service to the HIV/AIDS patients, were established by the qualitative research and in Chapter 6 were compared to the relevant literature studies.

This proved to be appropriate since the multidisciplinary team’s experiences were presented as direct quotes and themes. They could describe circumstances in their own words. This created a deeper understanding of the problem. The research findings indicated a specific relationship between poor socio-economic circumstances and the ability to adhere to antiretroviral treatment.

Question 2: “What are the existing biopsychosocial circumstances influencing adherence of HIV/AIDS patients already on antiretroviral therapy?”

The researcher hoped that the answers to this question would specifically establish the reality and the practical factors influencing a patient’s adherence to ART.



In Chapter 6 the empirical findings from the quantitative section of the study were also presented, discussed and compared to relevant literature studies. These findings were found to be very significant for future service delivery since they indicated a specific relationship between poor socio-economic circumstances and the ability to adhere to antiretroviral treatment. The research identified unemployment, families headed by women, little support and total dependency on social security. In addition, family support for adherence to ART, as also HIV/AIDS support services, specifically counselling, were mainly found to be inadequate.

Question 3: “How can these identified biopsychosocial factors be utilized in service rendering to enhance HIV/AIDS patients’ adherence to antiretroviral therapy in order to minimize the development of resistance?”

By posing this question the researcher wished to explore ways to use the acquired knowledge to enhance the rendering of service to such patients. She identified criteria that should be used in assessing patients for ART and proposed them in the form of an assessment schedule (Annexure 7). Recommendations to improve service are presented in this chapter.

The combination of the approaches was appropriate because the data collected could answer all research questions.

The hypotheses: The biopsychosocial circumstances of HIV/AIDS will influence adherence to ART. This research has proved/establish a definite relation between the two variables (1) biopsychosocial circumstances of HIV/AIDS patients and (2) adherence to ART.

7.2.4 Phase 3: Planning

The research methodology was finalized and the research proposal was submitted and approved by the Research Proposal and Ethics Committee of the Faculty of Humanities, as well as the Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria.



The researcher conducted a literature study as part of her objectives, in order to assess the research findings against the background of existing literature. She utilized a wide variety of sources, including scientific books, articles, the internet, government guidelines and local and international reports. This study was very meaningful, and provided thorough background knowledge on the research subject. It also confirmed the need for more knowledge and research on this topic.

The research design that was selected to meet the goal of the qualitative aspect of this study was the quantitative-descriptive (survey) design, specifically the randomized, cross-sectional survey. Utilizing this design worked very well since a large percentage of respondents could be involved and many facts could be explored using the questionnaire.

The research strategy that was selected to meet the goal of the qualitative part of the research was the collective case study. This strategy facilitated the gaining of knowledge about the research topic and rich, in-depth data could be collected (Fouche, in De Vos, 2005:276).

The data collection method used for the quantitative section of the research was the questionnaire, for which the biopsychosocial model was used as a basis. The researcher is of the opinion that the personal questionnaire, as a data collection method, was appropriate for the quantitative element of the study.

The researcher was involved in obtaining the necessary informed consent from participants and could also explain any uncertainty. This was very time-consuming but proved to be most worthwhile because it limited misunderstandings and very few questionnaires were faulty.

The method of information collection employed for the qualitative element of the study was that of the interview, to gain a better understanding of this social issue. Semi-structured interviews were conducted (using an interview schedule to guide these) with the multidisciplinary team members for these case studies. The schedule was based on biopsychosocial principles.



The sampling technique proved to be appropriate since suitable team members could be identified by means of the researcher's involvement and experience in the field of research. She decided to focus on multidisciplinary team members involved in HIV/AIDS. The team members were eager to participate in the research and no problems were experienced.

For the quantitative part of the research the sampling consisted of 201 patients, selected in terms of the probability sampling procedures and specifically the random sampling method, which ensured the representativity of the population. Pre-testing of data collection was successfully conducted, which reinforced the proposed method of research. The questionnaire could be tested and mistakes rectified. The interview schedule utilized for the interviews could also be evaluated.

7.2.5 Phase 4: Implementation

The quantitative part of the study was conducted during October and November 2005 at the ARV Clinic, Tshwane District Hospital. The researcher is part of the multidisciplinary team at the above clinic and her employer, the Department of Health, as well as the Superintendent of the hospital, endorsed the research, which made the study easier to conduct. The researcher purposively selected 20 respondents in terms of the non-probability sampling method. The researcher identified 20 multidisciplinary team members who could provide rich information and were seen as experts in the field of HIV/AIDS.

The qualitative element of the research was also successfully conducted from October to November 2005. In chapter 6 the findings of this part of the empirical research were presented as direct quotes.

7.2.6 Phase 5: Interpretation and presentation

All data captured from the questionnaires was statistically processed using the SAS, version 8.2 statistical software program with the assistance of the Dept. of Statistics, University of Pretoria. It was analyzed and these interpreted findings



of the quantitative part of the empirical research were presented in text, percentages, frequency graphs and tables.

The qualitative element consisted of tape recordings of the interviews conducted with the multidisciplinary team involved in ART. The researcher transcribed the interviews and sorted them into themes and sub-themes. The data was then validated by means of generalization from the different categories. Themes and recurrent ideas, stemming from the different categories used in the interview schedule regarding the bio-, psycho- and social circumstances influencing adherence to ART, were identified. The researcher made use of the linear model for data analysis as presented by De Vos (2002:340).

Triangulation, by mixing the complementary styles of qualitative and quantitative research, contributed to the comprehensiveness of the study and led to more confidence in the results.

The researcher presented the findings of both the qualitative and quantitative processes in text, tabular, quote and graphic form in the ensuing research report. These findings and conclusions were also presented at a doctoral seminar held at Tshwane District Hospital at the end of 2006, where the feedback was very positive.

She is of the view that the findings of this research would be useful in other settings and that they are transferable to settings with a similar population.

7.3 Summary of Literature Study

The researcher reviewed current literature in depth, focusing on the research goal. By this means, she obtained a clearer understanding of the nature and meaning of the problem that had been identified. She also established, through the literature, the path of prior research and determined how this exploratory study could be linked to current knowledge.



The researcher has further established that this project will definitely contribute to knowledge about an extremely relevant social work concern. The following matters were reviewed by means of textbooks, government guidelines, journals, research reports and the internet.

7.3.1 Chapter 2: Clinical Aspects of HIV/AIDS

In chapter two the clinical aspects of HIV/AIDS and antiretroviral therapy were discussed. The researcher holds that unless we understand the virus and anti-retroviral therapy we cannot try to conquer this epidemic.

Matters discussed in this chapter were the aetiology of AIDS; morphology of HIV; infection routes; VCT; human immune system; CD4 cell count; viral load and WHO stages.

7.3.2 Chapter 3: Antiretroviral therapy

Since antiretroviral treatment was introduced in 1986, it has been demonstrated to reduce deaths and accompanying opportunistic infections in patients with advanced HIV infections. According to the World Health Organization (2002:2) guidelines regarding the use of antiretroviral therapy, mortality has dropped significantly in Europe and North America, owing to access to HAART.

In this chapter the following matters related to ARV were discussed: the goals of antiretroviral therapy, different antiretroviral drugs, response to and prognosis of antiretroviral treatment and treatment failure. The researcher believes that it is only when one understands the pathophysiology of HIV/AIDS and the pharmacology of ARVs and the body's response to these, coupled with the importance of adherence, that strategies for the long term can be developed.

7.3.3. Chapter 4: Adherence and resistance and the role of adherence to anti-retroviral therapy

The introduction of HAART has extended and improved the quality of life for people living with HIV by reducing their viral load, often to undetectable levels.



However strict adherence to the antiretroviral treatment regimen is essential, as pointed out above.

In this chapter adherence to antiretroviral (ART) and drug resistance were consequently explored, the following matters being discussed: resistance; adherence; predicting of adherence; special adherence groups; patient, providers and regime matters influencing ART; with a specific focus on the adherence team. Support in the different adherence phases and strategies to support adherence, such as medication alerts and measuring adherence, were also considered.

7.3.4 Chapter 5: The social worker's role in assessing the HIV/AIDS patient for anti-retroviral therapy utilizing the biopsychosocial model

Medical advances alone, no matter how effective in reducing the number of AIDS-related deaths, cannot support the needs of the many HIV-positive people, now living normal lives as a result of ART. (Strug, Grube, and Beckerman, 2002:7) postulate that social workers will increasingly become involved in primary prevention efforts since medical interventions alone are insufficient to prevent new infections, especially in the light of the increasing number of HIV/AIDS people now living normal lives as a result of ART. Infected persons will need a wide variety of medical and psychosocial support services for long periods because HIV/AIDS becomes a chronic condition for persons living with the disease.

People on antiretroviral therapy are doing so with guarded optimism about how long these medications will be effective and feel limited in their ability to live life fully. Prevention of the spread of this virus will again have to be focussed on.

In this chapter the focus was placed on the social worker's role in utilizing the biopsychosocial model for assessing HIV/AIDS patients for receiving ARV. The specific factors to be focused on in assessing the patient and utilizing the



biopsychosocial model were discussed in this chapter. Factors discussed included physiological, psychological and social needs.

A guideline for utilizing the biopsychosocial model in assessing HIV patients for their adherence to ART was proposed. Insight was obtained into the factors influencing such adherence.

An in-depth understanding of all the concepts and related dynamics of HIV/AIDS and ART was gained by means of the above literature reviews.

As a result, the researcher asserts that a thorough and detailed assessment of each individual regarding adherence to ARV treatment is essential. It is not possible for health care providers to predict reliably which individuals will ultimately be adherent to their treatment plan, as adherence does not correlate with gender, cultural background, social-economic, educational level or language barriers between provider and patient. Adherence has been rightly called the Achilles heel of antiretroviral therapy (Wilson and Fairall, in Abdool Karim, 2005:489).

7.4 Summary of Empirical Study (Findings)

The findings of the empirical study were analyzed and interpreted in conjunction with the format of the interview schedule and questionnaires. These findings were also integrated with the literature findings.

The researcher decided beforehand on 4 main themes for the research, which were used in compiling the questionnaire as well as the interview schedule. Recurrent ideas and patterns of beliefs emerged and were discussed and formulated into categories during data analysis, during which the researcher identified, described and compared the data. She further interpreted the quantitative data and linked it to the available literature.

The biographical section of the study has revealed that the majority of respondents taking part in this research were women, in the age category < 40



years. This correlates with literature and other research findings in that women are the more vulnerable group and men are underrepresented in ARV clinics.

The research has also confirmed that many people are not married or in stable relationships, which could complicate disclosure since the majority of respondents reported being single and unemployed. Hence this finding shows why patients are reluctant to disclose their status to their sexual partners. The assumption can be made that people are practising unprotected sex whilst not in stable relationships.

The research further indicated higher educational levels amongst patients, in contrast with the general assumption that it is mainly less-educated people who suffer from HIV/AIDS. The researcher considers that this finding might indicate that the better-educated person seeks treatment sooner; thus literacy plays a role in seeking medical treatment and adhering to it, but not in being infected.

The majority of respondents were, as could be expected, speakers of North Sotho since the research was conducted in the ART clinic at Tshwane District Hospital, and this is the local language of prevalence.

Regarding accommodation, the findings indicated that most patients were residing in an urban area, living in properly constructed dwellings.

As far as medical and adherence issues are concerned, respondents mainly reported factors which enhance adherence to ART as consisting of family support. More than half of the respondents reported receiving no support at all, which is alarming. A lack of interest in support groups was reported.

In contrast, respondents reported the assistance received as regards ART, from the Government's comprehensive ART clinics, as very important and often their primary form of support.

CD 4 counts of respondents were mostly reported to be <200 but >100, which could indicate that patients are still suffering from minor AIDS-related symptoms



but also that they are adhering to ART, since the initial indication for initiating ART is a CD 4 count <200. Most respondents had been on ART for a short period of only 6-12 months; this short time-span could be explained in that the Government's ART Rollout plan was only initiated during July 2004. Respondents could thus be seen as adherent.

Respondents reported that their current performance status (according to the Karnofsky scale) and physical appearance have improved, and also that they were experiencing mostly normal health.

Regarding their social circumstances, the research revealed financial needs to be the most urgent. Most of the respondents were unemployed and thus economically dependent on either a disability grant or family support. Hence the high rate of unemployment and poverty generally hinders access to a number of services, including adherence to ART. Patients living under poor socio-economic conditions are more susceptible to HIV infection. Specifically, women are disproportionately more severely affected by poverty and HIV/AIDS because of the inequalities in society and a general lack of resources. They are traditionally responsible for caring for the sick and also more vulnerable to HIV-infection due to their inferior position and often cannot negotiate safe sex or are obliged to sell sex for money or material goods in order to improve their living conditions.

Furthermore the majority of patients require assistance in applying or reapplying for disability- or foster-care grants. Deficits in external systems, such as the bureaucratic delays in approval of grants, were noted as major barriers.

Alcohol, drugs, accommodation or criminal records were not significantly reported, while regarding sexual activity more than half of the respondents indicated that they are sexually active, but practising safe sex. Respondents reported the use of condoms as the major means of practising safe sex.

Owing to the sensitive matters surrounding HIV/AIDS/ART, respondents reported disclosure mainly to family members. Disclosure was considered still to



be an issue, which could also be attributed to the fact that respondents are single and not in any stable relationship. Among HIV/AIDS patients' needs, socio-environmental problems were the most prevalent.

Side-effects of ART are reported by more than half of the respondents as a problem. The lack of available or intact social support systems was also reported.

Alternative healing methods and the influence of traditional culture and beliefs should not be underestimated because more than half of the patients reported that they were making use of alternative healing methods.

The patient's motivation for receiving ART was seen as an important determinant for adherence. Respondents reported their major motivations in this respect as being the following: to care for their families; to stay alive; be physically stronger; symptom-free; and the fear of losing control. These motivations can be seen as the patients' reasons to live and should be focussed on in matters of adherence.

The majority of respondents did not indicate a particular need for counselling, leading the researcher to posit that the reason is that their basic human needs, regarding socio-environmental issues, are not being met.

It is evident from the study that the emphasis placed on counselling should focus on furnishing trained, skilled and experienced counsellors who can deliver a comprehensive service. The specific counselling needs reported were those for adherence counselling.

A large number of respondents expressed satisfaction with their current quality of life since they generally reported positive feelings coupled with improved physical appearance and enhanced quality of life, as noted earlier.

In conclusion, these research findings have again confirmed that while ART has brought hope to and enhanced their quality of life for millions of HIV/AIDS



sufferers; it has also created special challenges with regard to treatment adherence and support.

7.5 Conclusions

The following conclusions regarding challenges to adherence to ART are drawn from the literature study and the quantitative and qualitative empirical findings.

7.5.1 Biographical

Gender has always been a prominent issue in HIV/AIDS discussions. The gender distribution of the participants in this study appears to be more that of heterosexual, African, women, the majority of respondents, a result which correlates with literature and other research findings, in that women are the more vulnerable group. The qualitative element of the study also indicated women to be more adherent than men in general. The researcher therefore speculates that women are testing for HIV and seeking ART sooner than men. She reports that women are actively targeted through various programmes focussing on woman and child related issues, such as PMTCT, and is of the opinion that men are underrepresented because they are not actively targeted.

The higher educational levels established by the study lead the researcher to the opinion that the better educated might seek treatment sooner. This could be an indication that literacy does play a role in seeking medical treatment but it also shows that education and knowledge do not offer a deterrent to becoming infected with HIV / AIDS.

Furthermore the effect of alternative healing methods and the influence of culture and beliefs should not be underestimated.

The research also indicates that church and spiritual leaders should become more fully involved in HIV education programmes, because the majority of respondents reported membership of a church such as the ZCC, Apostolic, or Roman Catholic. This is significant because it indicates the important part



religion and spiritual beliefs play and the influence that church groups could exert in educating, motivating and supporting patients on ART.

The research findings indicated that the majority of respondents are not married or in stable relationships. Hence the researcher has arrived at the view that, in spite of sex education and HIV awareness programmes; people are still practising unprotected sex, whilst not in stable relationships. The qualitative aspect of the study has also drawn attention to the lack of relationships with life partners which also negatively impacts on the call for disclosure. The researcher tentatively concludes that it is difficult to disclose if one is not in a stable, trustworthy relationship.

The higher educational level also proves to influence adherence since patients have developed more insight into HIV/AIDS in general.

7.5.2 Biomedical

Regarding their performance status, according to the Karnofsky scale, respondents reported normal health or that they were merely suffering from minor illness. This is positive and could indicate that patients are adhering to ART.

Both the qualitative and quantitative elements of the research established the side-effects of ART as a significant difficulty. Routine clinic visits are perceived as offering good support, but owing to impoverished socio-economical circumstances are also reported as a financial difficulty. This is an indication that better access to ARV clinics is needed. The daily responsibility of taking medication, which leads to pill fatigue, was also indicated. Education regarding this responsibility of chronic medication regimes is consequently necessary.

The respondents' CD4 counts were mostly above 200 but still under 300, which could indicate that patients are still suffering from minor AIDS-related symptoms but are adhering to ART. An increase in the CD4 count serves as a strong



motivation for good adherence, as do patients' desires to be symptom-free, physically stronger and to stay alive in order to care for their families.

It has been confirmed by the findings of this research that since the advent of HAART, HIV/AIDS has been transformed into a manageable and chronic condition. However the study also confirms that ART is a complex intervention, which is accompanied by severe biopsychosocial implications, requiring near-perfect adherence to prevent the development of resistance.

7.5.3 Social

The respondents reported socio-economic problems to be the most prevalent factors. In the majority of respondents their lack of money featured strongly as a factor affecting adherence. Most of the respondents reported unemployment and their being economically dependent on either a disability grant or family support. This indicates the need for a national programme to support the unemployed. The researcher is of the opinion that food parcel programmes are not enough: people need financial support.

The researcher further confirms that poverty seriously affects the life of a person infected by HIV and impedes adherence. Poverty directly influences attendance at clinics and many other matters, indicating the need for employment-creating programmes where patients can earn while recuperating.

The findings demonstrated that patients rely strongly on ART clinics as their primary means of support and often the only form of support. Yet transport costs are still a hindrance.

As is evident from this study, respondents face serious financial problems and matters regarding social security must be addressed. The fear that the disability grant could be stopped if the CD4 counts rise above 200 seriously affects adherence. A disability grant should not be linked to a high CD4 count.



The social interlinking of HIV/AIDS and poverty is endorsed by this research empowering impoverished HIV/AIDS sufferers to adhere to antiretroviral therapy is therefore essential.

The qualitative part of the study also reported that patients require assistance in applying or reapplying for various grants such as disability-, foster-, or care dependency grants. Deficits in external systems like the bureaucratic delays in approval of grants and screening criteria constitute primary barriers according to the qualitative research. The lack of identification/ birth documents is also delaying these processes. Consequently the Departments of Home Affairs, of Health and of Social Development should work more closely together to streamline the procedures.

The findings reveal further that respondents reported clinic staff and daily medication charts, as supplied by the Tshwane clinic's pharmacist, and their family as major forms of support. Patients prefer to visit a specialized ART clinic, rather than a local clinic, for support, as they fear a lack of confidentiality and discrimination in their own areas. They also assume that medical treatment in urban areas is better than that available in rural treatment centres. This is a contraindication as a need for greater accessibility to ART clinics and lower transport costs are indicated, yet patients prefer to travel further to urban clinics.

Other social factors include a lack of family support, and of interest in support groups: the researcher attributes the latter to the conspiracy of silence surrounding sexual matters in most cultures and the lack of a governing body to control support structures. The researcher is also of the opinion that owing to the sensitive issues related to HIV/AIDS/ART, the respondents are not motivated to be part of a support group. In the present study, such groups were not indicated as being of any significant influence as far as adherence is concerned. Thus the focus in counselling should fall on family support.

As already mentioned, the majority of respondents who participated in this study were single women, unemployed and financially dependent on a grant or family support. Hence disclosure is not always possible for the following reasons:



respondents are not in stable relationships; they have no contact with the person who has infected them; they are in new relationships and they do not want to disclose their status as they fear discrimination, abandonment, loss of financial support and / or income. The researcher is therefore of the opinion that non-disclosure should not exclude patients from ART. The buddy system should be re-evaluated. Respondents reported that they disclosed mainly to family members, which could also be attributed to the fact that respondents are single, and only have relatives to disclose to. Most respondents were forced by factors beyond their control such as the appearance of symptoms or deterioration in health, or a lack of productivity, to disclose their status and achieve critical support from family members. Supportive stable relationship is, however, indicated for good adherence.

The request for a buddy to accompany a patient as in the guidelines, is also undermined by the fact that patients are single and just do not have anybody to bring to the clinic as a treatment buddy – for example patients who work in an urban area but whose family lives in a rural area. Such patients are not willing to disclose their status to employers. To require the company of a buddy/or family member who is not living with them and supporting them does not serve any purpose. Furthermore, there are patients who can take medicine responsibly and simply do not need a buddy. The researcher is of the opinion that to demand a buddy, against the patient's will, is discriminatory. The equality clause of the Constitution of South Africa (Act 108 of 1996) as well as the National Health (Act 61 of 2003) makes it illegal to discriminate unfairly against any person. "The right to equality is violated whenever a person is treated differently in a way that is unfair discrimination." (HIV/AIDS and the Law, 2001:70). No other diagnosis requests a buddy before treatment is given.

Devices such as pillboxes do not seem to be popular, although respondents report that cell phones can be used as a reminder to enhance adherence.

More than half of the respondents indicated that they are sexually active, further mainly reporting using condoms for contraception and / or safe-sex practices. Confusion regarding safe sex still prevails: some patients still perceive methods



such as hormonal contraception as a safe-sex method. The researcher is of the opinion that abstinence is not an appropriate alternative to promote as a method of safe sex, since sexual behaviour is part of basic human needs and is not always a planned deed but is based on emotions and linked to specific circumstances. Respondents further reported an increase in sexual drive, which could be contributed to the above-discussed improvement in quality of life. Thus safe-sex practices should be addressed in all adherence counselling.

From the above it is evident that social work interventions need to be altered, supporting millions of HIV/AIDS/survivors now living with a chronic disease.

7.5.4 Psychological

Respondents reported that the major motivations for receiving ART were to stay alive and be symptom-free (related to quality of life), as well as wanting to take care of their children and see them grow up. The researcher is of the opinion that whatever the person's motivation for ART, it will be one of the strongest determinants for adherence.

The research has further indicated that the majority of respondents do not report a particular need for counselling, and in the researcher's opinion will not do so until they have their basic human needs met.

It is evident from the qualitative research in particular that there is a general problem regarding counselling services. Trained, skilled and experienced counsellors, who can deliver a comprehensive service, are called for, and the Department of Health places a high priority on counselling, but there is little monitoring, training and support of such people. The public service should start turning this situation around by being both a guardian of standards and an advocate of the committed support structure. Lay counsellors in the public sector specifically are not employed, receiving a stipend, are often living with HIV themselves and receive minimum training.



The researcher argues that in the recruitment of counsellors, universal standards regarding education and the motivations for their involvement, specifically in HIV/AIDS matters, should be laid down since people in such a position of responsibility, regarding patients' most intimate circumstances, should be governed by high standards. These, if implemented by a regulator, might increase confidence in counselling services.

Counsellors further indicated that they are not valued, and that this affects their morale.

It was felt that knowledge, training and experience is essential for effective service provision to traumatized individuals, groups and communities and to deal with ethical issues surrounding HIV/AIDS issues. The need for the social work profession to render a comprehensive service was strongly indicated.

Regarding their quality of life the majority of respondents expressed satisfaction with their current circumstances. A remarkable number reported positive feelings or results such as that their health had improved drastically on ART and that they have regained lost roles. The researcher concludes that physical improvement leads to psychosocial improvement and thus in general to improvement of quality of life.

7.6 Recommendations

Based on the above conclusions, the following recommendations are proposed, directed at the 3 main categories in adherence issues namely: provider, patient and regimen.

7.6.1 Recommendations focused on the provider

7.6.1.1 Recommendations regarding Government guidelines

The researcher considers that the *Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment accepted during November 2003* (2003:4), which guides the treatment of



HIV/AIDS patients in South Africa, is very comprehensive and makes provision for various aspects, but the following further recommendations are proposed:

Guidelines should be evaluated and updated regularly at least annually to remain appropriate, effective and relevant as well as to keep up with the latest research.

Provision must be made for individual circumstances. The researcher is of the opinion that it is discriminating to demand certain behaviour before treatment can be initiated. These demands include: patients disclosing their status; patients to bring a buddy or support person; the need for multiple visits before initiating, ART; the requirement that identification documents be produced. This is contraindicated by the Equality and Prevention of Unfair Discrimination Act (2000) and contravenes The Bill of Rights in the Constitution of the Republic of South Africa (Act, No 108 of 1996).

7.6.1.2 Recommendation regarding closer co-operation between service providers

Closer co-operation between the Departments of Home Affairs, Health, and Social Development is called for. People in need of ART do not have the time (3-6 months) to wait for legal documents. The rapid issuing of emergency identification documents for medical reasons, or in order to obtain a grant, is crucial. Financial support is an essential requirement and may enhance adherence to ART.



7.6.1.3 Recommendation regarding equal standards of care for HIV/AIDS patients on antiretroviral therapy

Patients do not receive equal standards of care at treatment facilities. There are no standard assessment criteria prior to initiating patients for ART. Hence these are necessary and should be applied uniformly within the private as well as the public sector in order to facilitate ease of migration of patients between hospitals and clinics, in rural as well as urban areas. Training programmes should also conform to common standards.

7.6.1.4 Recommendations regarding education

Recommendations focusing on men

These findings further call for education and information programmes regarding ART, specifically targeting men: workplace programmes, or male wellness clinics are required. There are no active case findings for men which would provide similar results to findings regarding PMTCT programmes for woman. Such a clinic could perhaps be attached to an antenatal clinic. The researcher is of the opinion that for every pregnant woman there is at least one sexually active man who could be actively involved or enrolled at such a “male wellness clinic”.

Recommendations regarding education focusing on woman

The importance of preventing the spread of HIV infection is crucial. The research has indicated that women are still the more vulnerable group. Prevention strategies should aim at improving life skills and awareness, specifically in terms of empowering people regarding health and safe sex issues. Teenagers and young females should also be targeted. Patients still harbour the idea that using a contraceptive pill constitutes safe sex – education should counteract this fallacy.

7.6.1.5 Recommendation regarding social grants

The state shoulders the responsibility, underpinned by section 27(1) (c) of the Constitution, to provide social assistance in the form of grants for varying levels of need. Studies have demonstrated that households affected by HIV/AIDS are



significantly poorer than non-affected households. This study has reflected the complexity of socio-economic issues and their influence on adherence to ART.

While high levels of poverty and unemployment are manifest, access to social grants is hindered by issues such as eligibility, violations of dignity, and bureaucratic red tape, in particular the lengthy period between applying for and receiving the grants. This issue has been formulated in various documents and policies, on the national and provincial levels, but still needs to be addressed in the broader context of HIV/AIDS and access to ART.

Recommendations regarding disability grants

The researcher recommends a definite guideline regarding disability grants for persons suffering from HIV/AIDS. There should be uniformity regarding who is eligible for the grant, with clearly defined criteria, as well as concerning when it should be reviewed. The medical report which must be completed for the disability grant exhibits shortcomings as regards HIV/AIDS patients, especially HIV/AIDS patients on ART.

The use of the CD4 count, as a benchmark for the purpose of determining physical impairment in order for patients to access grants, is problematic and counter-indicated for adherence to ART. The fear that the grant, usually the only means of income, will be stopped when the CD 4 count is above 200 was evident in this study. The researcher recommends that the definition of disability be changed in the light of HIV.

Recommendations regarding social relief

The Department of Social Development's role in offering sustainable programmes and / or developmental projects and activities to address poverty and unemployment issues should receive priority. All patients receiving grants could be enrolled in skills development / or entrepreneurship training programmes or community projects prior to the termination of the grant. Various other forms of social relief, such as food parcels or coupons, are not successfully implemented at the grassroots.



The grant-in-aid (an extra amount) for which patients could apply for, if they already receive a grant, but need full-time care from someone, needs to be extended to include HIV/AIDS positive individuals, who is dependent on support, regarding adherence.

Recommendation regarding care dependency grant

The care dependency grant (focusing on children with special needs and disabilities) could be extended to include HIV/AIDS children on ART. The researcher contends that the cost (symptom control, transport, nutrition and medication) incurred to maintain a child successfully on ART warrants the inclusion of such children in this grant. This will promote treatment and adherence to ART.

7.6.1.6 Recommendation regarding social structures

Greater availability of, and easier access to foster-care or a place of safety will also encourage better adherence to ART. Caregivers of HIV/AIDS children/orphans are not always aware of these resources.

The researcher holds the view that child-headed households should not exist. The reality of AIDS is that children are caring for the sick and assuming adult responsibilities. All children without care, according to the Child Care Act (74 of 1983), should be placed in substitute care. This includes children orphaned as a result of HIV/AIDS.

The Constitution and the said Act (1983) and the new Children's (Act 38 of 2005) (not yet in force), makes provision for children to be cared for. According to section 28 of the Bill of Rights of the Constitution (1996), "every child has the right to family care or parental care, or to appropriate alternative care when removed from the family environment, to basic nutrition, shelter, basic health care service and social services to be protected from maltreatment, neglect, abuse or degradation." This is often overlooked in children's matters, especially regarding HIV/AIDS.



7.6.1.7 Recommendations regarding the multidisciplinary team members involved in antiretroviral adherence issues

HIV/AIDS and antiretroviral issues, specifically adherence to antiretroviral therapy, are dynamic in nature. There is a need for on-going assessments and the training and support of the multidisciplinary team. The Government ARV training programmes regarding antiretrovirals should be extended to include all parties involved in ARV and to make provision for newly appointed staff. Ongoing training programmes are essential.

Recommendations focused on the social work profession

The social work profession needs to take responsibility for psychosocial services, education and training regarding HIV/AIDS. Social workers' specialized knowledge, skills and training cause them to be the most suitable profession to deal with all psychosocial issues regarding HIV/AIDS.

Social workers need to define their role clearly and claim their rightful place in the rendering of service to HIV/AIDS patients. Patients do present with various psychosocial problems, some of which involve work regulated by statute. This can only be performed by registered social workers and not lay counsellors.

The social work profession should also be actively involved in making available prevention strategies, education, training and policy development to different stakeholders on all levels. The profession could also develop more training programmes and actively participate in the training of other professions and lay counsellors as well as in policy development. The social work profession, with its specialized skills regarding human interaction, should become actively involved in the supervision of counsellors.

The dissemination of basic social work skills, knowledge and attitudes to other lay and professional team members is recommended. It is each social worker's obligation to ensure that a portion of his/her role involves an education and training component, but as yet there are many graduate and postgraduate



social workers with various inadequacies in their skills, knowledge and attitudes regarding HIV/AIDS and ART matters.

Recommendations regarding counsellors

Lay counsellors are rendering very valuable services to HIV/AIDS patients. There is a dire need to improve these counsellors' working conditions as well as skills. Formal or in-service training is proposed for them.

The researcher is strongly of the opinion that a workforce regulator of counsellors is necessary to protect the public, promote high standards of practice and build professional credibility. This will accord increased status to the workforce, which should lead to improved recruitment, retention and morale and to the overall raising of standards. Universal standards will culminate in better services for the people in need of counselling.

It is recommended that lay counsellors, being in a position of responsibility, be placed on a nationwide register; adhering to universal standards could increase confidence in the services that they provide. This will demonstrate to others their commitments to high standards, abilities and skills and could guard against malpractice or abuse.

Such standards could include: Physical and mental fitness; good character; qualifications; training and agreeing to a code of conduct. Patients and families along the HIV continuum require constant and in-depth counselling, the goal of which is to impart accurate information that empowers patients and families to make informed decisions and also mobilizes adequate mechanisms of support and adaptation for these people to cope with multiple biopsychosocial problems and stressors.

Recommendations regarding community support and NGO's

The research findings indicated that formal clinics and support structures are important but the lack of social support was highlighted in this research.



There is no confidence in most support groups. Support groups are not perceived as consistent and their credibility is questioned. As with the counselling services a workforce regulator is proposed to protect the public, promote high standards of practice and reinforce credibility. There are many organizations dotted around the country with similar aims in supporting people affected by HIV/AIDS, and all of them need to be coordinated. Until they are, there will invariably be conflicting and contradictory messages.

As a result the researcher recommends a National AIDS Support Front, where all NGOs and support groups are part of a nationwide register and adhere to set standards; before being affiliated their credentials should be assessed. This could increase confidence in the services that are provided. Furthermore the country can no longer afford the mismanagement of funds directed at alleviating HIV/AIDS suffering and poverty.

Closer networking with NGO's and better utilization of their services may be beneficial and they could contribute to the reinforcement of adherence by means of home visits, thus supporting patients. By utilizing NGO's the workload of social workers could be shared and relieved.

Recommendation regarding support from religious and spiritual denominations

As most respondents are part of some religious or spiritual community, churches are urged not only to respond to the burden of HIV/AIDS individuals, but also to the challenges of motivating and supporting people regarding treatment. These institutions could become more involved in promoting stable relationships, be more visible and take part in policy development and programmes, for instance through public and public statements.

7.6.1.8 Recommendations re adjustment of salaries in the public sector

The public service and, more specifically, the Department of Health is steering the ART programmes. Within the HIV/AIDS directorate, public servants in managerial positions are earning salaries in excess of R300 000.00 per year.



Social workers, and pharmacists who are primarily responsible for adherence counselling and support, earn salaries less than R90 000 a year. Lay counsellors are not officially employed and only receive a stipend of R12 000 a year (R1 000.00 per month). If the government wishes to see these programmes succeed, it should adjust salary structures more fairly. Employees at the grassroots, who are responsible for doing the actual work, should be sufficiently remunerated.

Millions of rands worth of foreign currency are being donated for HIV/AIDS causes in South Africa. A portion of this money could be used to attract and retain experienced, dedicated people to work in the field of HIV/AIDS. For example, employees could receive an incentive to be willing to do so.

7.6.1.9 Recommendations regarding the faces of AIDS in South Africa

The researcher is of the opinion that the face of AIDS, specifically in the public sector (public servants), should be multiracial and not primarily be represented by one race as is prevalent. This fuels the perception that AIDS is an illness suffered by certain population groups.

7.6.2 Recommendations regarding patient factors

Assessment of HIV/AIDS patients' biopsychosocial circumstances

The researcher recommends the use of a standard biopsychosocial assessment schedule to include all criteria to be evaluated. Such a schedule was developed as part of this research and is attached as Appendix 7.

The social worker could lead, but at least should be actively involved in assessing patients for adherence to ART and not leave this to lay counsellors and other members of the multidisciplinary team.

Patients must be educated to take responsibility for their own wellness. The perception that "the Government must do something" about individuals' choices and behaviour must be challenged. Education should incorporate emotions and sexual needs, life skills and informed decision-making. Educational



programmes focusing on intellectual decisions should be complemented by education focusing on peoples' emotions and basic needs, since sexual behaviour is not primarily a cognitive decision.

7.6.3 Recommendations regarding regime factors

Recommendations regarding adherence education

Mass campaigns should be launched. The community must be educated about antiretroviral treatment and the importance of adherence to ART. Coupled to the above is the necessity of educating the public in general about pill-taking, about adherence in general to medication and specifically to chronic medication. A culture of general adherence to dose regimens should be campaigned for.

Recommendations regarding the responsibility of the pharmaceutical profession

The pharmacist should take responsibility in counselling and supporting patients regarding adherence to ART treatment, for instance by supplying information leaflets to accompany instructions to patients regarding taking their medication, and the side-effects and contra-indications of ART.

Treatment awareness should be included in all educational activities. The Department of Education could consider running clinics at schools. With such clinics, a culture of health education and awareness could be developed from a young age. Pharmacists should take responsibility for educating children regarding their medication.

7.6.4. Recommendations regarding future research

The social work profession should carry out more research into improving their profession's involvement in rendering services to HIV/AIDS patients, specifically regarding prevention, educating and training. The researcher strongly believes that the social work profession should have been in the forefront in this field. Yet this profession has up to now taken a back seat to lay counsellors, PWA's and AIDS activists - who lead the field in rendering service to the HIV



community. The researcher is of the opinion that this situation should be challenged by the social work profession. Undergraduate training is an appropriate place to introduce prospective social workers to deal with the greater involvement of multidisciplinary teams in HIV/AIDS matters.

Continued research is needed within South African social work to measure attitudes towards and knowledge of various aspects of sexuality, by virtue of its central role in the transmission of HIV, adherence to medication and HIV/AIDS matters. Results would provide insight into the way the profession is confronting the challenges of HIV/AIDS and suggest what still needs to be done so as to meet the new challenges of millions of people living on ART. Social workers are in danger of themselves becoming victims of the abolition of the social work profession or at least seeing their jobs being passed on to others in the field who will provide what the market demands (Phillips & Waterson, 2002:183).

Also recommended are the development of relationships between the social worker and the other professional and lay workers in the field of HIV/AIDS. Social workers are urged to become mentors and to strengthen networks.

Further research regarding motivations, needs and quality of life as indicators of adherence to medication, specifically focused on the South African situation, is recommended.

Future research regarding behaviour change and educating people regarding sexual behaviour, a basic human need, is also called for.

Further research by pharmaceutical companies to improve antiretroviral medication, focusing on pill burden, toxicity and side effects, is also necessary.



7.7 Closing Remarks

Recommendations were made in this chapter to address some of the issues identified, which include legislative and policy changes in order to improve socio-economic difficulties.

An intensified effort is required from social welfare services, and in particular the Department of Social Services and Development in conjunction with the Department of Health and Department of Home Affairs, regarding legal documents and material support, and the improvement of all social support and social relief programmes to meet the specific needs of HIV/AIDS adults and children on ART. Specifically, the medical criteria for obtaining disability grants should be reviewed.

Increased awareness campaigns and access to ART medication have been recommended, as well as improvements in counsellors' working environments, training and possibly registration. The social work profession is urged to take up the psychosocial challenges of HIV/AIDS patients and become leaders in the field of service rendering.

The high rate of HIV/AIDS infection calls for an integrated and coordinated response to the epidemic. The South African government is leading by example through its commitment to a multi-sectoral approach, working closely with a range of government departments, business community and NGOs. The government has at many levels attempted to address this epidemic through the South African National AIDS Council (SANAC), comprising the Minister of Health, provincial ministers of health and provincial and local government AIDS councils. The broad framework for HIV/AIDS and the STI strategic plan for South Africa 2007-2011, which represents the country's multi-sectoral response to the challenge of HIV infection and the wide-ranging impact of AIDS (South Africa, 2006) have again demonstrated the government's commitment to tackling the HIV/AIDS pandemic.



From the researcher, the following final remark: *The Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment accepted during November 2003* (2003:4) is one of the most comprehensive treatment programmes in the world. It has shown commitment by the government but the final responsibility to adhere to treatment still lies with the individual. People should be empowered to make informed decisions about their lives and social workers should play a more active role in HIV/AIDS matters.



REFERENCES

- Abdool Karim, S.S. & Abdool Karim, Q. 2005. *HIV/AIDS in South Africa*. Cape Town: Cambridge University Press.
- Ajemianh, I. 1999. In Doyle, D., Geoffrey, W.C., Hanks, W.C. & Macdonald, & Macdonald, N. *Oxford textbook of palliative Medicine*. Oxford: Oxford University Press.
- Alpaslan, A.H. & Mabutho, S.L. 2005. Caring for AIDS orphans: The experiences of elderly grandmother caregivers and AIDS orphans. *Social Work*, 41(3): 276-295.
- American Psychiatric Association. 1994. *Diagnostic and Statistical Manual of mental Disorders (DSM IV)*. 4th ed. Washington DC: American Psychiatric Association.
- Anderson, J. 2000. *A Guide to the clinical care of woman with HIV*. USA: U.S. Dept of Health and Human Services.
- Apollo, A., Golub, S.A., Wainberg, M.L. & Indyk, D. 2006. Patient provider relationship, HIV and adherence: requisites for a partnership. *Social work in Health Care*. Vol. 42, (30): 209-224.
- Arkava, M.L. & Lane, T. A. 1983. *Beginning Social Work Research*. Boston: Allyn and Bacon.
- Babbie, E & Mouton, J. 1998. *The practice of Social Research*. California: Wadworth Publishing Company.
- Baran, R.A., Byrne, D. & Branscombe, N.R. 2002. *Social Psychology*. 11th. ed. New York: Pearson.



Barker, R.L. 1991. *The Social Work Dictionary*. 2nd ed. United States of America: NASW Press.

Bartlett, J.G. & Gallant, J. E & Joel. 2005. *2005-2006 Medical Management of HIV Infection*. USA: Johns Hopkins Medicine Health Publishing Business Group.

Bless, C. & Higson-Smith, C. 1995. *Fundamentals of Social Research Methods: An African perspective*. 2nd Ed. Cape Town: Juta & Co, Ltd.

Botes, M.E. & Levay, P.F. 2004. The management of HIV: A practical Approach. *Family Practice*, 46(2): March: 13-20.

Botes, M. E. 2005. Interview with Dr. Mariette Botes. General Physician specializing in HIV/AIDS. [Transcript]. November 2005. Pretoria.

Boyer, A., Indyk, D. 2006 *Shaping Garments of Care: Tools for Maximising Adherence Potential*. *Social Work in Health Care*. Vol. 42, (3) 151-166.

Brannon, R. & Feist, S. 1992. *Theories of Personality*. 3rd Ed. Fort Worth: Harcourt Brace College.

British HIV Association (BHIVA) / British Association for Sexual Health & HIV (BASHH). 2003. *Guidelines on provision of adherence support to individuals receiving Antiretroviral therapy*. United Kingdom: Poppa, A.; Davidson, O.; Deutsch J.; Godfrey D.; Fisher M.; Head S., Horne R. & Sherr L. Anna Poppa, annapoppa@tiscali.co.uk

British HIV Association (BHIVA) 2005. *Treatment guidelines for 2005*. Available: <http://www.bhiva.org/guidelines/2005/BHIVA-guidelines>. Accessed on 2007/02/10.



Brouard, P. 2005. Interview with Pierre Brouard, Director of the Centre for the Study of AIDS, University of Pretoria. [Transcript]. November 2005. Pretoria.

Cabrera, D., Pitt, D. & Staugard, F. 1996. *AIDS and the Grassroots: Problems, challenges and opportunities*. Nairobi: Ipelegeng Publishers.

Centre for Disease Control and Prevention. 1993. George Washington University. 1993. Washington: Medical Center.

Centre for Health Policy Research, George Washington University. 1999. Washington: Medical Centre.

Chesney, M. 1997. Compliance. *HIV Newslines*, 3(3) 1-9.

Childs, J. & Cincotta, N. 2006. Pediatric HIV Adherence: An ever-evolving challenge. *Social Work in Health Care*. Vol 42, (3): 189-208

Cockerham, W.C. 2001. *Medical Sociology*. 8th ed. New Jersey: Prentice Hall, Upper Saddle River.

Concise Oxford Dictionary. 1995. 9th ed. Oxford: Clarendon Press.

Cournoyer, B. 2000. *The social work skills workbook*. 3rd ed. United States of America: Wadsworth Publishing Company.

Cowles, Fort, L.A. 2000. *Social work in the Health Field: A care perspective*. New York: The Haworth Press.

Davidson & Clarke 1990. *Social work in Health Care: A Handbook for Practice Part II*. New York: The Haworth Press.

Delpont, C.S.L. & Strydom, H. 2002a. Quantitative data collection methods. In De Vos, A.S. (Ed.), Strydom, H., Fouche, C.B. & Delpont, C.S.L. *Research at*



Grass Roots: for the social sciences and human service professions. 2nd ed. Pretoria: Van Schaik Publishers.

Dennill, K., King L. & Swanepoel, T. 1995. *Aspects of Primary Health care*. Halfway House: Thomson Publishing Company.

Dennill, K., King L. & Swanepoel, T. 1999. *Aspects of Primary Health care*. Halfway House: Thomson Publishing Company.

De Vita, V.T., Jr. Hellman, S. & Rosenberg, S.A. 1997. *AIDS Etiology, Diagnosis, Treatment and Prevention*. Lippincott: Raven.

De Vos, A.S. (Ed.), 1998. *Research at Grass Roots: A primer for the caring professions*. Pretoria: Van Schaik.

De Vos, A.S., Fouche, C.B., & Venter, L. Quantitative data analysis and interpretation. In De Vos A.S., Strydom, H., Fouche C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*, 2nd ed. Pretoria: JL Van Schaik Publishers.

De Vos, A.S. (Ed.), Combined quantitative and qualitative approach. In De Vos A.S., Strydom, H., Fouche C.B. & Delpont C.S.L. 2002b. *Research at Grass Roots: For the Social Sciences and Human Service Professions*, 2nd ed. Pretoria: Van Schaik Publishers.

De Vos, A.S. Qualitative data analysis and interpretation. 2002c. In De Vos A.S., Strydom, H., Fouche C.B. & Delpont C.S.L. *Research at Grass Roots: For the Social Sciences and Human Science Professions*, 2nd ed. Pretoria: Van Schaik Publishers.

De Vos, A.S. and Schulze, S. 2002. The sciences and the professions. In De Vos A.S., Strydom, H., Fouche C.B. & Delpont C.S.L. *Research at Grass Roots: For the Social Sciences and Human Service Professions*, 2nd ed. Pretoria: JL Van Schaik Publishers.



Dorland's Illustrated Medical Dictionary. 1994. 28th ed. Philadelphia: W.B. Saunders Publishers.

Ellis, A.E., Gogel, R.P., Roman, B.R., Watson, J.B., Indyk, D. & Rosenberg, G. 2006. The STARK Study: A cross-sectional study of adherence to short-term drug regimens in urban Kenya. *Social Work in Health Care*. Vol. 42. (3/4): 237-250.

Engel, G.L. 1980. The clinical application of the bio-psycho-social model. *American Journal of Psychiatry*, 137: 535-544.

Evian, C. 2000. *Primary Aids Care: A practical guide for primary health care personnel in the clinical and supportive care of people with HIV/AIDS*. South Africa: Jacana.

Fouche, C.B. 2002a. Problem formulation. In De Vos A.S. (Ed.), Strydom, H., Fouche C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*, 2nd ed. Pretoria: JL Van Schaik Publishers.

Fouche, C.B. 2002b. Selection of a researchable topic. In De Vos A.S. (Ed.), Strydom, H., Fouche C.B. & Delpont C.S.L. *Research at Grass Roots: For the Social Sciences and Human Service Professions*, 2nd ed. Pretoria: JL Van Schaik Publishers.

Fouche, C.B. 2002c. Research strategies. In De Vos A.S. (Ed.), Strydom, H., Fouche, C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*, 2nd ed. Pretoria: JL Van Schaik Publishers.

Fouche, C.B. 2002d. Writing the research proposal. In De Vos A.S. (Ed.), Strydom, H., Fouche C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: JL Van Schaik Publishers.



Fouche, C.B. & Delpont, C.S.L. 2002. Introduction to the research process. In De Vos A.S.(Editor), Strydom, H., Fouche, C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*, 2nd ed. Pretoria: JL Van Schaik Publishers.

Foundation for Professional Development. 2004. *Adherence to ART*. Pretoria: [sn].

Foundation for Professional Development. 2005. *Adherence counselling for ART*. Pretoria: City Bridge.

Foundation for Professional Development: 2006. *Adherence*. Pretoria: City Bridge.

Friedland, G. 2003. Adherence to Highly active antiretroviral therapy. *South African Journal of HIV Medicine*, March (7): 35-40.

Germain, C.B.1984. *Social Work practice in Health Care: An ecological perspective*. New York: The Free press

Gerntholtz, L. 2003. An Overview of some of the key legal Developments in HIV/AIDS and the Law. *South African Journal of HIV Medicine*, March 3(1): 15.20.

Ghood, C. 2005. Interview with Dr. Ghood, Physician in Private Practice & Consultant at Tshwane District Hospital. [Transcript]. 10 October. Pretoria.

Golub, S.A., Indyk, D. & Wainberg, M.L. 2006. Reframing HIV adherence as part of the experience of illness. *Social Work in Health Care*. Vol 42, (3): 167-188.



Gray, G., Morris, L. & McIntyre, J. 2002. MTCT Regimen Choice, Drug resistance and the treatment of HIV-1-infected Children. *Southern African Journal of HIV Medicine*, 10(9): 5-8.

Gray, M. 1996. Towards an understanding of developmental social work. *Social Work Practice*. March: 9-48.

Greeff, M. 2002 Information collection: Interviewing. In De Vos A.S. (Ed.), Strydom, H., Fouche, C.B. & Delport C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: Van Schaik Publishers.

Green, J and Shellenberger, R. 1991. *The dynamics of health and wellness: A Bio-psychosocial approach*. Fort worth: Holt, Rinehart and Winston, Inc.

Grinnell, R.M. & Williams, M. 1990. *Research in Social Work: A primer*. Illinois: F.E. Peacock Publishers.

Grinnell, R.M. 1993. *Social Work Research and Evaluation*. 4th ed. Itasca Illinois: F.E. Peacock Publishers.

Health Canada. 2000. To Share and To Learn: The Case For Canadians To Act Globally Against HIV/AIDS. Ottawa, Ontario: Health Canada.

Health Illness and Families: A life span perspective. New York: John Wiley & Sons.

Hepworth, D.H, Rooney, R.H. & Larsen, J.A. 2002. *Direct Social Work Practice Theory and Skills*. 6th ed. United States of America; Wadsworth Group.

Hippocrates. 2004. Available: <http://classics.mit.edu/Brose/browse> - Accessed on 2004/11/10.

Holy Bible: Luke 17:11 and Leviticus 13.



Horizon/Population Council International Centre for reproductive health. 2005. *Adherence to antiretroviral therapy in adults: A guide for trainers*. Mombasa: Coast Province General Hospital.

HIV/AIDS and the Law. 1997. South Africa: HIV/AIDS Law project and Lawyers for human rights.

HIV/AIDS and retroviral therapy. 2004. Luftey. Available: <http://www.who.int/hiv/en> - Accessed on 2005/08/29

Isselbacher, K.J., Braunwald, E., Wilson, J.D., Martin, J.B., Fauci, A.S. & Kasper, D.L. 1999. *Harrison's Principles of Internal Medicine*. New York: McGraw-Hill.

Jones, K. 1991. *Sociology of Health and Illness*. Cape Town: Juta & Co. Jones & Nelson, 2005 p71

Karnofsky Scale (Karnofsky index). 1940. [0]. Available: http://www.cancerbacup.org.uk/Qas/AboutcancerQAs/AllQAs/related_faqs/Qas/993:28.02.2006 - Access on 2007/04/01

Kaplan, H.I., Sadock, B.J. & Grebb, J.A. 2005. *Synopsis of Psychiatry*, 7th ed. U.S.A.: Williams & Wilkins.

Karoly, P. 1985. *Measurement Strategies in Health Psychology*. New York: John Wiley & Sons.

Kasper, D.L., Braunwald, E., Hauser, S.L., Longo, D.L., Fauci, A.S., Jameson, J.L. 2005. *Harrison's Principles of Internal Medicine*. 16th ed. New York: McGraw-Hill.

Lachman, S.J. 1989. *A second look at AIDS: The acquired Immunodeficiency Syndrome*. South Africa: Lennon Limited.



Lachman, S.J. 1995. *Heterosexual HIV/AIDS as a Global Problem*. South Africa: Natal Witness Printing and Publishing Comp. (Pty) Ltd.

Louw, D.A., Van Ede D.M., Louw, A.E. 2005. *Human Development*. 2nd ed. Cape Town: Kagiso Tertiary.

Martin, D. *The 9th European AIDS Conference. 2003*. What lessons have we learned? 25 – 29 October. Warsaw.

Mashologu-Kuse, T. 2005. The relationship between HIV/AIDS and poverty: The case of three administrative areas in the Transkei. *Social Work*, October 41(4): 378-387.

Meyer W., Moore, C. & Viljoen, H. 2003. *Personology: From individual to ecosystem*. 3rd ed. Heineman.

Mouton, J. 2001. *How to Succeed in your Masters and Doctoral Studies*. Pretoria: Van Schaik Publishers.

Mosby's Pocket Dictionary of Medicine, Nursing & Health Profession. 2002. 5th Edition. USA: Elsevierfor.

Nelson Mandela Foundation. 2005. National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey. South Africa: HSRC Press.

Neuman, W.L. 2003. *Social Research Methods - Qualitative and Quantitative Approaches*. 5th ed. United States of America: Pearson Education.

New Dictionary of Social Work. 1995. Terminology Committee of Social Work. (Eds.) Cape Town: CTP Bookprinters (Pty) Ltd.

Nkhwashu, K. 2005. Interview with Dr. Nkhwasu Director, Department of Health, HAST Unit. [Transcript], 10 October. Pretoria.



O'Brien, M. 1990. Compliance behaviour and long-term maintenance dialysis. *American Journal of Kidney Disease*. Vol XV: 209-214.

Oxford English Minidictionary. 1999. 5th ed. United States of America: Oxford University Press.

Page, J, Louw & Pakkiri, D. 2006. *Working with HIV/AIDS*. Cape Town: Creda Communications.

Phillips, J & Waterson, J. 2002. Care management and social work: a case study of the role of social work in hospital discharge to residential or nursing home care. *European Journal of Social Work*. Vol. 5(2): 171-186

Potgieter, M.C. 1998. *The Social Work Process: Development to empower people*. Engelwood Cliffs: Prentice Hall.

Rier, D.A. & Indyk, D. 2006. Flexible Rigidity: Supporting HIV Treatment Adherence in a rapidly changing treatment environment. *Social work in health care a quarterly Journal*. Vol. 42(3/4): 137 &138.

Rizzo, V.M. & Abrams. 2000. Utilization Review: A powerful Social work role in Health Care Settings. *Health and Social Work*. Vol 25(4): 33-

Ross, E. & Deverell, A. 2004. *Psychosocial approaches to health, illness and disability*. Pretoria: Van Schaik Publishers.

Rossouw, T.M. 2005. Interview with Dr. Theresa, Clinical Head of ARV Clinic, Tshwane District Hospital. [Transcript]. 10 October. Pretoria.

Rossouw, T.M. 2006. Ethical dilemmas in an antiretroviral clinic – a narrative. *CME: The SA Journal of CPD*. Jan:16-18.



- Rossouw, T.M. 2007. *ARV clinical protocols*. Pretoria: Tshwane District Hospital.
- Roux, P. Children's Adherence to HAART. *Southern African Journal of HIV Medicine*. October (9): 2002: 34-36.
- Rubin, A. and Babbie, E.R. 1992. *Research Methods for Social Work*. California: Wadworth.
- Sabrawi, S.R., Octavery, K & MacLaren, L. 1996. *11 Steps to understanding AIDS*. Wartawan: LP3Y.
- Saloner, K. Rising to the challenge: The critical role of social workers In the fase of the HIV/AIDS pandemic. 2002. *Social Work/Maatskaplike Werk*. 38(2): 154-160.
- Sekudu, J. 2001. *Abortion: A social work Study*. Pretoria: University of Pretoria. (PhD. Thesis).
- Shannon, M.T. 1989. Health Promotion and Illness prevention: A Bio-psychosocial Perspective. *Health and Social Work*, February: 32-39.
- Sherr, L. 1995. *Grief and AIDS*. England: John Wiley & Sons Ltd.
- Schlesinger, E.G.1985. *Health Care Social Work Practice: Concepts and Strategies*. USA: Times/Mosby College publisher.
- Skidmore, R.A. & Thackeray, M.C. 1982. *Introduction to Social Work*. 3rd ed. Englewood Cliffs, New Jersey: Prentice Hall, Inc.
- South Africa. Child Care Act. 1983. (Act No. 74 of 1983). *Government Gazette*. Pretoria: Government Printer



South African Council for Social Service Professions (SACSSP) Interview with SACSSP. 2007 [Transcript]. 1 May. Pretoria.

South African HIV Clinicians Society, 2005, *Antiretroviral treatment guidelines*.

South Africa. The New Childrens' Act. 1983. (Act No. 38 of 2005). Not yet in force. Pretoria: Government Printer

South Africa Bill of Rights. Constitution of the Republic of South Africa. 1996. (Act No. 108 of 1996). *Government Gazette*, Vol. No. (3 Aug). Pretoria: Government Printer.

South Africa. Equality and Prevention of Unfair Discrimination Act. 2000. *Government Gazette*. Pretoria: Government Printer.

South Africa. Ministry of Health. 2003a. *Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment*. Pretoria: Government Printer.

South Africa. Ministry of Health. 2003b. *Full report of the joint Health and Treasury Task Team charged with examining treatment options to supplement comprehensive care for HIV/AIDS in the Public Health Sector*. Pretoria: Government Printer.

South Africa. Ministry of Health. 2004. *National antiretroviral treatment guidelines*. Pretoria: Minuteman Press.

South Africa. Gauteng Provincial Government. 2004. *Comprehensive HIV/AIDS, ARV Treatment Programme*. Pretoria: Government Printer.

South Africa. Ministry of Health. 2005. *National HIV and Syphilis Sero-Prevalence Survey of woman attending Public Antenatal Clinics in South Africa*. Pretoria: Government Printer.



South Africa. Ministry of Health: 2006. *Broad framework for HIV& AIDS and STI strategic plan for South Africa 2007-2011*. Pretoria: Government Printer.

South Africa. 2007. *HIV/AIDS and STI Strategic plan for South Africa 2007 – 2011*. Pretoria: Government Printer.

South African National Health Act, 2003 (Act 61 of 2003). *Government Gazette*. Pretoria: Government Printer.

Southern African HIV Clinicians Society Expert Committee, 2004. Pre-Art Guidelines. *Southern African Journal of HIV Medicine*, Nov 7(3): 18-31.

Spencer D.C. 2005. *The clinical Practice of HIV Medicine: A practical guide to the care of the HIV infected*. Johannesburg: Goldstream Books.

Spies, M. 1999. Die multidissiplinere hantering van die HIV/VIGS pasient: Pretoria: University of Pretoria. (MA (MW) unpublished mini-dissertation).

Spies, M. & Carbonatto. C.L. 2004. 'n Multidissiplinere benadering ten opsigte van die HIV/VIGS pasient: 'n Geneeskundige Maatskaplikewerkondersoek. *Die Maatskaplike Werk Praktisyn*, July Vol 16 (2): 153-169.

Spies, M. 2006. *Protocol for HIV/AIDS patient's adherence to ART*. Tshwane District Hospital. Pretoria: Unpublished

Steiner. HIV/AIDS and retroviral therapy. 2004. <http://www.who.int/hiv/en> - Accessed on 2005/08/29

Stoltz, A. 2005. Interview with Dr. Anton Stoltz, Specialist Physician Pretoria Academic Hospital. [Transcript]. 5 October. Pretoria.



Strug, D.L. Grube, B.A., Beckerman, N.L. 2002. Challenges and changing roles in HIV/AIDS Social Work: Implications for training and education. *Social Work in Health Care*, Vol. 35(4). 1-19.

Strydom, H. 1998. The pilot study. In De Vos A.S., Strydom, H., Fouche C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: JL Van Schaik Publishers.

Strydom, H & Delpont, C.S.L. 2002. Sampling and pilot study in qualitative research. In De Vos A.S., Strydom, H., Fouche C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*, 2nd ed. Pretoria: JL Van Schaik Publishers.

Strydom, H. 2002a. Ethical aspects of research in the social sciences and human service professions. In De Vos A.S., Strydom, H., Fouche C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: JL Van Schaik Publishers.

Strydom, H. 2002b. Information collection: participant observation. In De Vos A.S., Strydom, H., Fouche C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*, 2nd ed. Pretoria: JL Van Schaik Publishers.

Strydom, H. 2002c. The pilot Study. In De Vos A.S., Strydom, H., Fouche C.B. & Delpont C.S.L. 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: JL Van Schaik Publishers.

Strydom, H., Cronje, F.J., Roux, A.A., Strydom, C. & Wessels, C.C. 2005. Die Wisselwerking tussen MIV/VIGS en armoede: 'n Psigososiale perspektief. *Social Work*. March 2005 41(1): 63-83.

Strydom, H., & Venter 2002. *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: JL Van Schaik Publishers.



Taylor, S.E. 2003. *Health Psychology*. 5th ed. New York: McGraw-Hill Comp.

The Science of AIDS. 1989. USA: W.H. Freeman and Company.

UNAIDS. 2006. *The Joint United Nations Programme Report on HIV/AIDS Epidemic for 2006*. USA: United Nations.

University of Pretoria. 2003. *Over extended AIDS Review*. Pretoria: Centre for the Study of AIDS.

University of Pretoria. 2004. *HIV/AIDS in South Africa*. Pretoria: Centre for the Study of AIDS.

University of Pretoria. 2006. *Social Work Interventions: Individuals and Groups*. Pretoria: Content Solutions.

University of Pretoria, 2006. *Resource Pack. 2006*. Pretoria: Centre for Study of AIDS

University of Pretoria. 2007. Department of Social work and Criminology. *Introduction to Social Work. Reader for MWT 110*. Pretoria: Content Solutions.

Van Dyk, A.C. 1993. *AIDS: The Health Care Challenge: A Practical Guide for Nurses, Doctors And Health Care Professionals*. 2nd ed. Pretoria: Alteks Publishers.

Van Dyk, 1999. *HIV/AIDS Care & Care Counselling: A Multidisciplinary Approach*. Cape Town: Creda Communication

Van Dyk, A.C. 2004. *HIV/AIDS Care & Counseling a Multidisciplinary Approach*. 2nd ed. South Africa: CTP Book printers.

Van Schalkwyk, G.J. 2002. *Human Development Perspectives*. Pretoria: Content Solution Online.



Venter, W.D.F. 2005. A critical evaluation of the South African State antiretroviral programme. *Southern African Journal of HIV Medicine*, Vol 5 (3): 18-31.

Viljoen. F. 2005. *Righting stigma: exploring a rights-based approach to addressing stigma*. Pretoria: University of Pretoria.

Vourlekis, B.S. Kathleen, E and Padgett, D. 2001. *Journal of Social Work Education*. Vol 37 (1): 177.

Webster, R.D. & Barr, D. 1999. *Adherence to Highly Active Antiretroviral Therapy*. Forum for collaborative HIV Research. USA.

Westerfelt, A. 2004. A qualitative investigation of Adherence issues for men who are HIV positive. *Social Work*. Vol. 49(2): 4-12.

Whiteside, A. & Sunter, C. 2000. *AIDS: The Challenge for South Africa South Africa*: South Africa: Human & Rousseau Tafelberg.

Wilken *et al.*, 2007 p71

Woods, R. 1992. Social work responses to AIDS: A programme for social work education in South Africa Assessing risk behaviour. *Social Work/ Maatskaplike Werk*, 28(4): 3-47.

World Health Organization (WHO). 1994. *AIDS images of the epidemic*. Geneva: Unpublished.

World Health Organization (WHO). 2002. *The use of Antiretroviral Therapy: A simplified Approach for resource-constrained Countries*. Geneva: Unpublished.

World Health Organization (WHO). 2003. *Global Health-Sector Strategy for HIV/AIDS 2003-2007. Providing a framework for Partnership and Action*. Geneva: Unpublished.



World Health Organization (WHO). 2003. *Provision of antiretroviral therapy in resource-limited settings – a review up to August 2003*. Geneva: Unpublished.

World Health Organization (WHO). 2005. *HIV/AIDS*. Geneva: Unpublished.

World Health Organization (WHO). 2006. *Antiretroviral therapy for HIV infection in Adults and Adolescents in resource-limited setting: Towards Universal Access. Recommendations for a public health approach 2006 revision*. Geneva: Unpublished.

World Health Organization (WHO). 2006. *Global Program on AIDS*. Geneva: Unpublished.

Medicine guideline. 2007. [0]. Available: <http://www.medscape.com/px/px/hivscheduler> - Access on 2007/03/01

Zastrow, C. 2004. *Introduction to social work and social welfare*. USA: Thomson.

Zastrow, C. 2007. *The practice of social work, a comprehensive work text*. USA: Thomson.

Zuger, A. 1997. Adherence to highly active antiretroviral therapy. *AIDS Clinical Care*, 9(11):86/87.



APPENDIXES

Appendix 1: Permission from Faculty of Humanities Research proposal and Ethics Committee, University of Pretoria.

<p>Members: Research Proposal and Ethics Committee Dr P Chiroro; Dr L Davis; Prof C Delpont; Dr JEH Grobler; Prof KL Harris; Prof E Krüger; Prof B Louw (Chair); Prof D Prinsloo; Prof G Prinsloo; Dr E Taljard; Prof H van der Mescht; Prof J van Eeden; Prof A Wessels; Mr FG Wolmarans</p>	
<p>University of Pretoria Research Proposal and Ethics Committee Faculty of Humanities</p>	
<p>18 October 2005</p>	
<p>Dear Doctor Carbonatto</p>	
<p>Project:</p>	<p><i>The biopsychosocial factors influencing HIV/AIDS patient adherence to antiretroviral therapy (ART): a social work study</i></p>
<p>Researcher:</p>	<p>M Spies</p>
<p>Supervisor:</p>	<p>Dr CL Carbonatto</p>
<p>Department:</p>	<p>Social Work and Criminology</p>
<p>Reference number:</p>	<p>7713215</p>
<p>Thank you for the application you submitted to the Research Proposal and Ethics Committee, Faculty of Humanities.</p>	
<p>I have pleasure in informing you that the Research Proposal and Ethics Committee formally approved the above study on 6 October 2005. The approval is subject to the candidate abiding by the principles and parameters set out in her application and research proposal in the actual execution of the research.</p>	
<p>The committee requests you to convey this approval to Ms Spies.</p>	
<p>We wish you success with the project.</p>	
<p>Sincerely</p>	
<p>Prof Brenda Louw Chair: Research Proposal and Ethics Committee Faculty of Humanities UNIVERSITY OF PRETORIA</p>	