

**Experiences of long-term highly active antiretroviral treatment by adolescents  
in Tembisa, Gauteng Province**

、  
by

MUSA MASETSHABA

submitted in accordance with the requirements  
for the degree of

DOCTOR OF PHILOSOPHY

in the subject

PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

PROMOTER: DR SD MHLONGO

MAY 2016

## DECLARATION

Name: MUSA MASETSHABA  
Student number: 3087-258-8  
Degree: DOCTOR OF LITERATURE AND PHILOSOPHY

EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL  
TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

I declare that the above dissertation/thesis is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.



\_\_\_\_\_  
SIGNATURE

1 May 2016  
DATE

## ACKNOWLEDGEMENTS

I would like to declare my infinite cleverness at having completed this thesis project. However, that would be ill-advised and in bad taste, for my wife and life's chosen partner was literally the engine and fuel behind this project.

Therefore, I humbly declare my immeasurable gratitude to you my love, Mantepu Tshepo Meladi MaseTshaba. With your ever-present presence, I would have thrown the proverbial towel into the ring. You believed in me when I doubted myself. You lifted me up when I could not walk. Your name should be on the cover of this thesis. I will hold the title and keep it safe until you reach yours. We are a great team you and I. Thank you ever so much Mrs MaseTshaba.

I would also like to thank our son, Sabata Tshepiso Duma MaseTshaba, for your uncontaminated support and unknowing wisdom. You are my HERO.

Thank you Mhani, my mom, Tselane Hilda Tshabalala, for always enquiring about the graduation date. Your follow-up always reminded me never to lose sight of the goal posts. Papa, Sikheto Thomas Tshabalala, you are my therapist. You always knew just the supportive words to say when I was feeling despondent.

To the rest of the Tshabalala family, thank you for having such great vision for my life. My ancestral name, Rhangani, became the self-fulfilling prophecy that encouraged me to lead in most positive things, including, but not limited to, academic achievements. To the rest of the Masemola family, thank you for giving us the Mase of MaseTshaba, I married well.

Dr Sibusiso Dumisani Mhlongo, thank you for your supervision. Without your guidance and ever-growing supervisory skills, I would not have made it. Thank you and God bless you Dr Mhlongo.

Professor Solly Matshonisa Seeletse, '*ke lebogela dikeletso.*' Your name is a noun-turned verb; you actively advise and provide patient support. I will be eternally grateful.

This project would not have been a success without funding. I would therefore like to thank my funders during my studies. I am grateful to the Unisa Bursary, the National Institute for Social Sciences (NIHSS) and to the South African Humanities Deans' Association (SAHUDA).

I would also like to acknowledge the support of my working place, Tembisa Provincial Tertiary Hospital for allowing me to conduct my research at the hospital. Special thanks to Dr T.N. Socikwa for supportive understanding and the Masakhane Clinic for access to their personal and work spaces.

I also appreciate the services of Khomotso Bopape of Let's Edit (Pty) Ltd for editing my thesis.

My gratitude would be incomplete without the higher being, my Almighty God. Thank you God for blessing me with my worldly gifts that made this project possible. I appreciate that you placed the right people to help me navigate the journey of this doctoral research.

## ABSTRACT

Adolescence is a significant period of change in physical and psychosocial development of human beings. Being HIV positive and growing up on a dynamically multifaceted HAART treatment, adds to the complexity of adolescence. This study was aimed at exploring the nature of experiences of adolescents who are on long-term Highly Active Antiretroviral Therapy (HAART) in Tembisa, Gauteng province. The study is based on a qualitative research method using in-depth semi-structured open-ended interviews and a focus group for data collection. The sample consisted of seven individual adolescent participants, three parents, guardians and caregivers, as well as 11 health care professionals. The thematic data analysis and the phenomenological analysis methods were used to analyse qualitative data while descriptive statistics were used to analyse quantitative biographical data.

The study findings cover the negative and positive experiences and the perceived role of HAART treatment over a long period of time. The predominant themes identified from adolescent participants were disclosure of HIV positive status and the stigma surrounding a positive status, early childhood experience of parental death, challenges of taking HAART treatment, factors influencing adherence and non-adherence to HAART treatment, and lastly, the impact of religion on HAART treatment adherence. The findings suggest that adolescents who are on HAART treatment over an extended period of time experience drug fatigue. Drug fatigue has far-reaching implications for the health of an adolescent, as it has a higher likelihood that poor adherence or even complete refusal to take HAART treatment will occur. Poor adherence or refusal to take HAART treatment will most likely lead to cross infection and further spread of HIV and AIDS.

A recommendation was made to include the establishment of a youth and adolescent-friendly centre by the hospital – one that is designated for the provision of tailored adolescent services and sensitive to adolescent developmental stages so as to minimise the likelihood of infected adolescents falling through the health care cracks. The introduction of a hospital-based school, an education unit run by dedicated and qualified facilitators focusing on aiding hospitalised learners with catch-up scholarly programmes, was a further recommendation. It was further recommended that reproductive health care needs of adolescents who grow up on HAART treatment be given attention in further research.

### **Key terms:**

Adherence; Adolescent; Adolescents on HAART; Experience; HAART treatment; HIV/AIDS; HIV-Infected Adolescents; Phenomenology; Qualitative Study; Subjective; Tembisa Hospital.

## TABLE OF CONTENTS

<b>DECLARATION</b>	<b>II</b>
<b>ACKNOWLEDGEMENTS</b>	<b>III</b>
<b>ABSTRACT</b>	<b>IV</b>
<b>TABLE OF CONTENTS</b>	<b>V</b>
<b>LIST OF TABLES</b>	<b>XIV</b>
<b>LIST OF FIGURES</b>	<b>XV</b>
<b>LIST OF ABBREVIATIONS AND ACRONYMS</b>	<b>XVI</b>
<b>CHAPTER 1: BACKGROUND TO THE STUDY</b>	<b>1</b>
1.1 INTRODUCTION	1
1.2 MOTIVATION FOR THE STUDY	3
1.3 AIM AND OBJECTIVES OF THE STUDY	7
1.3.1 Aim of the Study	7
1.3.2 Objectives of the Study	7
1.4 SIGNIFICANCE OF THE STUDY	7
1.5 RESEARCH PROBLEM AND RESEARCH QUESTION	9
1.5.1 Problem Statement	9
1.5.2 Research Questions	10
1.6 STRUCTURE OF THE THESIS	10
<b>CHAPTER 2: LITERATURE REVIEW</b>	<b>12</b>
2.1 INTRODUCTION	12
2.2 HIV AND AIDS WITH REFERENCE TO ADOLESCENTS	12
2.2.1 The Psychosocial Impact of HIV and AIDS on Adolescents	16
2.2.2 The Impact of HIV and AIDS on Adolescents' Physical Well-being	19

2.2.3	The Impact of HIV and AIDS on Cognitive and Emotional Functioning of Adolescents .....	21
2.2.4	The Socio-economic Impact of HIV and AIDS on Adolescents.....	24
2.2.5	The Religious or Spiritual Impact on Adolescents Living with HIV and AIDS..	27
2.2.6	Section Synopsis .....	29
2.3	HAART TREATMENT WITH REFERENCE TO ADOLESCENTS.....	30
2.3.1	The Historical Background of HAART Treatment .....	30
2.3.2	Classes of Antiretroviral Treatment and their Mechanism of Action.....	34
2.3.2.1	Nucleoside Reverse Transcriptase Inhibitors (NRTIs).....	35
2.3.2.1.1	Zidovudine .....	35
2.3.2.1.2	Didanosine (2', 3'-Dideoxyinosine).....	36
2.3.2.1.3	Zalcitabine .....	36
2.3.2.1.4	Stavudine .....	37
2.3.2.1.5	Lamivudine .....	37
2.3.2.2	Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs) .....	37
2.3.2.2.1	Nevirapine .....	38
2.3.2.3	Protease Inhibitors (PIs) .....	38
2.3.2.3.1	Saquinavir .....	38
2.3.2.3.2	Delavirdine .....	38
2.3.2.3.3	Indinavir.....	38
2.3.2.3.4	Ritonavir .....	39
2.3.2.3.5	Nelfinavir .....	39
2.3.3	Current Trends of HAART Treatment in South Africa.....	39
2.3.4	The Goals of Antiretroviral Treatment Therapy .....	40
2.3.5	Indicators of the Effectiveness of HAART Treatment .....	42
2.3.6	Regiment Adjustment of HAART Treatment.....	42
2.3.7	Assessment of Immune Status and Viral Load.....	43
2.3.8	Section Synopsis .....	44

2.4	CONCEPTUALISATION OF ADHERENCE TO HAART TREATMENT WITH REGARD TO ADOLESCENTS .....	44
2.4.1	Measurements of Adherence to HAART Treatment .....	44
2.4.2	Factors Contributing to Adherence to HAART Treatment by Adolescents .....	49
2.4.3	Factors Contributing to Non-adherence to HAART Treatment by Adolescents... .....	50
2.4.4	Section Synopsis .....	57
2.5	EXPERIENCES OF PARENTS AND CAREGIVERS CONCERNING THE ADOLESCENTS' HAART TREATMENT .....	58
2.6	EXPERIENCES OF HEALTH CARE WORKERS WITH REFERENCE TO THE ADOLESCENTS' HAART TREATMENT .....	60
2.7	CHAPTER RÉSUMÉ .....	63
<b>CHAPTER 3: THEORETICAL ORIENTATION .....</b>		<b>64</b>
3.1	INTRODUCTION .....	64
3.2	THEORETICAL MODELS.....	65
3.3	THE HEALTH BELIEF MODEL .....	66
3.3.1	The Health Belief Model Critique.....	74
3.3.1.1	Strengths of the HBM.....	74
3.3.1.2	Limitations of the HBM.....	74
3.4	THE BIO-PSYCHOSOCIAL MODEL .....	75
3.4.1	The Bio-psychosocial Model Critique .....	80
3.4.1.1	Strength of the BPS Model.....	80
3.4.1.2	Limitation of the BPS Model.....	81
3.5	CHAPTER RÉSUMÉ .....	81

<b>CHAPTER 4:</b>	<b>RESEARCH DESIGN AND METHOD.....</b>	<b>82</b>
4.1	INTRODUCTION .....	82
4.2	RESEARCH APPROACH.....	82
4.3	RESEARCH DESIGN .....	83
4.4	RESEARCH SETTING .....	84
4.4.1	Population and Sample Frame.....	84
4.4.2	Inclusion Criteria .....	86
4.4.3	Sampling.....	86
4.4.4	Sample Size .....	88
4.5	QUALITATIVE APPROACH.....	88
4.5.1	Exploration.....	88
4.5.2	Hard to Recruit Population .....	89
4.5.3	Inductive Nature of Inquiry .....	89
4.6	PHENOMENOLOGY .....	89
4.6.1	Intentionality .....	90
4.6.2	Consciousness .....	91
4.6.3	Philosophical Existence .....	92
4.7	RESEARCH PROCEDURE .....	92
4.7.1	Gaining Access to Participants .....	93
4.7.2	Privacy and Confidentiality.....	93
4.7.3	Protection of the Participants .....	95
4.8	DATA COLLECTION APPROACH.....	96
4.8.1	Informed Assent and Consent.....	96
4.8.2	In-depth Individual Semi-structured Interviews.....	97
4.8.3	Structured Questionnaires for HCPPs.....	100
4.9	DATA STORAGE.....	101
4.10	DATA ANALYSIS.....	102

4.11	MEASURES TO ENSURE TRUSTWORTHINESS.....	103
4.11.1	Trustworthiness in Qualitative Research.....	104
4.11.2	Credibility of the Interview Guides.....	105
4.11.3	Prevention of Bias.....	105
4.12	ETHICAL CONSIDERATIONS .....	106
4.13	CHAPTER RÉSUMÉ .....	106
 <b>CHAPTER 5: PRESENTATION AND DISCUSSION OF FINDINGS .....</b>		<b>107</b>
5.1	INTRODUCTION.....	107
5.2	PROFILES AND NARRATIVES OF THE ADOLESCENT PARTICIPANTS .....	108
5.2.1	Profiles of Adolescent Participants.....	108
5.2.1.1	Gender Distribution of Adolescent Participants .....	109
5.2.1.2	<i>Adolescent Participants' Ages</i> .....	110
5.2.1.3	<i>Adolescent Participants' Length of Time on HAART</i> .....	111
5.2.1.4	<i>Adolescent Participants' School Grades</i> .....	112
5.3	PROFILES AND NARRATIVES OF THE FOCUS GROUP OF ADOLESCENT PARTICIPANTS .....	113
5.3.1	Profiles of Adolescent Focus Group of Adolescent Participants .....	113
5.3.1.1	Gender Distribution.....	113
5.3.1.2	Focus Group of Adolescent Participants' Ages .....	114
5.3.1.3	Focus Group of Adolescent Participants' Length of Time on HAART Treatment .....	115
5.3.1.4	Focus Group Adolescent Participants' School Grades .....	116
5.3.2	Themes Identified From the Focus Group of Adolescent Participants .....	116
5.3.2.1	Access to HAART Treatment.....	116
5.3.2.1.1	HAART treatment initiation .....	116
5.3.2.1.2	Experiences with HAART tablets .....	117

5.3.2.1.3	Purpose for HAART treatment .....	118
5.3.2.1.4	Significance of HAART treatment .....	118
5.3.2.1.5	Challenges of HAART treatment.....	119
5.3.2.1.6	Benefits of HAART treatment.....	120
5.3.2.2	Disclosure, Stigma and Denial .....	120
5.3.2.2.1	Death of parents .....	121
5.3.2.2.2	Parents, guardians and caregivers of adolescent participants on HAART treatment .....	122
5.3.2.2.3	Coping mechanisms used by FGAPs .....	122
5.3.2.2.4	Role of religion.....	124
5.3.3	Themes Identified from Individual Adolescent Participants' Interviews .....	124
5.3.3.1	Access to HAART Treatment .....	124
5.3.3.1.1	HAART treatment initiation .....	124
5.3.3.1.2	First time experience of HAART tablets .....	125
5.3.3.1.3	Purpose for HAART treatment .....	126
5.3.3.1.4	Challenges of HAART treatment.....	128
5.3.3.1.5	Negative approach to HAART treatment.....	128
5.3.3.2	Disclosure, Stigma and Denial .....	130
5.3.3.2.1	Death of parents .....	130
5.3.3.2.2	Effect on interpersonal life .....	131
5.3.3.3	Psychosocial Support .....	133
5.3.3.3.1	Parental support for adolescent participants on HAART treatment ....	133
5.3.3.3.2	Sexual relations and condom usage while on HAART treatment .....	135
5.3.3.3.3	Role of religion in the adolescent participants' lives .....	135
5.3.3.3.4	School performance.....	136
5.4	PROFILES AND NARRATIVES OF PARENTS, GUARDIANS AND CAREGIVER PARTICIPANTS .....	137
5.4.1	Profiles of the Parents, Guardians and Caregiver Participants.....	137

5.4.2	Themes Identified with the Parents, Guardians and Caregiver Participants .	137
5.4.2.1	Access to HAART Treatment .....	138
5.4.2.1.1	Durations since initiating HAART treatment .....	138
5.4.2.1.2	Adolescents' knowledge of the HAART treatment.....	138
5.4.2.1.3	Meaning of being on HAART treatment as understood by adolescents.... .....	138
5.4.2.1.4	PGCPs' challenges about adolescents on HAART treatment .....	139
5.4.2.1.5	Challenges experienced by adolescents on HAART treatment .....	141
5.4.2.1.6	Benefits experienced by adolescents on HAART treatment .....	141
5.4.2.2	Disclosure, Stigma and Denial .....	142
5.4.2.2.1	Reaction to being told of being HIV positive.....	142
5.4.2.2.2	Mode of information delivery to adolescent regarding adolescent's status .....	142
5.4.2.3	Psychosocial Support .....	143
5.4.2.3.1	Changes of adolescents' homes .....	143
5.4.2.3.2	Peers on HAART treatment .....	144
5.4.2.3.3	Father involvement in adolescent regarding adolescent's status.....	144
5.4.2.3.4	Coping mechanisms and strategies .....	144
5.5	PROFILES AND NARRATIVES OF THE HEALTH CARE PROFESSIONAL PARTICIPANTS .....	145
5.5.1	Health Care Professional Participants' Demographic Characteristics.....	145
5.5.2	Health Care Professional Participants' Work Experiences .....	149
5.5.3	Health Care Professional Participants' Qualifications.....	152
5.5.4	Health Care Professional Participants' Specific Professions .....	152
5.5.5	Review on Closed-ended Questions .....	153
5.5.6	Themes Identified from HCPPs' Responses .....	154
5.5.6.1	Experience on Dealing with Adolescents on HAART Treatment .....	154
5.5.6.2	Stigma and Disclosure of HIV positive Status .....	155

5.5.6.3	Challenges Experienced by Adolescents on HAART Treatment .....	156
5.5.6.4	<i>Benefits Experienced by Adolescents on HAART Treatment</i> .....	158
5.5.6.5	Psychosocial Support and Coping Mechanisms.....	159
5.6	INTEGRATION AND DISCUSSION OF STUDY FINDINGS.....	160
5.6.1	Disclosure of HIV Positive Status and Stigma .....	161
5.6.2	Early Childhood Experience of Parental Death .....	164
5.6.3	Challenges of Taking HAART Treatment .....	165
5.6.4	Factors Influencing Adherence to HAART Treatment.....	167
5.6.5	Factors Influencing Non-adherence to HAART Treatment .....	168
5.6.6	The Impact of Religion on HAART Treatment Adherence .....	169
5.7	CHAPTER RÉSUMÉ .....	170
 <b>CHAPTER 6: CONCLUSION AND RECOMMENDATIONS .....</b>		<b>171</b>
6.1	INTRODUCTION .....	171
6.2	RESEARCH FINDINGS SUMMARY .....	171
6.3	LIMITATIONS OF THE STUDY .....	172
6.4	STRENGTHS OF THE STUDY .....	173
6.5	RECOMMENDATIONS FOR PRACTICE AND POLICY .....	174
6.5.1	Timely and Developmentally Appropriate Disclosure of HIV positive Status.	174
6.5.2	Establishment of a Hospital-based Education Unit.....	174
6.5.3	School Outreach Programmes by Health Care Professionals .....	175
6.5.4	Adolescent-tailored Services.....	175
6.5.4.1	<i>After-hours Appointments and Support Groups</i> .....	175
6.5.4.2	<i>Community-based Support Programme</i> .....	175
6.5.4.3	<i>Establishment of Adolescent and Youth Centre</i> .....	176
6.5.4.4	<i>Use of Technology and Social Media</i> .....	176
6.5.4.5	<i>Fixed-dose Treatment Roll-out</i> .....	176

6.6	RECOMMENDATIONS FOR FURTHER RESEARCH STUDIES .....	176
6.7	RESEARCH STUDY CONCLUSION .....	177
	<b>LIST OF REFERENCES.....</b>	<b>178</b>
	<b>APPENDIX A: REQUEST FOR PERMISSION TO HOSPITAL .....</b>	<b>205</b>
	<b>APPENDIX B: PERMISSION GRANTED TO CONDUCT RESEARCH .....</b>	<b>206</b>
	<b>APPENDIX C: ASSENT FORM .....</b>	<b>207</b>
	<b>APPENDIX D: CONSENT FORM .....</b>	<b>208</b>
	<b>APPENDIX E: INTERVIEW GUIDE FOR INDIVIDUAL ADOLESCENTS .....</b>	<b>209</b>
	<b>APPENDIX F: INTERVIEW GUIDE FOR PARENTS, GUARDIANS AND CAREGIVERS .....</b>	<b>210</b>
	<b>APPENDIX G: INTERVIEW GUIDE FOR FOCUS GROUP OF ADOLESCENT PARTICIPANTS.</b> <b>.....</b>	<b>211</b>
	<b>APPENDIX H: INTERVIEW GUIDE FOR HEALTH CARE PROFESSIONALS .....</b>	<b>213</b>
	<b>APPENDIX I: SAMPLE INTERVIEWS.....</b>	<b>215</b>
	<b>APPENDIX J: UNISA ETHICAL CLEARANCE LETTER .....</b>	<b>228</b>
	<b>APPENDIX K: LANGUAGE EDITOR’S REPORT.....</b>	<b>229</b>

## LIST OF TABLES

Table 3.1: Summary of the Concepts of the Health Belief Model Identified for the Study ....	72
Table 5.1: Adolescent Participants' Gender Distribution .....	109
Table 5.2: Adolescent Participants' Ages .....	110
Table 5.3: Adolescent Participants' Length of Time on HAART Treatment.....	111
Table 5.4: Adolescent Participants' School Grades .....	112
Table 5.5: Focus Group of Adolescent Participants' Gender Distribution.....	113
Table 5.6: Focus Group of Adolescent Participants' Ages.....	114
Table 5.7: Focus Group of Adolescent Participants' Length of Time on HAART Treatment .....	115
Table 5.8: Focus Group Adolescent Participants' School Grades .....	116
Table 5.9: Genders of Health Care Professional Participants.....	145
Table 5.10: Ages of Health Care Professional Participants .....	146
Table 5.11: Health Care Professional Participants' Work Experiences.....	149
Table 5.12: Qualifications of Health Care Professional Participants .....	152
Table 5.13: Health Care Professional Participants' Professions .....	153

## LIST OF FIGURES

Figure 4.1: Participants and Mutually Influential Relationship.....	85
Figure 5.1: Adolescent Participants' Gender Distribution.....	109
Figure 5.2: Adolescent Participants' Ages.....	110
Figure 5.3: Adolescent Participants' Length of Time on HAART Treatment.....	111
Figure 5.4: Adolescent Participants' School Grades.....	112
Figure 5.5: Focus Group of Adolescent Participants' Gender Distribution .....	113
Figure 5.6: Focus Group of Adolescent Participants' Ages.....	114
Figure 5.7: Focus Group of Adolescent Participants' Length of Time on HAART Treatment .....	115
Figure 5.8: Focus Group Adolescent Participants' School Grades .....	116
Figure 5.9: Genders of Health Care Professional Participants in Percentages .....	145
Figure 5.10: Ages of Health Care Professional Participants .....	146
Figure 5.11: Health Care Professional Participants' Work Experiences.....	150
Figure 5.12: Qualifications of Health Care Professional Participants .....	152
Figure 5.13: Health Care Professional Participants' Professions .....	153

## LIST OF ABBREVIATIONS AND ACRONYMS

<b>ADHD:</b>	Attention Deficit Hyperactivity Disorder
<b>AIDS:</b>	Acquired Immune Deficiency Syndrome
<b>ART:</b>	Antiretroviral Treatment
<b>ASSA:</b>	Actuarial Society of South Africa
<b>CDC:</b>	Centers for Disease Control and Prevention
<b>CEO:</b>	Chief Executive Officer
<b>DoH:</b>	Department of Health
<b>EFV:</b>	Efavirenz
<b>EPO:</b>	Erythropoietin
<b>FACE:</b>	FAMILY CEntered
<b>FDA:</b>	Food and Drug Administration
<b>FDC:</b>	Fixed-dose Combination
<b>FGAP:</b>	Focus Group of Adolescent Participant
<b>FTC:</b>	Emtricitabine
<b>HAART:</b>	Highly Active Antiretroviral Therapy
<b>HCPP:</b>	Health Care Professional Participant
<b>HCT:</b>	HIV Counselling and Testing
<b>HIV:</b>	Human Immunodeficiency Virus
<b>HPCSA:</b>	Health Professions Council of South Africa
<b>HSRC:</b>	Human Sciences Research Council
<b>HTC:</b>	HIV Testing and Counselling
<b>IHLC:</b>	Internal Health Locus of Control
<b>NNRTI:</b>	Non-nucleoside Reverse Transcriptase Inhibitor
<b>NRTI:</b>	Nucleoside Reverse Transcriptase Inhibitor
<b>PHIV:</b>	Perinatally HIV-infected
<b>PI:</b>	Protease Inhibitor
<b>PTSD:</b>	Post-traumatic Stress Disorder
<b>PTSS:</b>	Post-traumatic Stress Symptoms
<b>PGCP:</b>	Parents, Guardian and Caregiver Participant
<b>REACH:</b>	Reaching for Excellence in Adolescent Care and Health
<b>RNA:</b>	Ribonucleic Acid
<b>SAJHIVMED:</b>	South African Journal of HIV Medicine
<b>SSRI:</b>	Selective Serotonin Reuptake Inhibitor
<b>STI:</b>	Sexually Transmitted Infection

<b>TAC:</b>	Treatment Action Campaign
<b>TDF:</b>	Tenofovir
<b>UNAIDS:</b>	United Nations Programme on HIV/AIDS
<b>UNCRC:</b>	United Nations Convention on the Rights of the Child
<b>UNFPA:</b>	United Nations Population Fund
<b>UNICEF:</b>	United Nations Children's Emergency Fund
<b>WHO:</b>	World Health Organization
<b>YLWHA:</b>	Youth Living With HIV and AIDS

# CHAPTER 1: BACKGROUND TO THE STUDY

## 1.1 INTRODUCTION

The study focused on adolescents' experiences of the Highly Active Antiretroviral Therapy (HAART) treatment, a universally recommended aggressive medication for treating the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) (United Nations Programme on HIV/AIDS [UNAIDS], 1997). When the use of HAART treatment is inevitable, then the life of the affected individual is at stake. If at the age of adolescence the person is ailing with HIV and/or AIDS, then the chance of reaching adulthood is generally slim. According to several authors (Regnerus, Smith, & Smith, 2004; Pressley & McCormick, 2007; Simons-Morton, 2007; Rice & Dolgin, 2008; Steinberg, 2011), the first use of the term adolescence appeared in the 15th century. The term was a derivative of the Latin word *adolescere*, which means to grow up or to grow into maturity (Sigelman & Rider, 2009). Although Feldman and Elliot (1990) define adolescence as the period that extends from the age of 10 to 18 years, and it encompasses profound physical and social changes, late adolescence may occur beyond the age of 18.

Adolescence is therefore a time of significant change in human development from youth to adulthood, including physical growth and psychosocial transition, usually encompassing the second decade of life. The most common health problems of adolescents relate to growth and development, and childhood illnesses continuing into adolescence. As such, congenital HIV status usually finds expression in this period. The desire for experimentation and exploration with new behaviours is another challenge navigated by adolescents. As adolescents try new behaviours, they become vulnerable to certain conditions related to behaviours which further complicate their health status (Berkow, Beers, Bogin, & Fletcher, 1997).

Adolescence is further subdivided into early, middle and late sub-stages. Early adolescence occurs between age 10 and 14 years and is characterised by profound physical changes that occur with puberty, as maturation begins and social interactions become increasingly centred on members of the opposite sex. Middle adolescence ranges from 15 to 17 years, and it is a time of increasing independence. Late adolescence occurs between 18 and 20 years, and it occurs for those individuals who, because of educational goals or other social factors, delay their entry into adult roles (Feldman & Elliott, 1990).

HIV and AIDS is a terrible scourge. Because of HIV and AIDS and an uneven economic and political development, much of sub-Saharan Africa seems stuck in continued, widespread poverty (Badri & Bekker, 2004). The region is the epicentre of the continuing pandemic, and unfortunately, South Africa is not immune to problems affecting the rest of the African continent. Although the prevalence of the disease was somewhat smaller in 2011 than it was in 2005, in numbers, people are still dying on a large scale (Doherty & Colvin, 2004). Many are young, and as parents die, according to Ojivth and Zheng (2008), the number of orphans keeps increasing. Most of these orphans are left with the burden of HIV positive status, which they have to navigate by themselves or with minimum support (Phiri & Webb, 2002). It is within this context that the study aimed at exploring the adolescents' experiences of being HIV positive and having to grow up, literally, on HAART treatment, with its multifaceted dynamics on the growing young person.

HAART treatment is defined as a combination of at least three drugs from at least two classes: nucleoside and non-nucleoside reverse transcriptase inhibitors and protease inhibitors (Van Sighem, van de Wiel, Ghani, Jambroes, Reiss, Gyssens, Brinkman, Lange & De Wolf, 2003). Since the year 1996, the introduction of antiretroviral (ARV) drugs transformed the treatment of HIV and AIDS, improving the quality of life of those with HIV and AIDS, and greatly prolonging the lives of many infected people. Velasco-Hernandez (2002) explains that HIV is the virus that is believed to cause AIDS. On the other hand, AIDS is the collection of illnesses or symptoms that ultimately result in death (Sieleunou & Souleymanou, 2009).

HAART is the treatment that has been applied to combat advanced HIV in a bid to slow down the progression towards AIDS and ultimately to help prolong the life of the infected individual. Also, HAART is a treatment that possesses the basic medications in ARVs and has been advanced to treat a more severe stage of the HIV and AIDS progression. Adolescents form a significant part of the population receiving HAART treatment at Tembisa Hospital, thereby creating a need for special research focus aimed specifically at investigating the adolescents' experiences of HAART treatment.

## 1.2 MOTIVATION FOR THE STUDY

The study was influenced by the high rate of non-adherence to HAART treatment by the HIV positive adolescents who were taking treatment at the Masakhane Clinic of Tembisa Provincial Tertiary Hospital, in Gauteng. The researcher, who observed the non-adherence behaviour first-hand, works as a Clinical Psychologist in the hospital. Acknowledgement is made that despite the perceived high rate of non-adherence, some adolescents seemed to adhere to their treatment properly. However, there were indications that among the adolescent group, a high percentage struggled with adherence to their HAART prescriptions. As a result, they were referred to the psychology department at the hospital for intervention. Such referrals thus initiated interest in determining what influences adherence and non-adherence by adolescents on HAART treatment. The experiences of defaulting adolescents could provide enlightenment on the factors contributing to adherence and non-adherence. The factors for adherence might then be applied in order to assist adolescents struggling with treatment adherence.

The study appreciates that advancement in the medical field has given some hope to those living with HIV and AIDS for long-term survival and a better quality of life. These include the young and the old who have been on long-term HAART treatment. The primary goal of HAART treatment for children is to increase survival and decrease HIV and AIDS related morbidity and mortality. The child's CD4 count should rise and remain above the baseline count. On the other hand, the child's viral load should become undetectable (< 400 copies and ml) and remain undetectable on HAART treatment. In some children, a suppressed though detectable viral load with sustained elevation in CD4 count and absence of inter-current and/or opportunistic infection may be the best achievable goal (Department of Health [DoH], 2014). For those on HAART treatment, adherence to medication can assist in maintaining the high CD4 count and the low viral load.

At present, the majority of children are diagnosed on the basis of symptomatic HIV disease and on the positive HIV antibody test of the mother of the child. The child of an HIV-infected mother acquires HIV antibodies from his or her mother during pregnancy. These HIV antibodies may persist in an adolescent's blood until 15-18 months of age, even if the child is not infected with HIV. Thus, a child may test HIV positive without actually being infected (DoH, 2014).

The development of HAART treatment has helped turn HIV and AIDS infection into a relatively manageable, though still serious, chronic disease. Proper use of HAART treatment has been seen to lengthen life and sustain the good health of HIV patients. Hence, HAART treatment could be seen as a basis for hope of a longer and healthier life for those living with HIV and AIDS, and taking HAART treatment according to schedules and doses prescribed by professional medical and health practitioners. On the other hand, non-adherence to HAART medication for HIV and AIDS has been cited as a major problem in South African health care, resulting in high rates of relapse, hospitalisation, and mortality (Venter, 2006).

There is a shortage of literature on the experiences of adherence and non-adherence among adolescents who are on HAART treatment. For instance, research by Karamagi (2007) focused on outcomes of HAART treatment among children under six years of age. No child of this age can personally express their experiences. The study of Masokoane (2009) on adherence and non-adherence to HAART treatment focused on adults' experiences. The research displayed that both psychosocial and economic factors can positively or negatively affect adherence levels.

The Treatment Action Campaign (TAC) has created a handbook for people living with HIV and AIDS, and treatment advocates ARVs in people's lives (Geffen, 2010). This handbook describes personal experiences of people who are HIV positive and those on HAART treatment. Nonetheless, it falls short of focusing on the experiences of adolescents.

It is on record that adolescents receiving treatment comprise almost half of the patient population referred for counselling due to poor adherence to HAART treatment at the Masakhane Clinic at the Tembisa Provincial Tertiary Hospital (Isithembiso, 2011). It is assumed that positive or negative experiences of young people regarding ARV treatment differ with that of adult patients. Therefore, reasons for non-adherence will likely be unique. It is therefore important to gain insight into the nature of experiences of non-adhering adolescents separately. It is hoped that gaining insight into the experiences of long-term usage of HAART treatment by adolescents could lead to a better understanding of the factors influencing non-adherence and those affecting adherence to HAART treatment.

The HIV and AIDS endemic is severe and generally life-reducing. However, with current medical development and continuing researches, there is hope in the future for HIV and AIDS to be a manageable illness. At this point, HAART treatment has already improved the clinical status of many patients with HIV infection dramatically. The attention has been focused on the role of treatment adherence to this therapy (Turner, 2002). Adherence to

prescribed medication is necessary for the medication to be effective and to minimise the viral load and prevent drug resistance. At the same time, it is vital to get a better perspective of those taking such treatment properly and of those not adhering in order to intervene. This study finds it essential to view adherence or non-adherence from the patient's vantage point. Achieving and maintaining the health benefits of HAART treatment requires near-perfect adherence, which some of the HIV and AIDS adolescents do not achieve.

Adolescents at the Tembisa Hospital represent a clinically significant catharsis to the HIV and AIDS epidemic. This is another reason warranting further research in this area because a large proportion of HIV positive adolescents can be assisted. In addition, adolescents present an important dynamic in the long-term management of the HIV and AIDS epidemic. On that account, researching adolescents' experiences regarding HAART treatment might have significant contributions towards management of the epidemic.

Besides the Tembisa Provincial Tertiary Hospital situation, nationally, HIV positive adolescents seem to be becoming a progressively more sizeable and prominent subgroup in the South African HIV and AIDS epidemic (Lam, Seekings, & Sparks, 2006). As HAART treatment becomes increasingly available, mother-to-child infected children can be expected to survive into adolescence and then to adulthood. Additionally, sexual transmission of HIV remains a problem, and incidence and prevalence rates among South African youth are high. Experience from the developed world indicates that providing effective care and treatment for youth is a challenging task. The contribution of this study is on adherence to the HAART medications for HIV positive adolescents, with the ultimate aim of helping in the long life and good health of infected adolescents.

In light of the HAART treatment roll-out in South Africa, this study aimed to identify the experiences of adolescents growing up on treatment for HIV and AIDS in and around Tembisa Township. There has only been limited research exploring the lives of HIV positive adolescents or the ways in which the virus affects their outlook on the future. Understanding the perceptions, experiences and needs of this group is integral in order to inform policy and interventions that can help adolescents to live healthily and happily with HIV positive status. The starting point of receiving the benefits for HIV positive adolescents is to adhere to the medications prescribed, especially HAART treatment.

This study took a preliminary step towards filling the knowledge gap by reviewing existing literature and reporting on what a group of young people stated about their treatment in relation to their illness. South Africa is currently the country with the highest number of the

youngest and HIV positive adolescent people in the world (UNAIDS, 1997; WHO, 2007b). The virus affects individuals of all ages, including adolescents. According to a nationally representative 2012 Human Sciences Research Council (HSRC) survey, prevalence in 0 to 14-year-olds was 2.4%, the lowest rate of any age group (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Labadarios, Ononya & Team, 2014). This low figure was not surprising considering the fact that prior to the roll-out of HAART treatment, the vast majority of mother-to-child infected children died before reaching adolescence.

Most younger adolescents are not yet sexually active, resulting in low rates of horizontal infection. As individuals enter late adolescence and the likelihood of sexual initiation escalates, HIV prevalence rises steeply. In the HSRC survey, prevalence was 5.6% for females and 0.7% for males between ages 15-19 and 7.1% among 15 to 24-year-olds (Shisana et al., 2014), while a previous national survey measured rates of 15.5% and 4.8% in 15 to 24-year-old females and males respectively (Pettifor et al., 2005). Both studies show that adolescent females who are more biologically susceptible to contracting the virus experience higher rates of sexual abuse and are more likely to have a relationship with an older partner (Pettifor et al., 2005); they are therefore at higher risk of being sexually infected than young males. In absolute terms, South Africa also has the greatest number of people on HAART treatment. In September 2012, over 2,002,000 people were receiving HAART treatment through the public sector, 166,000 of whom were children under the age of 15 (Shisana et al., 2014).

There are no accurate statistics on the number of adolescents who are currently on or in need of treatment, as data about this population is most often subsumed into child or adult categories. However, using demographic modelling, it is possible to generate estimates of figures pertaining to adolescents. The Actuarial Society of South Africa (ASSA) has developed the ASSA2003 AIDS and Demographic Model (Davies & Kijko, 2003), which uses empirical HIV research in order to make projections about a wide range of epidemiological data. ASSA2003 can be used to estimate treatment needs and coverage for adolescents between the ages of 10 and 19 years.

When compared to the total adolescent population needing HAART treatment, the proportion of 15 to 19-year-olds needing treatment is also expected to increase, from 7% of all adolescents in need of treatment in 2008 to 22% in 2020 (DoH, 2008). This increase will be attributable to the ageing of the mother-to-child infected population, as the need for treatment in the horizontally infected population is expected to remain constant or to decline.

This study was based on the assumption that young people have the ability to speak about their experiences and are capable of contributing to the worlds in which they live. In the past, decisions about young people have been made by adults, and minors have been excluded from research. In addition to learning about the experiences of adolescents related to HAART treatment from the work of other researchers, this study explored the issue from the perspectives of young people themselves.

### **1.3 AIM AND OBJECTIVES OF THE STUDY**

#### **1.3.1 Aim of the Study**

The aim of the study was to explore the nature of experiences of adolescents who are on long-term HAART treatment in Tembisa, Gauteng province.

#### **1.3.2 Objectives of the Study**

The objectives of the study were

- to understand the adolescents' perspectives of being on HAART treatment;
- to understand experiences leading to adherence and non-adherence to HAART treatment;
- to determine factors contributing to adherence and non-adherence to HAART treatment; and
- to explore the meanings that these adolescents attach to HAART treatment.

### **1.4 SIGNIFICANCE OF THE STUDY**

The decision to study adolescents' experiences of HAART treatment was inspired by the changing nature of the global HIV and AIDS epidemic and the recognition that adolescents have distinct needs. The advent of HAART treatment has essentially transformed HIV from a fatal disease to a chronic condition. When the virus is left to its natural course, fewer than 50% of mother-to-child infected children survive beyond the first two years of life, and only a fraction are still alive at five years of age (Brahmbhatt et al., 2006; Dabis & Ekpini, 2006). However, HAART treatment has proved remarkably effective in delaying disease progression and reducing the risk of death in both adults and children (Aber & Aboulker,

1996). Hence, efforts to understand failure to adhere to HAART treatment and understanding determinants of adherence can be of benefit to long quality life.

In recent years, initiatives of groups such as the World Health Organization (WHO) have generated mounting political and financial support for treatment roll-out in resource-limited settings, resulting in a sevenfold increase in the number of individuals on HAART treatment since the year 2003 (WHO, 2004; UNAIDS, 1997; UNICEF, 2006). Because of improving treatment access, the population of mother-to-child infected children surviving to adolescence is expected to rise in the near future. HIV positive youth have been called a 'hidden population' because they tend to occupy marginalised positions in society and are difficult to distinguish from their uninfected peers (Bell, Devarajan, & Gersbach, 2003).

During adolescence, young people move from a more protected experience of childhood into a period of extremely rapid physical, psychological and social change. A successful transition into adulthood requires that the adolescents develop and practise new social skills, redefine and negotiate their places in the families, move towards adult decision-making and self-determination, and develop more mature patterns of interpersonal intimacy (McNeely & Blanchard, 2010). Unfortunately, contemporary adolescents are making decisions that can have life-threatening implications. Sexual experimentation may serve to fulfil normal developmental needs, but they can also have dire consequences, especially so for HIV positive adolescents who have been on HAART treatment. However, increased adherence to HAART treatment can offset some of the possible deadly results of HIV and AIDS.

Similar to young adults as investigated by Ijadunola, Abiona, Odu, and Ijadunola (2007), adolescents significantly underestimate risk levels in their assessment of personal vulnerability to harm. This attitude may include unprotected sexual intercourse, thereby putting them and their sexual partners at potential risk respecting the spread and reinfection of HIV. One of the important tasks that preventive efforts may need to address, therefore, is to convince adolescents that they are vulnerable while eluding to raise their fears to levels that encourage denial, inhibit preventive actions or negatively affect healthy sexual development.

In addition to dealing with standard human developmental processes, HIV positive adolescents should also confront a number of extra challenges. For adolescents on HAART treatment, the transition from childhood to adulthood is interlaced with concerns about medication regimens, doctor's appointments, life expectancy, disclosure, and transmitting HIV to others. Of course, the virus poses similar concerns for HIV positive individuals at

other life stages. However, the extensive changes that characterise adolescence make the second decade of life particularly unique.

The combination of ordinary developmental issues with HIV related worries creates a distinctive environment, which frames adolescents' daily experiences and their HIV interact with the normative changes that occur during adolescence. This stimulates research which examines adolescent HIV on its own merits, rather than as a subset of paediatric or adult knowledge about the virus' interactions with health care systems (Murimba, 2014). From a developmental perspective, it is thus important to consider ways in which adjustments associated with HIV interact with normative changes that occur during adolescence.

Furthermore, the research study sought to produce results that may enable the multi-disciplinary team at Masakhane Clinic, Tembisa Provincial Tertiary Hospital to design suitable interventions to address the specific problems of non-adherence.

## **1.5 RESEARCH PROBLEM AND RESEARCH QUESTION**

### **1.5.1 Problem Statement**

Mother-to-child infected adolescents have been exposed to HAART, and in some studies, many adolescents had successful viral controls that resulted in longer and healthier lives. However, these adolescents have multiple risk factors for mental illness (WHO, 2007a). Living with a chronic disease is associated with increased rates of mental illness. Many older adolescents were infected prior to the advent of HAART treatment and may have had a period of ineffective therapy with resultant uncontrolled viral infection in the central nervous system (Li, 2009). Many other adolescents have lost a biological parent to HIV and AIDS, and they may be living with another relative or foster parent. These adolescents are also frequently subjected to environments of poverty, crime, and substance abuse. The impact of these factors on adherence to HAART treatment can be far-reaching. Failure to adhere to prescribed HAART treatment should be offset by seeking intervention measures. Hence, the study searches for determinants leading to non-adherence in order to design intervention measures based on that knowledge and understanding of the causes. This study also sought to impact onto the deficient research literature relating to the experiences of adherence and non-adherence among adolescents who are on HAART treatment.

### **1.5.2 Research Questions**

Experiences, challenges, feelings, frustrations and positive encounters of being on HAART treatment for the communities surrounding Tembisa and Ekurhuleni have not been investigated formally through research. Furthermore, the current research generally illuminate on the health care professionals who are more concerned with scientific measurement of CD4 count and viral load and the realities of patients who do not fit the medical bill are automatically dismissed as a medical challenge, without necessarily understanding the patients' own subjective experiences of such treatment (Li, 2009).

It is essential to gain a better understanding of experiences that promote adherence while at the same time gaining a better view of experiences that contribute to non-adherence among adolescents. The research study aimed to address the following questions:

- What are the common (prevalent) experiences of being on long-term HAART?
- When you adhere, how do you feel? (When you default, what do you think?)
- What factors influence, motivate or lead you to adhere (or not adhere) to HAART treatment?
- As an adolescent, what are your perceptions on long term use of HAART treatment?

## **1.6 STRUCTURE OF THE THESIS**

This thesis is presented in five chapters, organised in the order described below.

Chapter 1 presents the introduction to the study, covering background information about the research problem, statement of the research design, motivation and aim of the study, rationale for the study, research problem and research question.

Chapter 2 discusses various aspects of literature which deal with adolescents, HIV and AIDS, and issues related to HAART treatment.

Chapter 3 presents the theoretical orientation of the study. The models related to treating HAART, in particular, the Health Belief Model and the bio-psychosocial model, are discussed with application to adolescents' experiences with regard to adherence and non-adherence to HAART treatment.

Chapter 4 deals with the research setting, design, methods, population, sample, data collection, data analysis, validity and reliability, as well as ethical considerations of the study.

Chapter 5 delves into data analyses using descriptive statistics and phenomenology at various sections of the study. Descriptive methods apply graphs, tables, and some chi-square statistical tests. The phenomenology part used units of meaning in which chunks of data were derived from some direct meanings emerging from the feelings and experiences of the adolescent participants of the study.

Chapter 6 concludes the study by providing the necessary conclusions, critiques, exposing limitations and strengths of the study, and reflecting on the extent of achievement of the study objectives.

## **CHAPTER 2:**

## **LITERATURE REVIEW**

### **2.1 INTRODUCTION**

The previous chapter provided an introduction and background to the study. This chapter will focus on a literature review. The literature review is a critical summary of research on a topic of interest, to put a research problem in context and to provide a basis for the implementation of a research project (Machi & McEvoy, 2012). It provides a foundation on which to base new knowledge. The primary purpose of reviewing relevant literature is to gain a broad background or understanding of the available information about a research problem. This background enables a researcher to build upon the work of others, since major breakthroughs or discoveries of new information in a field are based on previous works (Polit & Beck, 2006).

Moreover, a literature review can play a pivotal role in shaping the research by helping a researcher to conceptualise the research problem clearly and precisely. It also informs the researcher if others have used procedures and methods similar to the ones that he or she is proposing, which procedures and methods have worked well for them, and what problems they encountered. By becoming aware of potential problems and pitfalls, a researcher will be in a better position to select a methodology that is capable of providing valid answers to the questions (Burns & Grove, 2005).

This chapter presents a review of literature related to HAART treatment. The chapter further discusses, among other things, the impact of HIV and AIDS on the development of adolescents and HAART treatment with reference to adolescents. Also, the focus will be on indicators to effective HAART treatment as well as when to change treatment. Factors contributing both to non-adherence and adherence to HAART as viewed by adolescents will also be discussed. Lastly, the experiences of caregivers and health care workers are discussed.

### **2.2 HIV AND AIDS WITH REFERENCE TO ADOLESCENTS**

Adolescence is a formative period in a young person's life during which physical, emotional, and mental processes, as well as sexual identity, are evolving and maturing. Further, the social environment and responses of peers and parents have to be constantly integrated into

this evolving concept of self (Li, 2009). HIV and AIDS is only one among many potential health hazards the young person is expected to respond to and is especially challenging to youth who are facing marginalisation and stigma related to sexual orientation, poverty, and desperate living situations, abuse, as well as disparities in the provision of prevention and health care services based on race and ethnicity (Fielden, Chapman & Cadell, 2011)

Thirty years ago, it was difficult to imagine that one day children and youth with HIV and AIDS would be making plans for employment, raising families and other tasks of adulthood. Preparation for this new and welcome phase of their lives involves learning necessary skills, coping with social and emotional aspects of HIV and AIDS, and monitoring the effects of the virus. Psychologists, through research and clinical care, can play a role in helping shape the long-term outcomes for these youth (Nichols, 2013).

HIV and AIDS have a tremendous impact on adolescents, both those infected by HIV and AIDS as well as those affected by the illness of their loved ones. Pharoah (2004) states that it is often difficult to determine the full impact of HIV and AIDS on infected adolescents. This is due to the fact that these impacts occur in a number of overlapping and interdependent domains that affect their psychosocial development. Adolescents may experience a wide range of impacts including, but not limited to, poor health and nutrition, economic need, reduced levels of care, new responsibilities, and school dropout (Ndubuka, 2008). As children and adolescents infected with HIV continue to live longer, normal developmental milestones and educational needs will take on new significance. Many children will continue to be adversely impacted by non-HIV factors such as poverty, inadequate medical services, and a lack of social support (Brown, Lourie, & Pao, 2000; McCree, Wingood, DiClement, Davies & Harrington, 2002).

The term “adolescence” literally means “to emerge” or “to attain identity” and is essentially the period of rapid physical and psychological development starting from the onset of puberty to complete growth. All adolescents go through a myriad of physical, psychological, neuro-behavioural, hormonal and social developmental changes. Given the social taboos often surrounding puberty, the lives of millions of adolescents worldwide are at risk because they do not have the information, skills, health services and support they need to go through the enormous, rapid changes that adolescence brings. HIV-infected adolescents are particularly presented with enormous challenges (Mothi, Swamy, Lala, Karpagam, & Gangakhedkar, 2012, p1642).

The distinct groups of adolescents in the context of HIV and AIDS are those who were infected at birth and survived and those who became infected during adolescence. Risk factors and situations for adolescents contracting HIV infection are life on streets, lack of adult love/care and support, extreme poverty, child trafficking, migrant population, exploitation with reference to sex and labour. HIV-infected adolescents with long-standing HIV infection often face considerable physical challenges, such as delayed growth and development, late puberty, stunting/wasting, and malnutrition (Krauss, Letteney, Da Baets, Baggaley & Okero, 2013). Added to this are many other challenges related mainly to disclosure of HIV status, developmental delay, and transition from paediatric to adult care, including the choice of appropriate treatment regimens and adherence. Psychological and social factors deeply impact the ability to deal with the illness and must be addressed at all levels to encourage and support this vulnerable group (Mothi et al., 2012).

With widespread access to antiretroviral therapy in the United States, many perinatally HIV-infected (PHIV) children are surviving into adolescence and adulthood, becoming sexually active and making decisions about their reproductive health. The literature focusing on the reproductive decisions of individuals behaviourally infected with HIV can serve as a springboard for understanding the decision-making process of PHIV youth. Still, there are many differences that critically distinguish reproductive health and related decision-making of PHIV youth. Given the potential public health implications of their reproductive decisions, a better understanding of factors influencing the decision-making process is needed to help inform the development of salient treatment and prevention interventions (Fair et al., 2013).

A study revealed that the psychosocial issues associated with HIV infection in adolescents coalesce around five central themes: knowledge and understanding about personal serostatus, mental health, networks of support, treatment management, and healthy behaviour. These issues present challenges to HIV positive adolescents in the present and affect their outlook on the future. Findings reveal that despite the fact that young seropositive South Africans live in a country where social contexts, available resources and health care systems differ markedly from those in developed countries; they share similar concerns and face many of the same challenges as other HIV positive young people around the world (Li, 2009). The use of antiretroviral therapy has greatly increased the long-term survival of perinatally infected children so that AIDS is becoming a manageable chronic illness. These growing children are left facing the challenges of lifelong adherence with complex treatment regimens compounded by complex psycho-social, mental and neuro-cognitive issues. These unique challenges must be recognised and understood in order to provide appropriate medical management (Merchant & Lala, 2012).

Adolescents are critical in making efforts to end the HIV and AIDS epidemic. HIV and AIDS will continue to paralyse the growth potential of countries if adolescent HIV and AIDS is not given sufficient attention. Currently, adolescents are largely invisible in global, regional, and country HIV and AIDS reports, making it difficult to assess progress in this population. There is unprecedented knowledge to guide investment towards a greater impact on HIV and AIDS prevention, treatment, and care in adolescents, but it has not been applied to reach those who are most vulnerable. The cost of this is increasing HIV and AIDS-related deaths and largely unchanged levels of new HIV and AIDS infections in adolescents (Lowenthal, Bareeka-Kitaka, Marukutira, Chapman, Goldrath & Ferrand, 2014).

Adolescents form a pivotal role in the development of countries, thus posing a serious threat to the overall growth of such communities, societies and the world. In most countries, youth represent the potential for growth. However, such growth could be significantly paralysed because of the current youth HIV and AIDS infection rates (Harper & Riplinger, 2012). Long-term solutions will need to be crafted for these adolescents because the impact of HIV and AIDS will linger for decades after the epidemic begins to wane. Even if rates of new infections were to level off in the next few years, the long incubation period means mortality rates will plateau in a few decades. Greater understanding of the impact of HIV and AIDS on adolescents is important in the design and evaluation of programmes to support adolescents living in difficult circumstances (Kasedde, Luo, McClure, & Chaddan, 2013). Kasedde et al. (2013) further state that an HIV and AIDS-free generation will remain out of reach if the global community does not prioritise adolescents. National HIV and AIDS responses must be accountable to adolescents, invest in strengthening and monitoring protective and supportive laws and policies, and access for adolescents to high impact HIV and AIDS interventions.

Although HIV and AIDS is a life-changing experience for adolescents who have acquired the infection, the role of psychosocial support cannot be underestimated. Being diagnosed with HIV and AIDS is often accompanied by depression, low self-esteem, and fear of hurting or being rejected by family, friends, and loved ones. Many HIV and AIDS-positive teens overcome these barriers with the help of supportive family, friends, a multidisciplinary health care team, and their own inherent strength and creativity. This also holds true for youth with perinatally acquired HIV and AIDS infection who have to cope with treatment fatigue, crisis of trust due to delayed diagnosis disclosure, parental guilt and overprotection, as well as stigma (Li, 2009).

The formation of an individualised identity is considered by many theorists to be the primary developmental goal of the adolescent years and is one facet of adolescent development that may interact with receiving an HIV and AIDS diagnosis (Harper, Fernandez, Bruce, Sybil, Hosek & Jacobs, 2011). In the subsection that follows, a review of current, unique medical and psychosocial impacts of care for adolescents who are living with HIV and AIDS infection is presented.

### **2.2.1 The Psychosocial Impact of HIV and AIDS on Adolescents**

Before any psychosocial impact of HIV on adolescents, the issue of disclosure needs to be addressed. The need for supporting disclosure to the adolescent cannot be overemphasised. Disclosure is often the central issue that determines if, when, and how a child living with HIV and AIDS receives the services and support he or she needs. Lack of readiness and willingness – both on the parent/caregiver side (for example, reluctant to disclose their own HIV status) and the child's side – can be significant barriers to ensuring a child's well-being. There is no one formula for how disclosure to a child is managed, noting that there are multiple disclosures (of the child's status as well as the parents' status) over time. Disclosure is not a single event. Instead, disclosure needs to be a process over time that allows for appropriate action regarding what information is shared (for example, partial versus full disclosure), by whom, with whom, and when, factoring the readiness of the child and parent/guardian/caregiver (UNAIDS, 2007).

In addition to wanting to be told the truth about their illness, many adolescents expressed clear preferences about how this should occur. They described the ideal scenario of being told about their HIV status as taking place at a health care setting that included communication with a doctor, nurse, or counsellor. For adolescents, both the clinical space and the presence of a health care worker served to reinforce the reality of the illness: "I wanted to be told at the clinic just so I know that it's really true, that I've been tested, and it's true" (girl B, 17-year-old). Adolescents said that having a health care worker present was also important for obtaining accurate information about HIV and AIDS and answers to the many questions they might have at that time of uncertainty: "I wanted to be told by a nurse or a doctor because they are the ones who would be able to explain all about your disease, like what HIV is" (boy C, 18-year-old) (Kidia et al., 2014, p1). This indicates that the value of factual information about HIV and AIDS can be increased by giving adolescents the opportunity to discuss HIV and AIDS issues with health care professionals.

Because of the scale-up of antiretroviral therapy over the last decade, survival of perinatally infected children has improved dramatically, enabling them to live into adolescence and beyond. Such survival creates the need for addressing the issue of informing adolescents about their HIV and AIDS status. Although status disclosure can also refer to the act of a person living with HIV and AIDS sharing his or her status with others, this study aimed to address the issue of informing adolescents about their status and making this status understood. HIV disclosure often makes a distinction between giving the adolescent all information relating to their status (full disclosure) and limiting the amount of information (partial disclosure) (De Baets, Sifovo, Parsons, & Pazvakavmba, 2007; Midtbo, Shirima, Skodval, & Daniel, 2012). In this study, full disclosure is defined as having been achieved not only when an adolescent has received all the information about his or her HIV status but also when he or she entirely understands the ramifications of this information

Knowing one's HIV status is recognised as an important prerequisite for effective adherence to antiretroviral therapy. Disclosure has also been associated with a reduction in risk behaviour. Furthermore, while there is little evidence that disclosure causes psychological harm and research suggests that it may actually be beneficial for a young person's mental well-being, a recent study in Zimbabwe by Krauss et al., (2013) showed that learning about their HIV status is still one of the most difficult life events for adolescents living with HIV and AIDS. Despite these facts, the WHO guidelines for HIV status disclosure are limited to children under the age of 12 even though many perinatally infected children are not given disclosure until they are adolescents (WHO, 2013b).

It is stated that between 2005 and 2012, HIV related deaths among adolescents increased by 50%, while the global number of HIV related deaths fell by 30% (WHO, 2013b). This increase in adolescent HIV related deaths is due primarily to a variety of factors. These include poor prioritisation of adolescents in national HIV plans, inadequate provision of accessible and acceptable HIV testing and counselling (HTC), and treatment services and lack of support for adolescents to remain in care and adhere to antiretroviral therapy. HTC and HIV and AIDS counselling and testing (HCT) are used interchangeably to mean HIV testing and counselling depending on referral sources. For some adolescents, their lives are lived within the imbrications of poverty, multiple bereavements, displacement, and disruptions in schooling, and the care associated with normative notions of kinship having been complicated by living with a chronic, life-threatening illness (Parsons, 2012).

Children with HIV and AIDS experience more subjective distress than their peers and face multiple stressors related to HIV and AIDS. This is not only limited to the illness and death of

a parent, disclosure, stigma, discrimination, isolation, loneliness, and family conflict or uncertainty (Brown, Lourie & Pao, 2000). King, De Silva, Stein & Patel (2009) also note that children and youth living with HIV and AIDS (aged 4 to 21 years) are at an increased risk of experiencing mental health disorders. Compared with prevalence rates in the overall population, children living with HIV and AIDS have an increased risk of experiencing depression. HIV and AIDS infection creates an additional developmental challenge which adolescents have to contend with during this challenging stage.

HIV and AIDS represent one of the major worldwide health problems that have had a shattering impact on many countries, especially those in sub-Saharan Africa (WHO, 2004). There are psychosocial impacts such as abuse, trauma, stress and loss of social connectivity. It is stated that youth who have lost one or both parents to AIDS are particularly vulnerable to infection themselves, and this applies to adolescents as well (UNICEF, 2004). Many face exploitation, including physical and sexual abuse. These adolescents may also be placed at a greater risk of reinfection. As a result of HIV related mortalities, more children under the age of 15 have lost a parent due to HIV and AIDS. There are also many children who have HIV positive parents or primary caregivers; these children are affected by HIV and AIDS and are potentially vulnerable to HIV transmission. Children affected by HIV and AIDS are more vulnerable and face greater challenges to their psychosocial well-being compared to other children of the same age (King et al., 2009). With weakened family support, some engage in risky sexual behaviour or inject drugs into their systems. Those forced to live on the streets may turn to sex work and crime as a means to survive. After suffering the emotional toll of losing their parents, many also face stigma and discrimination (UNICEF, 2004).

Adolescents affected or infected by HIV and AIDS are at a higher risk of school dropout, child labour, sexual exploitation and child trafficking; these present real dangers to children as well as to society, and adolescents form part of those who are vulnerable. These psychosocial factors reduce individual and national developmental potential, marginalise and dehumanise children, and separate them from available sources of help and support, engender widespread disregard for children, and lead them to have close association with crime (Richter, 2001). Without schooling, both individuals' potential and social capital are lost, leaving affected individuals vulnerable to unemployment, menial working conditions, and poverty. Similarly, child labour is often physically damaging, psychologically stunting and demeaning to the dignity of children whose labour is exploited (Foster & Williamson, 2000). Such labour has particularly damaging effects on adolescents who still have to find their own identity within society.

There is a general fear that the HIV and AIDS epidemic may create generations of disenfranchised and potentially dysfunctional youth who lack the socialisation necessary for constructive social engagement. Uncared-for HIV and AIDS orphans may also behave irrationally due to stress and lack of guidance (Rotheram-Borus, Stein, & Lester, 2006). Mburu, Ram, Oxeham, Haamujonmpa, Iorpenda & Ferguson, 2001) further assume that children raised in difficult circumstances almost always suffer negative psychological, social and behavioural outcomes. Psychosocial distress, which includes anxiety, loss of parental love and nurture, depression, grief and separation of siblings among relatives to spread the economic burden of their care, can never be quantified.

Almost as lethal as the virus itself is the stigma and resulting discrimination faced by people living with, or affected by, HIV and AIDS. Because of the ignorance and denial that cloak the disease in many parts of the world, adolescents whose parents have died from HIV and AIDS are often singled out as targets of abuse in places they come to for support and care (Close & Rigamonti, n.d.). Adolescents are sometimes harshly treated in foster homes, denied access to schooling and health care, stripped of their inheritances, and left to the streets. Stigma and discrimination remain the most potent barriers to testing, treatment and prevention (Midtbo et al., 2012). These adolescents are often further traumatised by stigmatisation and rejection, which leave them still more vulnerable and isolated. Stigmatisation might prompt affected adolescents to stay away from school rather than enduring exclusion or ridicule by teachers and peers. Such stigmatisation might contribute to reluctance by adolescents to follow up with their HAART, thereby leading to poor treatment adherence.

### **2.2.2 The Impact of HIV and AIDS on Adolescents' Physical Well-being**

Initially, children born with HIV and AIDS did not grow beyond the age of seven years, but this has changed since the introduction of HAART treatment. However, adolescents living with HIV and AIDS live under the shadow of untimely death, unexpectedly and indeterminately deferred. Physically small for their ages, they often bear the outward signs of affliction and illness and constantly stand exposed to the unstable, potentially devastating possibilities of social stigma and rejection (Preda, 2005; Parsons, 2012). Steele, Nelson, and Cole (2007) reports that when compared to children from similar socio-economic situations, children with HIV and AIDS experience greater impairment of neurologic, cognitive and psychosocial functioning.

HIV and AIDS is carried on monocytes or macrophages and CD4 lymphocytes in the central nervous system early in infection. Some evidence suggests that the developing brain may be more susceptible to disruption and development of encephalopathy. By default, an adolescent would suffer a similar impact to their neurologic, cognitive and psychosocial functioning (Durham & Lashley, 2010).

The immune system is a complex system of blood proteins and white blood cells which work together to repel attacks by invading organisms. HIV and AIDS attack a particular set of cells in the human immune system known as CD4 cells. There are two types of CD4 cells. The first type is CD4 positive T cells which organise the body's overall immune response to foreign bodies and infections. These T helper cells are the prime target of HIV. For a person to be infected, virus particles must enter the body and attach themselves to the CD4 cells. These cells engulf foreign invaders and ensure that the body's immune system will recognise them in the future. Once the virus has penetrated the wall of the CD4 cell, it is safe from the immune system because it occupies the cell's DNA and therefore cannot be identified and destroyed by the body's defence system. Virus particles lurk in the cells until their replication is triggered. Once this happens, they make new virus particles that bud from the surface of the host cell in vast numbers, destroying that cell as they do so. These viruses then go on to infect more CD4 cells (Barnett & Whiteside, 2002).

When an adolescent is infected with HIV and AIDS, a battle starts between the virus and the immune system. There is an initial burst of activity during which many cells are infected, but the immune system fights back, manufacturing immense numbers of antibodies. This period is marked by an unseen and unfelt war in a person's body. The viral load is high, the immune system is taking a knock, and the person's HIV status cannot be detected using standard tests. This is commonly called 'the window period' and lasts from several weeks to several months. At this stage, the adolescent is highly infectious, as his or her viral load (the number of viral particles they are carrying) is considerable. This fact is of epidemiological importance. The more people there are in the early stage of infection, the greater the chance of effective transmission between people (Claxton & Harrison, 1991).

The window period is followed by the long incubation stage. During this stage, the viruses and the cells they attach to are reproducing rapidly and being destroyed as quickly by one another. Eventually, the virus is able to destroy the immune cells more quickly than they can be replaced, and slowly the number of CD4 cells starts falling. In a healthy person, there are 1,200 CD4 cells per microlitre of blood. As infection progresses, the CD4 cell number will fall. When CD4 cell count falls below 200, opportunistic infections begin to occur, and a

person is said to have AIDS. Infections will increase in frequency, severity and duration until the person dies. It is these opportunistic infections that cause the syndrome referred to as AIDS (Claxton & Harrison, 1991).

HIV and AIDS has a significant impact on the immune system of the adolescent. The progression of the disease is much faster in children than in adults as well as the risk of complications. Since most infections occur perinatally, the virus overcomes the capacity of the immature immune system to control the HIV replication, and dissemination occurs to all organ systems including the central nervous system.

Physical changes of puberty make some aspects of medical management of HIV in adolescents different from management in adults or children. Profound anatomic and physiologic changes are occurring that may affect drug distribution, metabolism, and excretion. During adolescence, sex hormones initiate processes of growth and sexual maturity. Gender-related changes in body composition occur: girls develop higher proportions of fat, while boys develop higher proportions of bone and muscle mass (Schietinger, Sawyer, Futterman, & Rudy, 1999).

The effects of physiological changes on the pharmacokinetics and pharmacodynamics of drug therapies are not well understood, but it is known that variables such as body composition and endocrine levels affect drug distribution, metabolism, and excretion. The physiological changes of early adolescence are markedly different from those of late adolescence, so that the metabolism of certain medications can vary considerably between a 13-year-old and an 18-year-old. Until more is understood about the interrelationships between developmental age and appropriate drug dosage, clinicians must rely on general guidelines in prescribing medications to adolescents (Schietinger et al., 1999; Shearer & Hanson, 2003).

### **2.2.3 The Impact of HIV and AIDS on Cognitive and Emotional Functioning of Adolescents**

The cognitive and behavioural problems in children and youth with HIV and AIDS have a number of implications for their daily functioning. Many children and youth with HIV and AIDS have significant obstacles to success in school, including cognitive difficulties, losing school time due to illness, doctor visits or family disruption, and living in areas with disadvantaged school systems and high dropout rates (Nichols, 2013; Shearer & Hanson, 2003). While antiretroviral therapy has significantly decreased HIV encephalopathy, as HIV

and AIDS-infected children survive into adolescence and young adulthood, more subtle manifestations of central nervous system disease are still seen.

The aforementioned cognitive deficits, problems with attention and psychiatric disorders, are far less acutely devastating than encephalopathy but may well have a tremendous impact on these youth as they survive into adulthood. The etiologic factors are complex and may include the effects of HIV infection (both ongoing central nervous system viral replication as well as past impact of infection on the developing brain), chronic inflammation, antiretroviral drugs toxic effects, social factors and other exposures (Mofenson & Cotton, 2013).

Researchers in Romania found a high rate of HIV and AIDS-associated neurocognitive disorders in a cohort of young adults who acquired HIV and AIDS infections parenterally during childhood. The study prospectively evaluated neurocognitive impairment in 49 infected adolescents and 20 age- and sex-matched HIV and AIDS-negative control participants using HIV associated neurocognitive disorder diagnostic criteria. All were about 18 years of age and had 10 to 11 years of education. Most of the participants had good immune status and undetectable viral loads at the time of evaluation. The investigators evaluated everyday functioning and assessed seven cognitive domains: verbal fluency, speed of information processing, attention and working memory, abstraction/executive functioning, learning, delayed recall, and motor function. Few confounders, such as previous drug abuse, brain injury, and other central nervous system conditions, were present. Overall, 25% of the HIV and AIDS infected cohort had asymptomatic neurocognitive impairment, 20% had mild neurocognitive impairment, 2% had HIV and AIDS associated dementia, and 53% had normal functioning (Keller, 2011).

Furthermore, more than half of the patients had impairment with regard to the speed of information processing (55%) and motor domain (53%). In contrast, 35% and 20% of the control participants showed impairment on each of these domains, respectively. Learning and abstraction domains were not greatly affected in the HIV-infected individuals (6% and 12% were impaired, respectively). First, HIV infection might have induced irreversible brain injury before a combination of ART was initiated. Second, there could have been a persistent low level of viral replication in the brain because of poor drug penetration or the presence of drug-resistant viral strains. Third, inflammation and immune activation might have persisted in the brain. Finally, the drugs themselves might have had a neurotoxic effect (Keller, 2011).

However, as a result of HAART, there are children who grow up to reach adolescence and beyond; thus, the impact of growing up with HIV and AIDS for adolescents has a significant

impact on society in general. Preda (2005) proclaims that from a medical viewpoint, HIV and AIDS is unique in the sense that it directly attacks and destroys the immune system which protects the body against viral, bacterial and parasitic infections. As a consequence, the clinical course is more accelerated in children and adolescents than in adults; hence, the immunological dysfunction is greater.

To understand the danger of HIV and AIDS infection fully, the functioning of the immune system will be explained briefly. The functioning of the immune system may be described metaphorically as a war within the body. The immune system functions like the defense system of a country. Just as the soldiers defend their country, so does the immune system defend the body.

Understanding the evolution of the adolescent's neurodevelopment in the context of active HIV infection is important. Factors associated with a central nervous system disease in children with HIV infection include maternal and child immune status, elevated cerebrospinal fluid and plasma viral load, and timing and route of infection. Risk is higher in those infants born to mothers with advanced disease (low CD4 count and high viral load) at the time of delivery. Also, children with immune suppression and high plasma load have higher rates of encephalopathy (Durham & Lashley, 2010).

Concurrently, environmental factors including maternal drug use, poverty, low maternal education and foster care placement also influence adjustment and may contribute to developmental delay. HAART, which reduces plasma and cerebrospinal fluid viral load, also reduces the risk of encephalopathy. While HAART halts progressive HIV encephalopathy in children and adults, high rates of residual impairment remain, including behavioural problems as well as neurological, cognitive and scholastic impairments (Durham & Lashley, 2010).

Once the adolescent has been diagnosed HIV positive, it is important to do a full clinical assessment of his or her health. Regular check-ups (at least four to six months if a person is healthy, but more frequently if he or she has symptoms) should be done to monitor changes in the person's health. Regular check-ups can help health care workers to identify and treat physical as well as psychological problems at any stage and to promote the general health of the patient. Clinical assessment also helps the health care worker to make decisions on when to start prophylaxis and when to start antiretroviral treatment. Regular medical and growth checks (at least once every two to three months) are important for monitoring the health of HIV-infected adolescents (Van Dyk, 1999).

#### **2.2.4 The Socio-economic Impact of HIV and AIDS on Adolescents**

The impact of HIV and AIDS on children and families is compounded by the fact that many families live in communities which are already disadvantaged by poverty, poor infrastructure and limited access to basic services. Strategies for coping of extended families have negative impacts on children in households indirectly affected by HIV and AIDS, thus enlarging the overall impact and number of children affected (Foster & Williamson, 2000).

World Health Organization reports that adolescents (10-19 years) and young people (20-24 years) continue to be vulnerable, both socially and economically, to HIV and AIDS infection despite efforts that have been made to date. This is particularly true for adolescents, especially girls, who live in settings with a generalized HIV and AIDS epidemic or who are members of key populations at higher risk of HIV and AIDS acquisition or transmission through sexual transmission and injecting drug use. In 2012, there were approximately 2.1 million adolescents living with HIV and AIDS. About one-seventh of all new HIV infections occur during adolescence (WHO, 2013a, WHO, 2013b). Access to and uptake of HCT by adolescents is significantly lower than for adults. Survey data collected from sub-Saharan Africa indicate that only 10% of young men and 15% of young women (15-24 years) were aware of their HIV and AIDS status (Bekker & Hosek, 2015).

Furthermore, there should be at least one identifiable caregiver who is able to supervise the child for administering medication. Disclosure of the child's treatment to another adult living in the same house should be encouraged. This adult can then assist with the child's HAART treatment to make sure that the child adheres to the medication. The child's caregiver or parent should be motivated and committed to the child's lifelong therapy. Caregivers should understand that adherence involves giving every dose of medication, exactly as prescribed every day of every year. Caregivers or parents should be counselled to anticipate and plan for weekends away, schooling and other activities which could mean that doses are missed. Caregivers or parents should understand that poor adherence is the single most important factor associated with drug failure and resistance. They should furthermore understand that resistance implies loss of future treatment options for the child. Good adherence is to be emphasised with every visit (Van Dyk, 2012).

Further impact of HIV and AIDS on adolescents is seen most dramatically in the rising numbers of children and adolescents orphaned by HIV and AIDS. The United Nations Children's Emergency Fund (UNICEF) documents that such children face grave risks to their education, health, and well-being. These children may have to forgo schooling; there may be

less food or clothing for them in the household; they may suffer from anxiety, depression and even abuse (UNICEF, 2004). In households affected by HIV and AIDS, the school attendance of children, including adolescents, drops off because their labour is required for subsistence activities and, in the face of reduced income and increased expenditure, the money earmarked for school expenses is used for basic necessities, medication and health services. Even where adolescents are not withdrawn from school, education often begins to compete with the many other duties that affected children have to assume (Pharoah, 2004; Bill, 2006).

Without schooling, both individuals' potential and social capital are lost, leaving affected individuals vulnerable to unemployment, menial working conditions, and poverty. Similarly, child labour is often physically damaging, psychologically stunting and demeaning to the dignity of children whose labour is exploited (Foster & Williamson, 2000). Such labour has particularly damaging effects on adolescents who still have to find their own identity within society. Children may also suffer from economic constraints as the household provider becomes sick, cannot work, and loses their job. The responsibility of earning money and providing food is left to the children. They often go hungry, become malnourished, and become unable to concentrate. Other economic impacts include no money for school fees, uniforms, materials, clothing and other necessities. Hunger is a common cause of poor school performance and dropout (Bezuidenhout, Elago, Kalenga, Klazen, Nghiphondoka & Ashton, 2005).

Together with sexual exploitation and the trafficking of children, school dropout and child labour indicate the disintegration of social institutions that serve to protect and develop children and, by their existence, they further undermine fragile families and communities. Moreover, child labour and sexual exploitation fuel crime as children become traded for profit. Adolescents are vulnerable to school dropout, forced and legal labour, sexual exploitation and trafficking that face children of other age groups (Foster & Williamson, 2000).

As a consequence of the foregoing, isolation from family and peer group also results. Many adolescents affected by HIV and AIDS have to drop out of school because of financial problems or their new responsibilities as caregivers. This cuts them off from their peer group, robbing them of an influence crucial to their ongoing identity development. The loss of learning has equally serious implications for their development (WHO, 2013a). Adolescents who are responsible for their parents have little or no time to play or spend leisure time with

same-age friends. Pharoah (2004) further notes that despite their shortcomings, schools have significant potential to play a critical role in obviating the worst effects of the HIV and AIDS epidemic on children. Apart from the accrued personal and social benefits of education for work and national development, schooling provides stability, institutional affiliation and the normalisation of experience for children. It also places children in an environment where adults and older children are potentially available to provide social support.

Adolescents who live with parents who are chronically ill live in households that have taken in orphans or have lost teachers and other adult members of the community to HIV and AIDS. As their parents become more ill and dependent on them, these adolescents find their roles changing from child to primary caregiver, as they have to take care of their parents. Older siblings have to take on the parenting of younger siblings, and the resultant loss of childhood has serious implications for normal childhood development (Mofenson & Cotton, 2013). At certain instances, caregivers change and siblings may split up.

Van Dyk (2012) reports that after their parents' death, children often lose their rights to family land or house. Relatives move in and often exploit the children by taking possession of their property but not providing support for them. Because these children no longer have access to education and because they lack work skills and family support of any kind, they often end up living on the streets with no money whatsoever. Richter (2001) points out that reduced financial and emotional resources available to children cause trauma and alienation. It effectively limits the realistic aspirations of the affected adolescents.

Adolescents orphaned by HIV and AIDS suffer more frequently from malnutrition, illness, abuse and sexual exploitation than those who are orphaned by any other causes (Van Dyk, 2012). Pharoah (2004) adds that a further impact of HIV and AIDS include deepening poverty, such as pressure to drop out of school, food insecurity, reduced access to health care services, deteriorating housing, worsening material conditions, loss of access to land and other productive assets. Vulnerable adolescents do not know how to protect themselves, and they have no access to doctors, nurses and other health care workers and facilities. As such, their risk of reinfection arises from the early onset of sexual activity, commercial sex and sexual abuse, all of which may be precipitated by economic need, peer pressure, lack of supervision, exploitation and rape (WHO, 2013a). In most cases, these adolescents have to live without basic human rights and dignity. Still, at other times, the pressures for basic survival far outweigh the future orientation required to avoid infection, and they find themselves having to worry more about food and shelter than consequences of unprotected sexual relations.

According to the United Nations Population Fund for every person living with HIV and AIDS, a family and community are affected. As the disease kills parents and caregivers, it fuels poverty and despair among children and adolescents and stretches family resources. Adolescent orphans infected or affected by HIV and AIDS frequently have their schooling disrupted. Dropping out is common, particularly for girls who have to care for sick family members or their siblings, to keep the family together. Inability to pay school fees also forces boys and girls to leave school. Others drop out because of stigma and discrimination by schools, teachers or classmates (UNICEF, 2006; WHO, 2007a). Loss of a parent in early childhood, at school age and in early or late adolescence affects children differently, both psychologically and developmentally (Foster & Williamson, 2000). The ripple effects of HIV and AIDS status of parents extend beyond just the physical health of parents but set the tone for generations to come.

### **2.2.5 The Religious or Spiritual Impact on Adolescents Living with HIV and AIDS**

Religion and spirituality are often interchanged. In essence, they encompass one's belief in the existence of a supernatural or high power to escape to when faced with overwhelming challenges. HIV and AIDS form part of such an overwhelming challenge. Adolescents might resort to religion and spirituality to help them cope or simply explain challenges for themselves. Spirituality as a protective factor for coping with HIV has been understudied in adolescents; however, a mixed picture seems to prevail as far as the role of religion/spirituality in adolescent living with HIV and AIDS is concerned.

Lippman and McIntosh (2010) state that spiritual beliefs and practices among youth are important to monitor, since research from developmental science, sociology, and character education has found that they are positively related to identity and moral development. They are also related to purpose and goal attainment; educational achievement and attainment; emotion and attention regulation; positive physical and mental health; life satisfaction and happiness; conflict resolution and social skills; prosocial behaviours; and a successful transition to adulthood. Spirituality can be experienced and expressed in diverse ways, including being or becoming aware of the sacredness of one's soul, a connection to a unity of life that transcends oneself and to a divine Creator and/or beings in a spiritual realm such as angels, ancestral spirits or guides.

To date, population-level surveys of these spiritual dimensions have been limited, focusing on, for example, belief in God. Lyon, Garvie, He, Malow, McCarter, & D'Angelo (2012) bring out that religion plays an integral part in the lives of adolescent patients in the United States.

A study by Lyon et al. (2012) assessed congruence in spirituality between HIV positive adolescent dyads and psychological adjustment and quality of life. The study used the Spiritual Well-Being Scale of the Functional Assessment of Chronic Illness Therapy, Beck Depression Inventory-II, Beck Anxiety Inventory and Paediatric Quality of Life Inventory at a baseline and 3-month post intervention. The study found that a high congruence existed for having a reason for living, rejection of life lacks meaning/purpose and 'HIV is a punishment from God' (Lyon et al., 2012, p9). Positive religious coping has been associated with a sense of wellness, regardless of markers of disease severity and increased physical functioning in patients (Bernstein, Lyon, & D'Angelo, 2012).

Spirituality is difficult to define. It involves looking within and having an awareness that there is something sacred. Spirituality and religion are often central issues for patients dealing with chronic illness. A study by Cotton, Puchalski, Sheraman, Mrus, Peterman, Feinberg, Pargament, Justice & Tsevat (2006) revealed that most patients with HIV and AIDS belonged to an organised religion and use their religion to cope with their illness. Patients with greater optimism, greater self-esteem, greater life satisfaction, minorities, and patients who drink less alcohol tend to be both more spiritual and religious.

Religion or spirituality may play a positive role among adolescents with HIV, acting as it does for other teens by decreasing risky behaviours, providing support, acting as a coping mechanism, and generating hope and comfort. Adolescent spirituality is associated with less anxiety and depression and adaptive coping with a chronic illness (McCree, Wingood, DiClemente, Davies, & Harrington, 2002). Having strong religious beliefs has been shown to be a protective factor against many risk behaviours, including tobacco, alcohol, drug use, violence, and initiation of sex. Spirituality is one of many ways teens with HIV and their families cope with the burdens of HIV (Cotton et al., 2006). Religion may protect youth from risky behaviours (McCree et al., 2002).

Spirituality is often a central issue not only for them but also for their families (Lyon, Garvie, Kao, Briggs, He, Malow, McCarter & D'Angelo, 2011). Surveyed HIV positive teens rated themselves as religious/spiritual (68%) (Garvie, He, Wang, D'Angelo, & Lyon, 2012) and reported regular attendance at religious services (72%); the teens highlighted that religions/spirituality helped 80% of them face their fears. Furthermore, it emerged that although important areas of congruence emerged, equally important areas such as the timing of these conversations and adolescents' end of life needs and wishes are not known by their families. Families need help initiating conversations with affected teens to assure their adolescents' end of life wishes are known to them (Garvie et al., 2012).

On the other hand, religion or spirituality may be a negative or painful factor, especially if it is viewed as a punishment, leading to worsened outcomes (Berstein et al., 2012). Some patients feel that their disease is a punishment from God, which negatively affects their coping with the illness (Berstein et al., 2012). Youth living with HIV and AIDS (YLWHA) are more likely to wonder “whether God has abandoned me.” The research by FAmily CEntered (FACE) Advance Care Planning study hypothesised that high spirituality would predict high medication adherence and stage of illness and that the belief that “HIV is punishment from God” would decrease medication adherence. Religious beliefs can increase spiritual distress. HIV positive teens were more likely to report “God abandoned me” than HIV-negative teens (Bernstein et al., 2012, p9). Fatalistic religious beliefs are associated with lower medication adherence. The belief that HIV was a punishment from God was associated with poor medication adherence among HIV positive teens (Lyon et al., 2011).

A different view explores the role of a health professional in the spiritual lives of their patients. Ehman, Ott, Short, Ciampa & Hansen-Flaschen (1999) suggest that most patients would like physicians to ask about their spiritual beliefs in some situations. Research demonstrating the benefit of spirituality in the physical and mental health of adolescents has not established whether spirituality is a topic which adolescents find acceptable to explore with their health care providers (Cotton et al., 2006). Clinically, spiritual or religious themes emerge when adolescents with serious medical conditions such as cancer or HIV and AIDS are asked what sustains them through difficult situations (Lyon et al., 2011). Armed with a better understanding of conditions under which adolescents find spiritual questions or discussions acceptable, health professionals can better tailor their counselling and treatment. Taking a holistic approach to health care may offer a better opportunity to protect adolescent well-being.

### **2.2.6 Section Synopsis**

This section was a discussion of the impact of HIV and AIDS on the development of adolescents who grow up with HIV and AIDS. HIV and AIDS-infected adolescents represent a unique, yet diverse, population requiring specialised medical and psychosocial HIV and AIDS care. Infected adolescents often have differing therapeutic needs but may share common difficulties, including medication non-adherence, high-risk sexual behaviour, and psychosocial stressors. The impact of HIV and AIDS on the functioning of adolescents is multifaceted and affects all aspects of the adolescent’s life. The impacts are immense insofar as they compel adolescents to battle with adult responsibilities for which they are not

adequately prepared. These impacts will have far-reaching consequences for their development as well as outlook on life.

## **2.3 HAART TREATMENT WITH REFERENCE TO ADOLESCENTS**

In the third decade of the HIV and AIDS epidemic, the prevalence of HIV and AIDS infection among adolescents and youth continues to increase as more youth become infected, and survival among perinatally infected adolescents has significantly increased since the introduction of HAART treatment (Li, 2009; WHO, 2007b). Health workers are just beginning to learn about the complications of chronic HIV infection and the toxicities associated with HAART treatment before and during sexual maturity. Understanding the effects on adolescents might be beneficial to their development. Managing the side effects while administering suitable and necessary active HAART treatment regimens in these heavily treated adolescents will be challenging, given the limited therapeutic options that are available.

### **2.3.1 The Historical Background of HAART Treatment**

The introduction of HAART treatment has led to increased life expectancy among adolescents with HIV and AIDS; however, it poses challenges including complex drug regimens that require strict adherence by patients. Treatment adherence by adolescents with HIV is generally considered suboptimal, although adherence reports vary by the method of assessment used (Hans, Spiegel, Donna, & Futterman, 2009).

Before the widespread introduction of HAART, most perinatally infected children did not survive beyond the first two years of life. With treatment, HIV positive children are living longer. In the developed world, where HAART treatment has been widely available since 1996, survival of perinatally infected children into adolescence is now the norm. Regarding a French cohort of perinatally infected children born before 1993, 58% were still alive and receiving HIV care 13 years later. In the UK, the proportion of HIV-infected children in care aged 10-19 years increased from 11% to 44% between 1996 and 2005. As HAART treatment becomes increasingly available in South Africa, similar trends can be expected (Jaspan, Li, Johnson, & Becker, 2009).

Hans et al. (2009) investigated the prevalence of post-traumatic stress symptoms (PTSS) in a sample of adolescents and young adults perinatally and behaviourally infected with HIV

and AIDS. The relationship of PTSS with treatment adherence and the role of internal health locus of control (IHLC) were explored. Twenty-eight participants (Mean age = 17.14, SD = 3.05; Range = 12-22) recruited from a paediatric immunology clinic completed measures of life events, PTSS, and health locus of control. Measures of treatment adherence used included viral load count, CD4 count, and provider ratings of adherence.

Findings revealed relatively good adherence levels and low disease severity among the sample. Eighty-two per cent of the participants reported experiencing at least one HIV related traumatic event, and 75% of the participants reported experiencing at least one non-HIV related traumatic event (Hans et al., 2009). Post-traumatic stress symptom severity scores fell in the moderate range of severity for both HIV related and general traumas. No differences were found in trauma scores based on mode of transmission or developmental level (adolescents versus young adults).

Provider ratings of adherence and viral load were correlated with PTSS. IHLC did not demonstrate a significant indirect effect on the relationship between treatment adherence and PTSS. Difficulties in recruitment for this study point to the many stressors facing youth with HIV and the barriers to successful recruitment of ethnic minority participants in research. Findings highlight the need to address psychosocial problems among youth with HIV, in particular, post-traumatic stress, in order to improve treatment adherence and health outcomes in data (Hans et al., 2009).

From 1981 to 1986, treatment of HIV and AIDS focused on therapies to treat the opportunistic infections caused by organisms from protozoa, parasite, bacterial and viral families, such as Candida, Toxoplasmosis, Histoplasmosis, Cryptococcus, and Coccidioides. However, there was no drug that could halt or alter the progression of HIV in the body. AIDS activists loudly insisted on the need for a drug that would fight the virus, if not cure it, then at least halt the virus' progressive attack on the body (Pope, White, & Malow, 2009).

Scientific discoveries in 1983-1984 by Robert Gallo and Luc Montagnier identified HIV as the cause of AIDS. Subsequent research showed that HIV causes AIDS primarily by destroying the body's immune system. HIV primarily infects white blood cells known as CD4<sup>+</sup> T-cells but also infects macrophages and dendritic cells. During the first few weeks of infection, HIV replicates rapidly, and patients experience a sharp decline in CD4<sup>+</sup> T-cells. As the body fights back, through the production of HIV antibodies and CD4<sup>+</sup> T-cells, viral replication is contained (Nattrass, 2007).

First introduced in 1986, HAART (Health Policy Project, 2013) treatment has evolved from mono (single)-drug therapy (AZT or Zidovudine) to dual-drug regimens (including AZT plus ddI, or AZT and/or ddI with d4t and 3TC) to triple-drug therapy, usually adding a protease inhibitor, in 1996. Single-drug therapy has been shown to have little effect on morbidity, add less than one year of disease-free survival and have no real beneficial effect on the length of life (Nattrass, 2007). In 1986, people infected with HIV gleaned renewed hope for survival when the Food and Drug Administration (FDA) approved the use of an experimental drug, zidovudine (AZT; ZDV; Retrovir), for the treatment of HIV and AIDS. AZT was a nucleoside analogue reverse transcriptase inhibitor drug that had originally been developed for the treatment of cancer but had so many toxicities in animal studies that it was withdrawn from further study (Pope et al., 2009; WHO, 2013c).

However, AZT became one of the first drugs tested in HIV clinical drug trials, and initial results showed great promise of efficacy. Over the next 10 years, AZT would become a household word, singularly associated with a deadly disease called AIDS. People taking AZT reported a variety of side effects, such as anaemia and fatigue, and drug toxicity became a concern. The AZT dosage initially recommended was replaced with a lower and less toxic dosage. However, a new problem arose. Some patients became drug resistant after 6 to 18 months of AZT therapy. Hope for a cure began to fade in the AIDS community, and questions began to be raised about the safety and efficacy of AZT. At this point, researchers began to study medication adherence in HIV care (Pope et al., 2009). Nevertheless, the focus of HIV and AIDS infection at this stage was not yet directed towards young people and adolescents, as such impact of treatment on adolescents could not be specifically investigated.

The rate of evolution of antiretroviral therapy has been phenomenal since the late 1980s when the first agent, zidovudine, was introduced. Huge amounts of research and investment have resulted in more than 20 licensed drugs from five individual classes, with more agents and classes in various stages of development. Highly active antiretroviral therapy as a combination of at least three drugs from two or more classes became possible with the advent of a second HAART treatment class, protease inhibitors. Following the introduction of HAART treatment in the mid- to late 1990s, dramatic reductions in both HIV and non-HIV related morbidity resulted (Hall, Hall, & Cockerell, 2011).

The development of a multi-drug combination therapy for treatment of HIV disease is considered one of the great success stories of modern medicine. In a period of approximately 10 years, the death rate from HIV disease was reduced by 50 to 80% and

changed from a nearly universally fatal and catastrophic illness to what is now often a manageable chronic illness. The story of how this was accomplished, however, is less well known than the outcome itself, which has been widely heralded in the medical and public media. The story of this accomplishment, though, has often been widely distorted in the popular press and varies considerably between countries (DoH, 2008).

HAART comprises a combination regimen to reduce viral load to undetectable levels. With HAART, the CD4 cell count rises and remains above the baseline count. Over time, HIV infection undermines the immune system through direct and indirect means, and the patient eventually develops AIDS. HAART treatment suppresses HIV, maintaining the integrity of the immune system and postponing development of opportunistic infections (DoH, 2008).

Antiretroviral therapy in adolescents preserves or restores immune function and provides sustained suppression of viral load as it does in adults. The general guidelines for the treatment of adolescents are as follows: all HIV and AIDS-infected children should be started on HAART treatment immediately. Children between one and five years of age should be started on HAART treatment when they are symptomatic or if the CD4<sup>+</sup> T-cell count is less than 750cells/mm<sup>3</sup>. Children who are five years and older should be treated with HAART treatment when they are symptomatic or with CD4<sup>+</sup> T-cell counts less than 350cells/mm<sup>3</sup> (Van Dyk, 2012; WHO, 2013c).

Today, four classes of antiretroviral medications are widely used, and several antiretrovirals are available in each class, but resistance and cross-resistance to these medications can occur very quickly if the patient does not adhere to strict medication dosing guidelines. One method to improve paediatric adherence to antiretrovirals is to focus on identified determinants of adherence at clinical visits, but very few studies have been conducted to identify determinants of adherence to antiretrovirals and the best methods to measure adherence in the paediatric population. This research synthesis found that adherence factors related to children can be divided into child-identified factors and caregiver-identified factors. Child-identified factors include medication-related, demographic-related, cognitive-related, psychosocial-related, and biological marker-related barriers to adherence. Caregiver identified factors include medication-related, cognitive-related, relationship-related, and psychosocial-related barriers to adherence (Delaney, 2006).

Rather than being the work of any single group, the development of HAART treatment is seen to be attributed to a long string of discoveries by multiple groups and individuals beginning in the 1970s, built upon in the 1980s, and brought to their ultimate fruition in the

1990s. Major contributions came from people working in basic science, biochemistry, drug development and clinical testing in dozens of institutions and companies. It was only through these collective contributions that the success heralded in the mid-1990s came to be, and it is only through similar, continuing contributions that patients today are benefiting from the potency, durability and ease of use associated with today's best regimens. It is a disservice to science, however, to suggest, as the media has done, that any individual or group was primarily or most responsible for these advances. Instead, they are the work and accomplishment of the entire field of HIV medicine (Delaney, 2006).

Historically, effective HAART treatment generally requires a minimum of three agents used in combination to show real benefits in disease-free survival times and quality of life. HAART treatment includes combinations of three and as many as five drugs, usually from one to three classes of drugs, multiple regimens and combinations, and intensive monitoring of patients for resistance. HAART treatment is an individualised treatment that evolves over time as patients develop resistance or side effects that cannot be tolerated, requiring alternative drug combinations. HAART treatment must be taken for life and requires high physician and patient compliance to be effective. For those who can comply with the therapy, it can greatly enhance the length and quality of life (Van Dyk, 1999).

In the paediatric population, antiretroviral therapy increases survival and reduces complications of HIV and AIDS, including opportunistic infections, improves growth and neurocognitive function, and leads to better quality of life. HAART treatment has taken HIV infection from a rapidly terminal illness to one that is a slowly progressive, chronic illness. HIV and AIDS-infected children can now live long, normal lives (Durham & Lashley, 2010). The implementation of highly active antiretroviral therapy among HIV and AIDS-positive youth results in immune reconstitution, slower progression of HIV and AIDS disease, and a decrease in the occurrence of opportunistic infections (Shrestha, Sudenga, Smith, Bachman, Wilson & Kemp, 2010).

### **2.3.2 Classes of Antiretroviral Treatment and their Mechanism of Action**

The main classes of antiretroviral treatment drugs that interfere with viral enzymes are nucleoside and nucleotide reverse transcriptase inhibitors (NRTIs and NtRTIs); non-nucleoside reverse transcriptase inhibitors; protease inhibitors (PIs); and integrase inhibitors (not available in Southern Africa) (Hall, Hall & Cockerell, 2011). The combined use of these agents shows great promise in reducing viral load and increasing longevity; however, significant toxicities and drug-drug interactions complicate therapeutic decisions. Patients

tend to be on multiple drug regimens for a variety of HIV related conditions, and individuals with an AIDS diagnosis have a higher incidence of drug reactions than the general population (Hall et al., 2011). These reactions or effects are discussed below.

### **2.3.2.1 Nucleoside Reverse Transcriptase Inhibitors (NRTIs)**

NRTIs remain the core of initial therapy and are also important in subsequent lines of treatment. NRTIs work by becoming part of HIV's DNA, thus derailing the HIV building process. Once damaged, HIV DNA cannot work to take control of the cell's DNA (Pope, White & Mallow, 2009). The four inhibitors are discussed next.

#### **2.3.2.1.1 Zidovudine**

The major toxicities associated with zidovudine are anemia and neutropenia. They are inversely related to the CD4 lymphocyte count, haemoglobin concentration, and granulocyte count and directly related to dosage and duration of therapy. Significant anemia most commonly occurs after four to six weeks of treatment. Granulocytopenia usually develops after six to eight weeks of therapy. Therefore, frequent monitoring of complete blood counts with differentials, haemoglobin, and haematocrit is recommended during the first eight weeks of treatment (Sande & Volberding, 1999).

Although lithium and hematopoietic factors (for example, filgrastim, sargramostim) have been used in the management of neutropenia, the current data is insufficient to support the efficacy and safety of these agents. The treatment of anemia requires multiple blood transfusions. Erythropoietin (EPO) is indicated for the treatment of anemia associated with zidovudine. Severe headache, myalgia, nausea, malaise and insomnia also may occur in zidovudine-treated patients. These side effects tend to wane despite continued therapy. Seizures, macular edema, and the Stevens-Johnson syndrome were reported with zidovudine, although the causal relationship is uncertain. Zidovudine was also associated with rare but potentially fatal cases of lactic acidosis in the absence of hypoxemia, in addition to severe hepatomegaly with steatosis. If a patient receiving zidovudine develops tachypnea, dyspnea or a fall in serum bicarbonate concentrations, lactic acidosis should be suspected, and the drug should be discontinued. Caution should also be exercised when zidovudine is prescribed to patients with hepatomegaly, hepatitis, or other risk factors that could cause liver disease (Guilfoile, 2011).

#### 2.3.2.1.2 *Didanosine (2', 3'-Dideoxyinosine)*

The major clinical toxicities associated with didanosine therapy include peripheral neuropathy and pancreatitis. Didanosine-associated neuropathy includes tingling, burning, or aching sensation in the hands and lower extremities, especially the soles of the feet. An intermittent, shooting 'electrical' pain in the legs that lasts for longer than one hour is also described. The drug should be withheld in individuals developing severe neuropathic pain. Two to 12 weeks may be required before the peripheral neuropathy subsides. After the drug is discontinued, the pain tends to progress or worsen before it improves (Sande & Volberding, 1999).

Pancreatic normally occurs during the first one to six months of didanosine therapy and resolves within one to three weeks after discontinuing the therapy. Patients present symptoms of vague abdominal pain, nausea and vomiting. Certain patients also experience an increase in serum triglyceride or glucose concentrations prior to the onset of pancreatitis. Amylase and lipase concentrations should be checked at baseline and then periodically or as needed if pancreatitis is suspected. Retinal changes, optic neuritis, and fulminant hepatitis have been associated with didanosine therapy. Patients should undergo periodic retinal examinations. Other dose-limiting toxicities include elevation in liver function test values, diarrhea, and asymptomatic hyperuricemia (Sande & Volberding, 1999).

#### 2.3.2.1.3 *Zalcitabine*

The most common adverse effects reported with zalcitabine is a dose-dependent sensorimotor peripheral neuropathy, with a 'stocking-glove' distribution primarily in the feet, occurring in 17% to 31% of treated patients. The neuropathy experienced with zalcitabine is characterised by numbness and burning dysesthesia. These symptoms usually become apparent during the first 7 to 24 weeks of therapy. If the drug is continued despite complaints, sharp shooting pains or severe continuous burning pain may develop, requiring opiate analgesics for relief. Additionally, patients may experience gait disturbances. When the drug is stopped, pain may progress or worsen for an additional three to four weeks. Recovery may require up to 3 to 18 weeks following interruption of therapy. Damage can become irreversible if the drug is not discontinued or the dose reduced as soon as the initial manifestations are noted (Schietinger et al., 1999).

Other potential adverse effects include esophageal ulceration, congestive cardiomyopathy, arthralgias, and dermatologic eruptions. Rash occurs fairly commonly and develops during

the first four to six weeks of therapy but usually resolves despite continued therapy. Caution must be taken in patients with a prior history of pancreatitis and in those with other risk factors for pancreatitis, such as alcohol abuse. Baseline serum amylase and lipase concentration should be checked in these situations (Schietinger et al., 1999).

#### 2.3.2.1.4 *Stavudine*

The most frequently reported adverse effect with stavudine is peripheral neuropathy, and it occurs in 15% to 21% of patients treated with stavudine. As with zalcitabine, the neuropathy is characterised by numbness, tingling or pain in the feet or hands. The drug should be withdrawn promptly at the onset of neuropathy. Patients should be counselled that symptoms may get worse when the drug is discontinued. Once the neuropathy comes to an end, the drug can be resumed at half the recommended dose (15 to 20mg twice daily). Other adverse effects that occur less frequently with stavudine include arthralgia, hypersensitivity, myalgia, anemia, asthenia, gastrointestinal disturbances, headache, and insomnia (Schietinger et al., 1999).

#### 2.3.2.1.5 *Lamivudine*

In certain paediatric patients treated with lamivudine, monotherapy developed pancreatitis. Paresthesias and peripheral neuropathy have also been reported. Other side effects include rash, cough, dizziness, fatigue, GI distress, headache, insomnia, and hair loss (Schietinger et al., 1999).

#### **2.3.2.2 *Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs)***

NNRTIs attached to the reverse transcriptase enzyme, preventing the enzyme from converting HIV RNA into DNA. NNRTIs hit the same target as the NRTIs but through a different mechanism that involves blocking a pocket of the RT enzyme. Insertion of an NNRTI into the pocket of the enzyme changes its shape, preventing the enzyme from making DNA. Since the NNRTIs and NRTIs have a different mechanism of action, often viruses that are resistant to one class of the drugs are not resistant to the other class of drugs. Side effects of these drugs include short-term central nervous system changes such as drowsiness, insomnia and hallucinations. There is also a risk of liver toxicity *with* all these agents. These drugs may also cause an increase in total cholesterol levels (Guilfoile, 2011).

#### 2.3.2.2.1 *Nevirapine*

The major side effect associated with nevirapine is rash, which occurs in 33% of patients. Stevens-Johnson syndrome, which may be a severe and even life-threatening reaction, may develop in up to 0.5% of patients. Liver toxicity was also noted with nevirapine (Schietinger et al., 1999).

#### 2.3.2.3 **Protease Inhibitors (PIs)**

Protease inhibitors worked at a later stage in the replication process. The protease inhibitors drugs worked by preventing the protease enzyme from effectively cutting HIV viral proteins into virions. The defective virions were then unable to infect other CD4<sup>+</sup> cells. The protease inhibitors bind competitively to the substrate site of the viral protease. This enzyme is responsible for the post-translational processing and cleavage of a large structural core protein during the budding from the infected cell. Pharmacokinetic enhancement of protease inhibitors by concomitant administration of low-dose ritonavir inhibits cytochrome P450-mediated metabolism of protease inhibitors. Metabolic complications such as insulin resistance, hyperlipidaemia and truncal fat accumulation are well described with protease inhibitors (Adler, Edwards, Miller, Sethi, & Williams, 2012).

#### 2.3.2.3.1 *Saquinavir*

Saquinavir produces diarrhea, nausea, abdominal discomfort, flatulence, and rash. In certain, cases, hypoglycaemia, hypertriglyceridemia, elevated calcium, potassium, and creatine kinase level have been noted (Guilfoile, 2011).

#### 2.3.2.3.2 *Delavirdine*

As with nevirapine, rash is the most common adverse effect noted with delavirdine and generally occurs within the first three weeks of therapy (Maartens et al., 2012).

#### 2.3.2.3.3 *Indinavir*

The most common, preventable adverse effects of indinavir are nephrolithiasis, which presents flank pain with or without hematuria within the first year of treatment. The formation of stones is generally painful but does not produce any permanent renal damage (Beal, Orrick, Lora, & Vandonkelaar, 2011).

The renal calculus is largely composed of a urinary precipitate of pure indinavir. Patients should be advised to drink 1.5 litres of fluids daily to prevent the development of stones. Patients should also stop indinavir therapy and call their physician immediately when severe back pain or bloody urine develops (Beal et al., 2011).

#### 2.3.2.3.4 *Ritonavir*

Ritonavir is the least-tolerated protease inhibitor, as 4% to 17% of patients discontinue the drug within the first week of therapy because of adverse reactions. The most frequently reported adverse effects of ritonavir include nausea, diarrhea, vomiting, anorexia, abdominal pain, taste perversion, circumoral and peripheral paresthesias (Beal et al., 2011). Patients should be informed that these effects tend to be mild to moderate and diminish with time in most cases. Additionally, clinicians should monitor patients for significant elevations in triglycerides, blood glucose values (Beal et al., 2011).

#### 2.3.2.3.5 *Nelfinavir*

Nelfinavir is the best-tolerated protease inhibitor. The most notable side effect of nelfinavir is diarrhea, which is generally controlled with oral antidiarrheal agents. In addition to diarrhea, patients may develop abdominal pain, nausea, flatulence or rash (Beal et al., 2011).

### **2.3.3 Current Trends of HAART Treatment in South Africa**

SA Journal of Medicine (2013) reports that in late 2012, the South African Minister of Health, Dr Aaron Motsoaledi, announced that fixed-dose combination (FDC) antiretroviral drugs would be used in the first line treatment of HIV positive patients from 1 April 2013. FDC is a combination of two or more active drugs in a single pill. The FDC ARV that will be rolled out in South Africa is a single tablet which contains a combination of the tenofovir (TDF), emtricitabine (FTC) and efavirenz (EFV). FDC is simpler, more effective and cheaper than the current regimen. The National Department of Health managed to negotiate R89.37 per month for FDC treatment. This is a significant saving from the old, single-drug tender.

The primary endpoints of FDC are adherence, especially of HAART treatment, and the quality of life of patients. The simplicity of the therapeutic regimen is an added value of HAART treatment that increases adherence and may improve long-term success (Tashima & Mitty, 2006; Maggiolo, Airoldi, Trotta, Sette, Bisi, Mussini, Bai, Bini, Orofino & Gori, 2008). The changeover to FDC will have a major impact on the quality of lives of people living with

HIV in South Africa. With the introduction of FDC, all new patients, pregnant women and breastfeeding mothers will be offered FDC. The main difference between FDC and the current ART regimen is that these patients will have to take one pill once a day instead of three or more pills multiple times a day (South African Journal of HIV Medicine [SAJHIVMED], 2013). Pill burden and scheduling are two of the factors associated with suboptimal adherence. An FDC combines the benefit of low pill burden (one pill) with the simplest scheduling (once daily) (Pujari, Dravid, Gupte, Joshi, & Belle, 2008; Agyarko-Poku, Sarkodie, & Atakorah-Yeboah, 2014).

FDC is more convenient, easier to take and has fewer side effects. The patient will also have to undergo fewer laboratory tests once he or she is on treatment (SAJHIVMED, 2013). The patient's judgement about simplicity, convenience, tolerability and efficacy of the FDC is significantly more positive when compared with the use of the same drugs and single pills (Maggiolo et al., 2008).

All HIV positive pregnant women, regardless of their CD4 count, will start FDC from 14 weeks of pregnancy and continue throughout the breastfeeding period. Following the breastfeeding period, women with CD4 counts less than 350 will peripherally continue FDC for life. There is hope that this will reduce mother-to-child transmission during the infant feeding period (SAJHIVMED, 2013). Pujari et al. (2008), however, mentioned that a limitation is the teratogenic effect associated with EFV, which necessitates careful use or avoidance of this regimen in women who are pregnant or who may become pregnant.

Although a majority of patients find the multiple dose regimes cumbersome, in a study by Agyarko-Poku et al. (2014), patients were found to be sceptical about the use of the fixed-dose combination treatment regime. The new regime may result in overdosing if they find it inadequate to provide the needed protection. Fear of serious adverse reaction from a combination of ARVs compared with separate drugs may discourage them from taking the treatment. Intensive adherence counselling, taking care of the above concerns, is essential before patients are switched to the fixed-dose ARV regime.

#### **2.3.4 The Goals of Antiretroviral Treatment Therapy**

Antiretroviral treatment has four primary goals. The first is virological goal, which is to reduce the HIV viral load as much as possible, preferably to undetectable levels for as long as possible. The second is immunological goal, which aims to restore and preserve immunological function so as to improve immune functioning and delay the onset of AIDS.

The third goal is therapeutic, and it improves the quality of the HIV-infected person's life. Lastly, there is the epidemiological goal, which entails reducing HIV related sickness and death and to reduce the impairment of HIV transmission in the community (Van Dyk, 2012; WHO, 2010).

The aforementioned four goals are achieved by suppressing viral replication as intensely as possible and for as long as possible by using tolerable and sustainable treatment for an indefinite period of time. By so doing, the CD4<sup>+</sup> T-cell lymphocyte count usually increases progressively with partial restoration of the immune system, dramatically reducing the morbidity and mortality associated with HIV infection (Pope et al., 2009).

Working together in combination, the drugs from different antiretroviral classes were able to block HIV at several points in its replication, slowing its spread in the body. This strategy became known as highly active (or highly aggressive) antiretroviral therapy (HAART). However, the powerful new drugs have side effects. Patients complained of nausea, inability to focus, and a general feeling of 'feeling lousy.' More severe side effects included fat redistribution and elevated serum cholesterol and triglycerides, which could indicate increased risk for cardiac disease (Pope et al., 2009).

Antiretroviral treatment is used mainly to treat established HIV infection and to prevent HIV infection of mother to child and post-exposure prophylaxis after occupational exposure, rape or sexual assault. HIV is currently treated with antiretroviral agents that block the actions of specific enzymes that are necessary for the interpretation of HIV ribonucleic acid (RNA) and the production of infectious virions. Genetic mutations of HIV occur spontaneously and frequently (Treisman & Angelino, 2004). A great many mutations are silent, that is, they produce an HIV particle that is less able to function or cease the production of an essential product, such that the virion produced is no longer viable. The troublesome mutations are those that alter the reverse transcriptase or protease enzymes slightly but significantly so that the antiviral drugs cannot stick to them and inhibit their action.

This mutant virus can continue propagation in the presence of antiviral medication (Treisman & Angelino, 2004). A wild-type virus, or the virus as it evolves in the absence of antiviral drug, has the best ability to infect and reproduce in the host. A mutant virus is usually less well adapted and will not survive unless an antiviral drug is present. This means that ideally patients take either no antiviral drug or take sufficient antiviral drug to completely stop viral replication and prevent mutations from developing. Perfect adherence increases the likelihood that the medications will suppress the formation of the virus almost completely and

thus give the body's defences an advantage in the fight against HIV. With current treatment, HIV is not eradicated from the body, but with ideal adherence, viral production is nearly completely suppressed, and the disease process can be interrupted, perhaps indefinitely (Blanchardt et al., 2013).

The first patients treated with antiretroviral medications received a single agent, zidovudine, because that was the only agent available. It was quickly discovered, however, that spontaneous mutations led to HIV strains that had less sensitivity to zidovudine in patients treated for six months or more. Such evidence led to the development of combination therapy or HAART. By using multiple agents, the rate of viral replication is slowed down so much that few mutations occur, and mutations that allow resistance to one agent do not protect the virus from another agent's effects (Treisman & Angelino, 2004).

### **2.3.5 Indicators of the Effectiveness of HAART Treatment**

The effectiveness of antiretroviral therapy should be monitored by looking at the HI viral load. Viral load tests should be done on the following occasion: baseline, before commencing HAART treatment. They must also be carried out six to eight weeks after commencement of therapy and, thereafter, every four to six months (Reeves & Derdeyn, 2007). It becomes clear that a patient's HAART treatment is effective when the viral load is low, preferably to undetectable levels. An increase in viral load indicates that the treatment is not working and that a patient's drug therapy needs to be re-evaluated and changed. The CD4<sup>+</sup> T-cell count is not a good indicator of HAART treatment failure and should preferably not be used to indicate the effectiveness of HAART treatment (Adler, 2001; WHO, 2010). A person with optimal virological suppression can in some cases have low CD4<sup>+</sup> T-cell count responses, and if the low CD4<sup>+</sup> T-cell count is taken as evidence of HAART treatment failure, the HAART regime will be inappropriately switched. The Southern African HIV Clinicians Society recommends that failure of HAART should be defined only on the basis of viral load, irrespective of the CD4<sup>+</sup> T-cell response (Reeves & Derdeyn, 2007).

### **2.3.6 Regimen Adjustment of HAART Treatment**

Because there are only a limited number of drugs available, careful consideration should be taken before changing antiretroviral therapy. Antiretroviral medication should be changed under the following circumstances: when the patient shows intolerance to the medication, despite adequate and appropriated treatment. Furthermore, treatment can be changed when

there is drug toxicity or when virological failure occurs, or when the viral load increases or shows an insignificant decline despite treatment (Hall et al., 2011).

Antiretroviral regimens imply a combination of certain drugs and range as follows:

Regimen 1    2 NRTIs:        for example, Zidovudine or Stavudine + Lamivudine or Didanosine Plus either

                  1 NRTI:        Nevirapine or Efavirenz

Or

                  1 PI :            Nelfinavir, Saquinavir soft gel or a low dose Ritonavir boosted PI

Or

                  2 PIs    :        for example, Saquinavir + Ritonavir

Regimen 2    3 NRTIs:        Zidovudine, Lamivudine + Abacavair (Adler, 2001).

When it comes to antiretroviral regimens for the initial treatment of chronic infection in adults, choice would depend upon efficacy, tolerability, and adherence and resistance profile of the regimen. Effective combination therapies are transforming HIV infection from an acute condition into a long-term chronic illness that is manageable and survivable. Regimens are becoming increasingly simple and tolerable, yet strict adherence is still required for optimal benefits for most regimes. Furthermore, regimens should also correspond to an individual's personal preferences and lifestyle to help ensure the high adherence that is required (Pope et al., 2009).

### **2.3.7 Assessment of Immune Status and Viral Load**

To manage HIV infection, opportunistic infections and AIDS, it is important to monitor the individual's CD4<sup>+</sup> T-cell lymphocyte count, as well as the viral load in the blood on an ongoing basis. CD4<sup>+</sup> T-cell counts are important to evaluate the status of the immune system; they indicate when to start to prevent or treat opportunistic infections and diseases and indicate when to start antiretroviral treatment (Van Dyk, 1999).

Viral load test is important to assess the severity of the HIV infection by revealing how far the immune system has been eroded; prescribe relevant antiretroviral medication; measure the person's response to antiretroviral treatment; and detect antiretroviral resistance (Van Dyk, 2012). The viral load is usually undetectable after six months of treatment.

### **2.3.8 Section Synopsis**

Given that the developmental issues of adolescence challenge the likelihood of successful adherence to HAART treatment, that the social context of many adolescents with HIV is unsupportive of adherence, and that the medical consequences of non-adherence are extremely serious, it is important that adolescents receive assistance in adhering to HAART treatment.

## **2.4 CONCEPTUALISATION OF ADHERENCE TO HAART TREATMENT WITH REGARD TO ADOLESCENTS**

This section looks at the conceptualisation of HAART treatment adherence by adolescents by focusing on the goals of HAART treatment. Furthermore, aspects contributing to both adherence and non-adherence to HAART treatment are also described.

### **2.4.1 Measurements of Adherence to HAART Treatment**

HIV positive adolescents are becoming a progressively more sizeable and prominent subgroup in the South African HIV and AIDS epidemic. As HAART treatment becomes increasingly available, vertically infected children can be expected to survive into adolescence and adulthood. Additionally, sexual transmission of HIV and AIDS remains a problem, and incidence and prevalence rates among South African youth are high (Li, 2009).

Adolescence, comprising roughly the second decade of life, is a key phase of human development during which children transition into adulthood. These years are characterised by major changes at the biological, psychological, and social levels, differentiating them from other stages of development. With the exception of early infancy, the changes which occur during adolescence are greater than in any other period of life (Li, 2009).

At a biological level, adolescents undergo puberty, during which they develop primary and secondary sex characteristics, the capacity for reproduction, and a mature physical appearance. These physiological events also have psychosocial implications as adolescents adjust to their changing bodies, redefine their self-image, and learn to manage their emerging sexuality. At a cognitive level, adolescents develop decision-making skills, greater short and long-term memory, and the ability to think critically and abstractly (Williams, Holbeck, & Greenley, 2002). Cognitive development is accompanied by an enhanced ability

to self-conceptualise, and accordingly, identity formation is also a crucial task of this period. At a social level, parent-child relationships are transformed as adolescents learn to make decisions independently and function autonomously (Williams *et al.*, 2002). Simultaneously, the peer group becomes increasingly important as young people seek intimacy and acceptance outside of the family unit.

Adolescents have to navigate major demands placed upon them by society. Progression through school, entry into the labour force and all the adjustments which accompany these events also occur during this period. These local interactions take place within wider societal frameworks, which carry dominant streams of expectations, values and ideologies. Adolescents must learn how to navigate these structures in order to become successful and active participants in society. HIV affects adolescents at each of the three previously mentioned axes of development. Biologically, perinatally infected children go through puberty significantly later and are smaller than their HIV-negative peers. From a social standpoint, autonomy from parents, peer acceptance and participation in society are complicated by the desire for secrecy about serostatus and fears of stigma or rejection (Li, 2009).

In addition to dealing with these direct encumbrances to standard developmental processes, HIV and AIDS-positive adolescents must also confront a number of challenges. For these young people, the transition from childhood to adulthood is interlaced with concerns about medication regimens, doctor's appointments, life expectancy, disclosure, and transmitting HIV to others. Of course, the virus poses similar concerns for HIV positive individuals at other life stages. However, the extensive changes that characterise adolescence make the second decade of life particularly unique. The combination of ordinary developmental issues with HIV related worries creates a distinctive environment which frames adolescents' daily experiences and their interactions with health care systems (Li, 2009).

Adherence entails sticking to the treatment plan by the patient. The prescribed HAART treatment must be taken at the right time and in the right dosage daily. The patient must meet scheduled medical appointments. The patient must collect medical repeats. Adherence arises from agreement, based on mutual understanding on the required action, between the patient and the experts as partners (Turner, 2002). Nothing could be more obvious than the simple fact that medications only work when people take them. The goal of antiretroviral therapies is the complete suppression of HIV replication. Although medication regimens vary in terms of just how much adherence is needed to achieve viral suppression, most combinations of medications require at least 85% adherence. Minimal levels of adherence

needed to sustain viral suppression are not necessarily the same across compartments of the immune system. Viral load can have transient spikes or rebound in the genital tract, even when blood plasma viral load remains undetectable. Studies show that the risk of HIV transmission among people receiving treatment can be as high as 22%. Another complicating factor is that treatment regimens vary in their penetration of the genital tract. High concentrations of most nucleoside and non-nucleoside reverse transcriptase inhibitors are recovered from the genital tract, whereas protease inhibitors achieve lower drug concentrations in this compartment (Kalichman, 2013).

The goal and benefit of HAART treatment may be defined both clinically and biologically. Clinically, HAART prolongs life and improves the quality of life of those living with HIV and AIDS, by reducing, as much as possible, the frequency of the HIV and AIDS-related illness that is known as AIDS. By reducing the mortality rate due to HIV and AIDS, ARV drugs also have the controversial effect of increasing the number of people living with HIV and AIDS because they tend to live much longer than they would do without the treatment. Biologically, HAART treatment is responsible for the immune reconstitution that is both quantitative (referring to the CD4 cell count in normal range) and qualitative (referring to the pathogen-specific immune response). HAART treatment also causes the greatest possible reduction in viral load (preferably to less than 50 *c/ml*) for as long as possible, in order to halt disease progression and to prevent or to delay progression (Bartlett, Gallant, & Conradie, 2008).

For teenagers with any chronic illness, adhering to treatment is particularly challenging from developmental and psychosocial reasons. Developmentally, teens often feel invincible, immortal, like they are living in the moment, and do not realise the long-term consequences of their actions (LaGreca, 1990). Perinatally infected adolescents have been exposed to HAART treatment, and in most studies, over 50% have successful viral control, resulting in longer and healthier lives. However, these adolescents have multiple risk factors for mental illness. Living with a chronic disease is associated with increased rates of mental illness and many older adolescents were infected prior to the advent of HAART treatment and may have had a period of ineffective therapy with resultant uncontrolled viral infection in the central nervous system. Many have lost a biological parent to HIV and AIDS and may be living with another relative or foster parent. These adolescents are also frequently subjected to environments of poverty, crime, and substance abuse. The HIV epidemic in adolescents now includes mostly those infected through high-risk behaviour. Similar to the perinatally infected adolescent, behaviourally infected teens generally live in areas of high poverty, crime, and substance abuse. Unlike those infected perinatally, these teens usually live with a biological

parent. Mental illness and substance abuse rates are predicted to be high in this population, since both are associated with high-risk sexual behaviours (Palmer, 2011).

Understanding prevalence rates and types of mental illness is important to practitioners treating HIV-infected adolescents. Mental illness and substance abuse in the HIV and AIDS-infected adolescent may lead to poor adherence to antiretroviral therapy and risky sexual practices. Prevalence rates for psychiatric disorders in perinatally infected children vary depending on the type of study but generally are 55-61%. The most common disorders found are anxiety disorders (24.3-49%) followed by attention deficit hyperactivity disorders (ADHD) (14-28.6%), conduct disorders (1-12%), oppositional defiant disorders (16.7%), and mood disorders (4.3-25%). Compared to the general population, psychiatric disorders are higher in HIV-infected children. The prospective cohort study of Gaughan, Hughes, Oleske, Malee, Gore & Nachman (2004) regarding the long-term effects of in utero and/or postnatal exposure to HIV and antiretroviral therapies found the rates of psychiatric hospitalisation in HIV-infected children (4-17 years of age) to be about six times higher than of infected youth reported ever having a substance abuse problem. Older adolescents are at a higher risk of substance abuse, which may increase risk-taking behaviours and medication non-adherence (Palmer, 2011).

HIV and AIDS clinicians should, therefore, be aware of possible mental health problems such as anxiety disorders and ADHD in perinatally exposed/infected youth and mood disorders in behaviourally infected youth. Therapy for psychiatric conditions in HIV-infected youth includes both behavioural and pharmacologic therapy. Approximately 20% of HIV-infected youth are treated with psychotropic drugs and between 25-50% receive some form of behavioural intervention. Psychotropic medications most frequently used include stimulants for ADHD, antidepressants, and antipsychotics for mood disorders. When compared to HIV-exposed but uninfected youth, HIV perinatally infected youth are more likely to be treated with medications and behavioural therapy for mental disorders. This difference may be explained by a disparity in interaction with health care providers between HIV positive and HIV-negative youth, although evidence to support this theory is needed. Selective serotonin reuptake inhibitors (SSRIs) are the most common pharmaceutical agents used for moderate to severe depression (Palmer, 2011).

Palmer (2011) states further that practitioners should also be aware of the many drug interactions that can occur between psychotropic medications and certain antiretroviral agents, antibiotics, and antifungals. Studies evaluating the efficacy of behavioural therapy in HIV-infected youth are extremely limited but suggest that group intervention may decrease

stress and improve behaviours such as improved medication adherence and safe sex practices. Mental illness has been associated with poor medication adherence in adults. Poor adherence was associated with low self-efficacy (one's sense of being able to adhere to medications prescribed) and low outcome expectancy (one's sense of benefit from antiretroviral drugs).

More than 50% non-adherence was seen in HIV-infected youth with low self-efficacy/outcome expectancy, structural barriers, and a mental health disorder. These findings were consistent between youth infected perinatally and those infected through high-risk behaviours. The only difference found between the two groups was more structural barriers related to non-adherence in the behaviourally infected group. It is not clear why a lack of association with poor medication adherence and a diagnosed mental health disorder in HIV-infected youth was not seen in these studies, but one explanation may be high rates of treatment for mental health disorders in their study population. Based on the results of these studies, the HIV clinician should address issues of self-efficacy, outcome expectancy, and structural barriers, in addition to treatment of mental disorders in order to maximise antiretroviral treatment adherence. HIV-infected adolescents have very high rates of mental illness (Palmer, 2011).

For HAART treatment to work, it requires near-perfect (95%) adherence (Paterson et al., 2000). Adherence plays a chief role in determining the quality of life, in either positive or negative ways. As social and behavioural factors affect adherent behaviour, these variables are likely to exert important influences on health care utilisation and therefore on health outcomes of people living with HIV (Abdool Karim & Abdool Karim, 2010). Adherence to HAART medication is the greatest patient-enabled predictor of treatment success and mortality of those who have access to drugs (Mills, Nachega, & Buchan, 2009).

Strict adherence to HAART is extremely important to achieve viral suppression and avoid the risk of mutation, the development of resistant strains and drug failure (Van Dyk, 1999). Drug resistance can develop very rapidly with missed or inadequate doses of medication. Missing even a few doses a week may lead to the development of drug resistance. In the case of perinatally infected adolescents, the young person's relationship with his or her primary caregiver is integral in mediating adherence. Caregivers who use drugs or alcohol, or are HIV positive themselves, are more likely to have non-adherent children, while those with a higher level of education and who are knowledgeable about their child's antiretroviral regimen tend to have more adherent children (Li, 2009).

Many perinatally infected children have survived into their second or third decade of life because of the advent of combination HAART and effective viral suppression with immunologic reconstitution. In many ways, this group represents a unique population of HIV positive adolescents compared with their counterparts who acquired HIV infection horizontally. The medical field is just beginning to learn about the complications of chronic HIV infection and the toxicities associated with HAART before and during sexual maturity. Managing the toxicities while administering suitable and necessary active HAART regimens in these heavily treated adolescents will be challenging, given the limited therapeutic options that are available (Ross, Camacho-Gonzalez, Henderson, Abanyie, & Chakraborty, 2010).

#### **2.4.2 Factors Contributing to Adherence to HAART Treatment by Adolescents**

Adherence to HAART treatment entails taking all ARV pills in the correctly prescribed doses at the right time and in the right way, including observing any dietary restriction. Soloway and Friedland (2000, p.1) define it as “the act of taking medications as prescribe a highly complex clinical behaviour.” It has also been defined as the extent to which a person’s behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical advice (Haynes, 1979).

The foregoing definition expands the concept of adherence beyond merely taking medications and includes maintaining healthy lifestyle practices, such as eating properly, getting sufficient exercise, avoiding undue stress, abstaining from smoking cigarettes, not abusing alcohol, and always practising safer sex. The word “adherence” is preferred by many health care providers, because “compliance” suggests that the patient is passively following the doctor’s orders. It is preferred that patients not be passive but rather follow a treatment plan based on a therapeutic alliance or contract between the patient and the physician (Levine, 1998).

Practitioners and researchers alike recognise that patient adherence is associated with better outcomes than patient compliance. For the purpose of this research, the term “adherence” is used rather than “compliance,” although the researcher recognises that they are often used interchangeably. The three most commonly identified factors supporting adherence were the importance of having a supportive family and community environment; having strong support groups of people living with HIV, both as self-help and as counsellors; and the importance of food security and nutrition (Schietinger, Sawyer, Futterman, & Rudy, 1999). A number of other factors were also identified which can be summarised as pertaining to accessibility (such as proximity of treatment centres, decentralised services,

timing, adapting to specific needs); affordability (of treatments, diagnostic tests, consultations, transport, child care); quality (practitioners' knowledge and skills, monitoring and support systems including psychological support); and the importance of employment or other income-generating opportunities for clients (Schietinger et al., 1999).

Some recent studies have examined HAART treatment adherence among children (including adolescents) in the context of sub-Saharan Africa. In a sample of 170 Ugandan children between the age of 2 and 18 years, Nabukeera-Barungi, Kaylesubula, Kekitjinwa, Byakika-Tusiime, and Musoke (2007) used multiple methods to measure the number of the participants who had > 95% adherence. Caregiver self-report indicated that 89.4% of children were adherent, clinic-based pill counts yielded a rate of 94.1%, and unannounced pill counts at the children's homes measured 72% compliance. The study also found that when the caregiver was the only person who knew the child's HIV status, the child was more than three times more likely to be adherent.

Additionally, children who had been hospitalised on more than two occasions exhibited better adherence than those who had not. No relationship was found between adherence and any of the other child factors, including age, gender, distance between the child's home and the hospital, orphan-status and disclosure to the child. However, a second Ugandan study did observe a relationship between disclosure and adherence. In this study, 8/12 children (aged 5-17) who knew their status had never missed a dose, compared to only 3/14 who did not know their status and 1/16 who had undergone partial disclosure (Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza, Malamba & Bunell, 2006). As expressed by the caregiver of a 14-year-old girl, disclosure helped because even when she gets tired of taking the drug, then she remembers that it is good to take the drug, and she takes it (Bikaako-Kajura et al., 2006).

### **2.4.3 Factors Contributing to Non-adherence to HAART Treatment by Adolescents**

Adolescents who are infected with HIV and AIDS also face challenges of adherence. Non-adherence to HAART treatment can be described in a variety of ways, ranging from a person missing one dose of a given drug, missing a dose of all the three drugs, missing multiple doses, not observing the time intervals, not observing the dietary restrictions, or not taking the correct dose of any drug. Non-adherence can lead to poor clinical, immunological and virological outcomes. At an individual level, the consequences of non-adherence include incomplete viral suppression, continued destruction of the immune system and decrease of CD4<sup>+</sup> cell count, progression of disease, emergence of resistant viral strains, limited future

therapeutic options, and higher cost for individual treatment which translates to higher programme costs (Wanjohi, 2009).

Whereas HAART treatment has significantly improved the lives of many patients worldwide, the lack of adherence to treatment remains a major challenge to HIV and AIDS care (Kambale, 2013). The lack of ARV adherence is the second strongest predictor of progression to AIDS and death, after the CD4 count (Machtinger & Bangsberg, 2006). Regardless of the mode of acquisition of the HIV infection, infected adolescents might have very low self-esteem, leading to depression, chaotic lifestyles, and drug addictions, together with mental illness and poor adaptation to the social environment of their disease, due to a lack of family and social support. Depression, alcohol or drug abuse, school truancy, and experiencing advanced HIV disease are correlated with non-adherence (Murphy, Belzer, Durako, Sarr, Wilson & Muenz, 2005).

Given the prevailing problem of treatment adherence in this population, research has focused on identifying factors contributing to non-adherence. Research on adults with HIV and children with other chronic illnesses suggests that post-traumatic stress disorder (PTSD), PTSS, and health beliefs may be important factors relating to non-adherence (Hans, Spiegel, Donna & Flutterman, 2009).

Advances in HIV care have given rise to a population, including adolescents, that is living longer with HIV. With the advent of HAART treatment, HIV and AIDS is now considered a chronic condition. Adherence with approximately 95% of prescribed doses is required to prevent treatment failure and development of resistance to HAART treatment – outcomes that would affect not only the individual but also the community at large. Caring for adolescents living with HIV and AIDS is especially challenging considering the impact the disease has on their well-being which impacts on their adherence to medication. Adolescents are a heterogeneous group that need to be known well if optimal care is to be provided to them (Wanjohi, 2009).

Non-adherence to HAART treatment is the leading cause of treatment failure. Not surprising, medicine adherence rates among HIV and AIDS-infected youth are poor. This population experiences many contributors to poor adherence, including mental health issues and substance abuse, caregiver fatigue and stress, HIV and AIDS stigma and disclosure, peer relations, and immature concrete reasoning. Strikingly, rates of depressive symptoms are consistently associated with lower adherence rates. For example, in the Reaching for Excellence in Adolescent Care and Health (REACH) cohort, depressed HIV and AIDS-

infected adolescents had a 55% rate of non-adherence compared with 29% in the non-depressed group. This statistic emphasises the need for depression screening and integrated mental health services for HIV and AIDS-infected youth. A recent study showed that unlike adult populations, health literacy has little effect on medication adherence among HIV and AIDS-infected youth, even after adjusting for age, education level, viral load, and self-efficacy to adhere to medication regimens. This finding underscores the uniqueness of the adolescent population and the need to identify novel solutions to improve adherence (Ross et al., 2010).

The use of hand-held personal computers to assist adolescents with HIV medication regimens and the organisation of health care appointments was studied, and it was found that most participants were willing to try this new technology (Rolando et al., 2016). Further investigation is needed to assess if these creative solutions have effects on measurable outcomes (for example, CD4<sup>+</sup> T-cell counts and plasma HIV-1 RNA levels). In the meantime, assessing barriers to medication adherence and frequent mental health screening on an individual patient level is critical to implementing strategies for improving adherence. Short-stay, hospital-based, directly observed therapy may also help if adherence is in question because a rapid decline in plasma HIV-1 RNA viremia by the end of such therapy is highly suggestive of non-adherence to ART (Ross, Camacha-Gonzalez, Henderson, Abanyie & Chakraborty, 2010).

Many perinatally infected adolescents have survived into their second or third decade of life because of the advent of combination HAART treatment and effective viral suppression with immunologic reconstitution. In many ways, this group represents a unique population of HIV and AIDS-positive adolescents compared with their counterparts who acquired HIV and AIDS infection horizontally. These are just the beginning stages of learning about the complications of chronic HIV and AIDS infection and the toxicities associated with HAART treatment before and during sexual maturity. Managing the toxicities while administering suitable and necessary active HAART treatment regimens in these heavily treated adolescents will be challenging, given the limited therapeutic options that are available (Ross et al., 2010).

Sticking to the treatment instructions for a long-term illness poses a great challenge to patients in general and with HAART treatment in particular, and adolescents are not immune to these challenges. A person who takes HAART treatment erratically will receive only marginal benefit; however, they will suffer similar side effects and will potentially limit their future treatment options. It is important that all patients demonstrate an understanding of this

before starting treatment. An adolescent who stops taking HAART treatment entirely will rapidly lose any benefit they may have received in terms of increased immunity as the virus flourishes and CD4<sup>+</sup> cells are destroyed. Adolescents must be made aware that HAART treatment is a lifelong treatment. Educating adolescents effectively and assessing their understanding can be time-consuming and labour-intensive, but it is never time wasted. Simply giving a prescription at the first visit without sufficient adherence counselling is clinically negligent, but unfortunately, this is a common practice and much more pronounced in adolescents who are inaccurately assumed to be ignorant; as a result, such education is subsequently ignored. HAART treatment providers who do not seriously address the complex issue of adherence will fail in their objective of helping their patient. At the public level, this may cause the development of multi-drug resistant strains within the population they serve, which would have dire public health implications. Adherence is therefore central to the success of HAART (Wanjohi, 2009).

Many factors associated with non-adherence to prescribed medication regimens have been identified from numerous studies. These factors range from patient variables, treatment regimen, disease characteristics, patient-provider relationship to clinical setting. With respect to non-adherence to HAART treatment specifically, a number of empirical studies and reviews have found that several factors were often associated with non-adherence, including presence of adverse drug effects, neuropsychological dysfunction, psychological distress, substance use, lack of social or family support, low patient self-efficacy, inconvenience of treatment, and poor reading literacy skills (Pope et al., 2009).

In a study by Tucker, Bien, Easterbrook, Doherty, Penazzato, Victoria & Peeling (2014), the most commonly cited barriers for adherence to HAART were as follows:

- simply forgot (39%)
- staying away from home (30%)
- slept through dose time (22.5%)
- busy with other things (18%)
- did not have adequate food (18%)

On the other hand, 10% of them reported that side effects prevented them from taking their medications.

Several factors render the combination therapies an especially challenging treatment. These include the relative absence of significant symptoms related to HIV and AIDS until later in

the course of the disease; the often prophylactic nature of treatment; indefinite duration of treatment; questionable treatment efficacy; and frequent and serious adverse effects (Pope et al., 2009). A different study shows that adolescents commonly experience such challenges as the taking of complex medication regimens and the following of a continuous medical care routine. However, adolescents might have long histories of poor adherence. Regardless of the mode of acquisition of the HIV and AIDS infection, infected adolescents might have very low self-esteem, leading to depression, chaotic lifestyles, and drug addictions, together with mental illness and poor adaptation to the social environment of their disease, due to a lack of family and social support. Depression, alcohol or drug abuse, school truancy, and experiencing advanced HIV disease are correlated with non-adherence (Murphy et al., 2005).

Botswana Ministry of Health notes that HIV and AIDS-infected adolescents have special psychosocial issues that often lead to a number of adherence problems. These include the denial of, and fear related to, HIV and AIDS diagnosis; misunderstanding related to diagnosis and health needs; lack of belief in the efficacy of HAART treatment; the distrust of family practitioners and the health care system; low self-esteem and an unstructured, chaotic lifestyle; and limited familial and social support (Kambale, 2013).

Proper education of adolescents before the initiation of and during HAART treatment is critical for the success of adherence. However, proper education before initiation of HAART treatment seems to be questionable when it comes to adolescents. Most adolescents only learn about the true reasons behind their taking HAART treatment much later while they have been taking medication for a few years; therefore, education thereof seems to have been missed, thus impacting adherence negatively. More attention needs to be given to the timing of disclosing to adolescents their HIV status. The value of an HIV positive adolescent being properly prepared for their status disclosure, so that they might come to accept the fact that they have been infected, should not be underestimated in terms of future adherence quality (Kambale, 2013).

The impact of the drug regimen on HAART treatment adherence is complex. The majority of those who are on HAART treatment are on a regimen of three or more ARVs. The likelihood of a patient's adherence to a given regimen declines with polypharmacy, the frequency of dosing, the frequency and severity of side effects, and the complexity of the regimen. Poor adherence has also been associated with patients' desire to avoid embarrassing side effects (like sweating) in certain situations such as on a date or at a job interview. Complicated regimens with rigid dosing intervals may also interrupt sleep. The physical aspects of a

particular medication (for example, taste, size or formulation) may also affect a patient's ability to adhere (Abdool Karim & Abdool Karim, 2010). Other factors cited as contributing to non-adherence relate to logistical concerns, such as missing an appointment for follow-up at the hospital. Some reasons given for missing such appointments range from being too busy or simply forgetting, to changes in the daily routines of patients (Dagneu, 2009).

Logistical considerations beyond the adolescent's control may also impact adherence to HAART treatment. For instance, the effect that the clinic setting has on HAART treatment adherence should not be underestimated. Clinic characteristics that impact on adherence include proximity to the patient's home or place of work; the expense of getting there; lengthy delays between appointments; clinic opening and closing times; long waiting times; and lack of services such as child care, privacy, confidentiality, and unsympathetic or inconsiderate staff. It is doubtful that most patients receiving ART as part of the national roll-out receive the same level of social, psychological, and instrumental support as their counterparts had in the MSF programme in Khayelitsha. Adherence levels of patients enrolled in the national HAART programme is not known. However, because of much lower levels of psychosocial support, they are assumed to be lower. In this study, attention has been called to the psychosocial barriers to optimal adherence that may potentially be faced by patients receiving HAART in the context of the national roll-out in South Africa. These barriers include poverty, health literacy, perceived social support, mental health, substance abuse, and stigma (Kagee, 2007). Adolescents also experience similar barriers as the adult population.

Strategies such as education should cover basic information about HIV and its manifestations, the benefits and side effects of ARV medications, how the medications should be taken, and the importance of not missing any doses. Adherence assessment should be combined with adherence counselling at each visit. With regard to adolescents, they tend to experience confusion and stress as a result of their rapid emotional, physical and social development, and this may cloud their understanding of adherence. Because young adolescents are just beginning to develop skills for abstract thinking, the facts and information they are given about HIV and AIDS and adherence must be direct, specific, frank and concrete (Van Dyk, 2012).

Adolescents who are infected with HIV and AIDS face diverse challenges with respect to adherence to HAART treatment. Several studies have identified the 'burden' that is placed on them to continue with the medications, which restricts their lifestyle options, leading to a situation that discourages them from wanting to keep their medications with them.

Adolescents need a general and basic overview on HIV infection that includes a clear description of how HIV is transmitted, how HIV is not transmitted, and how they can protect themselves from reinfection. Because these adolescents have already had HIV transmission, it then becomes crucial to address the often ignored issue of how they have contracted the virus (Van Dyk, 2012). An emotionally explosive area of anger and blame should preferably be allowed and responded to in a manner that acknowledges their frustration. Adolescents often tend to be rebellious against adults, and this may also apply to the refusal to take HAART treatment. This could be for a range of possible reasons including simply stopping or interrupting treatment, death, or finding alternative sources of HAART. The nature of loss to follow-up is that very often a patient's eventual whereabouts or outcome is unknown, even if efforts are made to trace such patients. Other factors involve patients feeling they need to take a break from HAART (treatment fatigue) (Kambale, 2013).

With the dramatic improvement in HIV and AIDS care over the past three decades, the infected adolescent and his or her caregivers are now faced with managing a chronic illness. In addition to caring for the physical needs of the HIV and AIDS-infected adolescent, it is imperative to recognise and address the psychosocial barriers to optimum health. Adolescence is a developmental stage characterised by immature concrete reasoning often manifested by denial of the diagnosis, a sense of invulnerability reflected by risk taking, and behaviours that are strongly influenced by peer norms. These characteristics all have a direct impact on the ability to adhere to medical recommendations in order to improve and maintain good health. Infants born early in the HIV and AIDS epidemic have now entered adolescence and young adulthood. Such individuals have lived with multiple stressors, which include having a socially stigmatised illness, the loss of one or both parents or siblings, and being raised by relatives, adoptive families, or within the foster care system (Ross et al., 2010).

As adolescents grow up, more studies are being conducted to address the impact of HIV and AIDS on the psychological and social functioning of this unique population. One study assessed 174 HIV-infected youth (aged 13-24 years) attending an inner-city clinic for exposure to violence and mental health disorders. They found rates of major depressive disorder (15%), generalised anxiety disorder (17%), and post-traumatic stress disorder (28%) to be much higher than national samples. In this study, 16% to 28% of the youth reported a history of physical or sexual assault, and 44% had witnessed family violence. HIV also has a direct impact on the child's physical and neurologic development, which may lead to cognitive delays and potential psychiatric disorders among long-term survivors (Ross et al., 2010).

A recent retrospective analysis of the psychological functioning of 81 participants (> 11 years of age) demonstrated an association of a history of severe HIV disease (Centers for Disease Control and Prevention [CDC] classification C) with psychiatric morbidity and neurocognitive delays among adolescents. In a pilot interview study of 47 perinatally infected HIV positive youth (aged 9-16 years) and their caregivers, more than 50% of the youth met diagnostic criteria for a psychiatric disorder, including anxiety disorder, conduct disorder, and attention-deficit/hyperactivity disorder. Comprehensive health care for the HIV-infected adolescent must include assessment of mental health, social and environmental stressors, and support systems, because these factors all can affect the ability to adhere to medical care and may impair the ability to reduce secondary HIV transmission (Ross et al., 2010).

Among the main challenges identified by Zuurmond (2008) were the need to tackle stigma and the need to address accessibility, affordability and quality concerns raised. Sustaining adherence of clients when these began to feel better posed huge challenges as did the disruptive nature of HAART treatment supplies in some countries. Issues specific to children and adolescents included lack of disclosure and consequent difficulty of explaining their need for medication, inadequate counselling skills for children and problems specific to guardians or grandparents. Adolescents want to explore sexual relationships, are reluctant to take medication in public, and do not want to differ from their peers (Zuurmond, 2008). Researching on experiences of HAART treatment will contribute to the understanding of factors contributing to non-adherence. The following are often cited factors related to the prescribed medication, health care system, patient and family/caregiver. Family/caregiver factors were crucial to paediatric adherence because infants and younger children depend almost entirely on a caregiver to administer medications. Their adherence to treatment, therefore, is largely determined by the resources and efficacy of caregivers. Caregivers who are biological parents of HIV positive children often share their diagnosis and confront challenges associated with their own illness and its comorbidities. In these cases, treatment can become a reminder of the parents' guilt about their role in their child's acquisition of infection, which is yet another challenge to adherence (Pope et al., 2009).

#### **2.4.4 Section Synopsis**

HAART treatment adherence is probably the most daunting challenge today's health professionals face. It can be a source of great concern and frustration. Drugs do not work in patients who do not take them, and in the management of HIV and AIDS infection, it is now well established that optimum adherence to HAART treatment is critical to the successful outcome of patients receiving treatment. As simplistic as it may seem to the observer, it

appears there are more challenges that compound the issues of both adherence and non-adherence. For effective assistance to be rendered, each case must be looked at on its own merit.

## **2.5 EXPERIENCES OF PARENTS AND CAREGIVERS CONCERNING THE ADOLESCENTS' HAART TREATMENT**

The experiences of parents/caregivers for support and guidance to care for and counsel adolescents to grow into emotionally and physically healthy youth and adults are important if one is to have a holistic understanding of HAART treatment by adolescents. The psychosocial well-being of children and their caregivers can improve adherence to HAART treatment and clinical outcomes. Parents/caregivers need manageable, consistent, and hopeful information from the outset that can help them take some initial steps/decisions for the child's well-being (Sneed, 2008). This is also an opportunity to identify any support that the parent/caregiver may need regarding his or her own HIV situation, including provision of couples testing and counselling.

In high HIV-prevalent, resource-constrained settings, limitations in human capacity, time and funds compound the challenge of providing psychosocial support at all levels – from clinics to communities, to families, and to individual caregivers and their children. Experts noted the reality that many families are struggling to meet basic needs, such as food, health care, shelter, and education costs, which leaves few resources (for example, time, caregiver energy, funds) to address the psychosocial needs of children. A few experts pointed out that finding ways to support providers/caregivers in meeting these basic needs also helps empower them to feel like they can make a tangible difference to a child. Experts stressed the importance of acknowledging and addressing these needs through holistic programmes or referral efforts (UNAIDS, 2007).

For the child, pre- and post-test counselling must be tailored to the appropriate development stage, which requires skill in being able to correctly assess and adapt both the process and manner in which counselling is provided. For older, more mature children or adolescents, it is critical to engage with them directly. Youth in both South Africa and Uganda expressed their anger at being taken for testing without being told why or given true information before or after testing: "I was hurt. They did not tell me they were taking off the blood sample for HIV testing" (a youth in Uganda). "Doctors lied to me. They gave it a funny name, told me it

was malaria. They gave my father the results, not me” (McCleary-Sills, Anjala, Brackarsh & Browsky, 2013, p8).

Many of the programmes reviewed dedicate specially trained child counsellors for this initial counselling, which youth, parents, and caregivers found helpful. Parents, caregivers, and children consistently noted the need for additional information, counselling, and support following initial HIV diagnosis to help them process emotions and develop care plans specific to the needs and situation of the child. Several HIV testing and counselling programmes have adopted standard protocols for children (dependent on age/developmental stage), including having time with both the child and the caregiver individually, as well as in a joint session. It is important to note that while guidelines exist, much depends on the individual assessment of the child (especially for younger children aged 4 to 10 years) to determine what information should be shared and how (Steele, Nelson & Cole, 2007). Creating time for joint counselling was highlighted as being a useful approach, allowing for the caregiver and child to hear and share information together with a trusted source, as well as providing an opportunity for the counsellor to observe the interactions between the caregiver and child. Some programmes, particularly those that did not offer testing and counselling services, have counsellors who can accompany a child and caregiver through testing, providing a valued touchstone and friend throughout the process and then linking children and parents to follow-up psychosocial support (Cooper, Risley, Drake & Bundy, 2007).

Although adolescents expressed a preference for being disclosed to in a clinic, health care workers have been guided to encourage parents to disclose in the home environment. This method created barriers to the initiation and completion of this process, and health care workers described having to reinforce or correct poorly conveyed concepts from caregivers who attempted to disclose in the home environment but failed to do so adequately.

Given the importance of psychosocial support to the long-term well-being of children living with HIV and AIDS, there is a critical need to ensure that continuous and individualised psychological and social services are fully integrated within a broad, integrated framework of care provided by parents, caregivers, and service providers (facility-, community-, and home-based) and adapted over time as children develop and mature (Steele et al., 2007).

## **2.6 EXPERIENCES OF HEALTH CARE WORKERS WITH REFERENCE TO THE ADOLESCENTS' HAART TREATMENT**

The experiences of health care workers respecting adolescent HAART treatment cannot be emphasised enough. Doctors and nurses are often confronted by adolescents whose adherence to HAART treatment is unsatisfactory, and it is often at these points where extra support is required to understand the circumstances of the adolescents and referral to social workers, dieticians and psychologists. Health care worker refers to any health service provider with whom the adolescent interacts with in the process of accessing health care services. Health care professionals range from medical doctors, nurses, pharmacists, psychologists, social workers, dieticians to other therapists whose goals is to improve the quality of life of the adolescents.

Because of the scale-up of antiretroviral therapy, increasing numbers of HIV-infected children are living into adolescence. As these children grow and surpass the immediate threat of death, the issue of informing them of their HIV status arises (Fair, Osherow, Albright & McKenoe, 2014). In cases where disclosure was done earlier, it might have been partial disclosure, and as these adolescents start questioning their health, an informed conversation about HIV and AIDS becomes necessary. It is at this stage where the role of health care workers becomes significant in order to clarify issues and dispel misconceptions the adolescents might have about HIV and AIDS.

Clinicians can improve the odds of youth succeeding with HAART treatment by incorporating psychosocial support into their practice. Furthermore, clinicians can enhance their psychosocial support by waiting to prescribe HAART to their adolescent clients until they have provided the appropriate preliminary groundwork (Brown & Lourie & Pao, 2000; Cluver & Garder, 2000). Psychosocial support is an essential component of ongoing care for all people living with HIV and AIDS. Psychosocial support is especially critical for children, creating the foundation from which they can establish their identity and place in society, manage their care and live positively, cope with challenges, and plan for their future (Lerner & Steinberg, 2009). The psychosocial needs of adolescents should preferably be identified based on needs specified by the adolescents.

Although adolescents are treated according to adult treatment protocols, they have special needs resulting from their stage in social and emotional development. In traditional societies, adolescence is a time for preparation for marriage and having children. Adolescence is often a time for experimentation and risk taking, which includes sexual risk taking. Special effort

must be made to ensure that adolescents understand their own feelings and frustrations, and that they know how to protect themselves against STIs and unwanted pregnancy (Hope, 2007).

Counselling, peer education, and support groups are particularly important for HIV-infected adolescents. HIV-infected adolescents have the additional burden of needing to prevent the forward infection of others with HIV and AIDS. Such adolescents will need additional psychosocial support. Abstinence and delayed sexual debut are important aspects of sex education. However, adolescents who are sexually active or who are going to become sexually active need to have knowledge about their sexuality, condoms, partner negotiation skills, and youth-friendly services available and accessible to them to prevent unwitting onward transmission of HIV. Sexually active adolescents also need information and services to protect themselves against other STIs and unwanted pregnancy (Pettifor, Rees, Kleinschmidt, Steffenson, MacPhail, Hlongwane-Madikizela, Vermaak & Padian, 2005).

Kidia, Mupambireyi, Cluver, Ndhlovu, Borok & Ferrand (2014) confirm that HIV-status disclosure to adolescents is distinct from disclosure to younger children and requires tailored age-appropriate guidelines. Disclosure to this age group in a health care setting may help overcome some of the barriers associated with caregivers disclosing in the home environment and make the HIV status seem more credible to an adolescent. The study of Kidia *et al.* (2014) also highlights the value of peer support among adolescents, which could help reduce the burden of psychosocial care on caregivers and health care workers. Health care workers and caregivers have minimal tailored guidance on how to approach the issue of disclosure to these adolescents, except that full disclosure is encouraged and that this should occur in developmentally appropriate stages.

WHO recently developed new guidelines for HIV testing and counselling in adolescents; however, these guidelines do not address the issue of disclosure to adolescents and only deal with disclosure of adolescents' HIV statuses to others. This study uncovered approaches for disclosure to HIV positive adolescents that were highly varied and that did not follow any standard protocol. It was found that although health care workers encouraged parents to initiate disclosure to their children in the home environment, adolescents themselves preferred a clinical setting. In the clinic, adolescents had access to accurate information from health care workers and an environment that made the illness seem more real (Kidia *et al.*, 2014).

Furthermore, Kidia et al. (2014) report that many adolescents did not learn much when they were first told about their illness. Instead, they turned to support from peers within the clinic, with whom they felt comfortable to share experiences and learn about HIV and AIDS. Health care workers explained that they did not have enough time to spend with each child, that this was how they work. They also assumed that adolescents were old enough to understand HIV related concepts and that they had been explained these concepts when they were younger, during post-test counselling.

Therefore, rather than being involved in the first communications with adolescents about their illness, health care workers tended to play a delayed and auxiliary role in the adolescent disclosure process whereby they reinforced or corrected information that was communicated by caregivers at home: Health care workers encouraged caregivers to initiate disclosure in the home environment. Nevertheless, many adolescents preferred disclosure to take place in the presence of health care workers at the clinic because it gave them access to accurate information as well as an environment that made test results seem more credible. Adolescents learned more specific information about living with an HIV positive status and the meaning of that status from shared experiences among peers at the clinic (Close, 2006).

According to Nichols (2013), what follows are some examples of ways in which psychologists, social workers and other professionals can assist with lessening the impact of these problems on the lives of affected young people. A neuropsychological evaluation can help detect problems with learning, attention, academic skills or other cognitive areas, as well as emotional issues such as depression or anxiety and describe the child or adolescent's strengths as well as weaknesses. Neuropsychologists and case managers can help identify the need for educational services and assist the youth or family in accessing them. They can also help youth obtain training in occupational and other life skills, an important aspect of making a successful transition to adulthood (Nichols, 2013).

For infants, developmental evaluations can identify lags in the attainment of milestones and risk for further delays. The neuropsychologist may make recommendations for interventions such as speech, language, occupational therapy, special education services or counselling. If cognitive problems are related to psychiatric issues such as depression or attention deficit disorder, referrals for appropriate therapy and/or medication management can be made. In addition, new impairments suspected to be due to HIV and AIDS can be followed up to determine whether treatment changes are indicated. Individuals with HIV or their caregivers may wish to discuss such an evaluation with their health care providers if they have noticed

problems with school or daily functioning, emotional or behavioural issues, or cognitive changes such as memory problems or slow thinking (Cooper, et al., 2007).

## **2.7 CHAPTER RÉSUMÉ**

This chapter discussed literature relevant to HIV and AIDS with regard to the conceptualisation of HAART treatment adherence with specific reference to adolescents. The impact of HIV and AIDS on the development of adolescents was elaborated. Impacts discussed included the psychosocial, the economic, and religious or spiritual effects on the adolescents. Factors contributing both to non-adherence and adherence to HAART treatment were also discussed. The goals and classes of HAART treatment, as well as their mechanism of actions, were further explained. Lastly, the experiences of caregivers and care workers were discussed.

Adolescents with HIV and AIDS face challenges at the point when they are negotiating developmental challenges. Accordingly, to assist adolescents to effectively cope with this stage, many factors must be considered according to the viewpoint of the adolescent. Any attempt to support an adolescent would yield positive results once the experiences of adolescents are thoroughly considered.

The chapter that follows will consider the theoretical framework employed in this study.

## **CHAPTER 3: THEORETICAL ORIENTATION**

### **3.1 INTRODUCTION**

The preceding chapter focused on a review of literature pertinent to this study. This chapter presents the theoretical framework used in the study. A theoretical framework consists of concepts, together with their definitions, and existing theories that are used for a particular study. The theoretical framework must demonstrate an understanding of theories and concepts that are relevant to the topic of the research and that will relate it to the broader fields of knowledge in the area of interest (Trochim, 2001). A common feature of theories is their proposition that attitudes and beliefs about a behaviour, as well as outcome expectancies, are critical determinants of health behaviour (Munro, Lewin, Swart & Volmink, 2007). Applied to the study, the adolescents' beliefs and attitudes about HIV and AIDS and its relationship to adhering to HAART are presented.

The theoretical framework strengthens the study in that it provides an explicit statement of theoretical assumptions that permit the reader to make a critical evaluation. The theoretical framework connects the researcher to existing knowledge. Guided by a relevant theory, it provides a basis for hypotheses and choice of research methods. Articulating the theoretical assumptions of a research study enables the researcher to address questions of why and how (Leshem & Trafford, 2007).

Furthermore, a theoretical framework permits the study to move from simply describing a phenomenon observed to generalising about various aspects of that phenomenon. Having a theory helps one to identify the limits to those generalisations. A theoretical framework specifies which key variables influence a phenomenon of interest. It alerts the researcher to examine how those key variables might differ and under what circumstances. Theory in the social sciences is of value precisely because it fulfils one primary purpose – to explain the meaning, nature, and challenges of a phenomenon often experienced but unexplained in the world in which people live, so that they may use that knowledge and understanding to act in more informed and effective ways (USC LibGuide, 2014).

### 3.2 THEORETICAL MODELS

In many fields, theories and propositions about concepts and relationships have been formulated to help give some kind of theoretical background about any study phenomena (Sinclair, 2007). For purposes of this study, the Health Belief Model and the bio-psychosocial model were applied to adolescents' experiences as regards adherence and non-adherence to HAART. Adolescence is a particularly vulnerable period for HIV-infected people in relation to mental health problems and engagement in high-risk behaviours, including non-compliance with medical treatment. The bio-psychosocial model contributes to an understanding of the psychosocial challenges as well as protective influences promoting socio-emotional coping in HIV positive adolescents in order to inform mental health promotion and HIV prevention programming for this population in South Africa (Petersen et al., 2010).

The Health Belief Model is a framework for explaining people's health-related behaviour, such as health care utilisation and adherence to a medical regimen (Polit & Beck, 2006). The model hypothesises that an individual's motivation to act depends on the perceived threat to their health and their belief that action will mitigate the threat. Individuals must first be convinced that they are personally susceptible, that the disease has serious consequences, that the recommended health action will prevent these consequences, and that the benefits of the new behaviour will outweigh the costs. Faced with a threat to their health, individuals evaluate all alternatives that can reduce the threat. To what extent do adolescents' understanding of personal susceptibility and seriousness of disease contribute to health-promoting behaviour?

Further, the bio-psychosocial model is juxtaposed alongside the Health Belief Model. The purpose is to render a comparative description of models in describing the unique experiences of adolescents as far as HAART is concerned. The bio-psychosocial model is a model that emphasises the biological, psychological and social changes of the adolescent developmental period (Williams et al., 2002). By utilising the bio-psychosocial model of care, illness impact on physical, psychological and social aspects of function is addressed and a wider range of therapeutic options offered that have meaning and relevance to the individual (Ryan & Carr, 2010).

The bio-psycho-social model is used in fields such as medicine, nursing, and sociology, and particularly in more specialist fields such as psychiatry, health psychology, family therapy, chiropractic, clinical social work, and clinical psychology. Moreover, the bio-psycho-social paradigm is also a technical term for the popular concept of the mind-body connection, which addresses more philosophical arguments between the bio-psycho-social and biomedical models, rather than their empirical exploration and clinical application (Sarno, 2007). Behavioural issues, through their effect on adherence, often lie at the root of antiretroviral failure. If not addressed, these issues are likely to jeopardise the success of any future treatment; the bio-psycho-social model thereby enables behavioural issues to be contextualised (Soloway & Friedland, 2000).

### **3.3 THE HEALTH BELIEF MODEL**

The Health Belief Model is probably the best-known model that attempts to explain health behaviour. It was developed in the 1950s to explain what makes healthy people engage in preventive behaviour – vaccination in particular. According to this model, individuals will choose to adopt behaviour depending on how much they value the goal and their belief that the behaviour will make it possible to achieve the goal. In other words, the key to understanding behaviour is to identify the person's health perceptions and beliefs (Mayer, 2007).

The Health Belief Model is still in its early stages. Adherence to this model is seen as a preventive health action. Patients will adhere more to treatment if they believe that they are susceptible to a disease they perceive as serious and that the treatment will be effective, provided the benefits outweigh the costs (Mayer, 2007). This model was appropriate for this study, as it provided a framework for understanding the adolescents' experiences of HAART and subsequent health-related decisions, such as adhering to treatment. As such, the extent to which adolescents' adherence to HAART is influenced by their personal perceptions about the seriousness of HIV and AIDS, their perceived benefits as opposed to perceived barriers, was explored. Adherence to HAART is also a challenge for HIV positive adolescents given their changing developmental stage, partial reliance on caregivers, interference with daily routines, peer affiliation needs and complex dosing regimens, all of which may lead to increased non-adherence and ultimately HAART resistance (Petersen et al., 2010).

The Health Belief Model is a psychological model that attempts to explain and predict health behaviours by focusing on the attitudes and beliefs of individuals. The Health Belief Model was developed in the 1950s as part of an effort by social psychologists in the United States Public Health Service to explain the lack of public participation in health screening and prevention programmes (for example, a free and conveniently located tuberculosis screening project). Since then, the Health Belief Model has been adapted to explore a variety of long- and short-term health behaviours, including sexual risk behaviours and the transmission of HIV and AIDS. The key variables of the Health Belief Model will be discussed (Rosenstock, Strecher, & Becker, 1994).

The Health Belief Model was one of the first and remains one of the best-known social cognition models. It is a health behaviour change and psychological model developed by Irwin M Rosenstock in 1966 for studying and promoting the uptake of health services. The model was furthered by Becker and colleagues in the 1970s and 1980s. Subsequent amendments to the model were made as late as 1988 in order to accommodate evolving evidence generated within the health community about the role that knowledge and perceptions play in personal responsibility. Originally, the model was designed to predict behavioural response to the treatment received by acutely or chronically ill patients, but in more recent years, the model has been used to predict more general health behaviours. The Health Belief Model suggests that one's belief in a personal threat together with one's belief in the effectiveness of the proposed behaviour will predict the likelihood of that behaviour (Rosenstock et al., 1994).

The Health Belief Model hypothesises that health-related action depends on the simultaneous occurrence of three classes of factors:

- The existence of sufficient motivation (or health concern) to make health issues salient or relevant.
- The belief that one is susceptible (vulnerable) to a serious health problem or to the sequelae of that illness or condition. This is often termed perceived threat.
- The belief that following a particular health recommendation would be beneficial in reducing the perceived threat and at a subjectively acceptable cost. Cost refers to perceived barriers that must be overcome in order to follow the health

recommendation; it includes, but is not restricted to, financial outlays (Lizewski, 2010).

The Health Belief Model is a psychological model that attempts to explain and predict health behaviours. This is done by focusing on the attitudes and beliefs of individuals. The model was first developed in the 1950s by psychologists Hochbaum, Rosenstock and Kegels working in the U.S. Public Health Service. The model was developed in response to the failure of a free tuberculosis health screening programme. Since then, the Health Belief Model has been adapted to explore a variety of long- and short-term health behaviours, including sexual risk behaviours and the transmission of HIV and AIDS (Colby & Baker, 1988; Rosenstock et al., 1994). Further developments allow the Health Belief Model to predict more general health behaviours.

The Health Belief Model is a behavioural model that focuses on two important elements in health-related behaviour, namely, the threat of illness and the behavioural response to the perceived threat. In perceiving the threat, the individual considers his or her personal susceptibility to harm or illness, the perceived severity of the threat of the illness and the value of behaviour or line of action to overcome the perceived threat, and the barriers to the action (Feldman & Elliott, 1990).

The Health Belief Model has identified many personal variables associated with adherence, namely, the patient's perception of susceptibility to disease, of the severity of the illness and of the efficacy of the proposed therapy. Other factors include perceptions of obstacles to adherence, attitudes towards therapeutic regimens, parents' and other significant adults' or peers' perception of the therapeutic regimen, and the level of influence of these people on the adolescent (Taddeo, Egedy, & Frappier, 2008).

The other critical factor to consider when discussing adherence in teens is their developmental stage. Adolescence is a crucial time for physical, pubertal and cognitive maturation, in addition to psychosocial changes, including identity formation and the development of independent social relationships. During the teen years, the child will move from complete dependence to a more autonomous lifestyle. Adolescents are expected to take increasing responsibility for their health and health care. This gradual and progressive process is without major turmoil and rebellion for most young people (Taddeo et al., 2008).

Ayopo (2009) describes the Health Belief Model as proposing that health behaviour is a function of the individual's demographic characteristics, knowledge and attitudes. According to this model, a person must hold the following beliefs in order to change his or her behaviour:

- The perceived susceptibility to a particular health problem, for example, 'am I at risk of HIV and AIDS?' Adolescents in this study have already contracted HIV and AIDS.
- The perceived seriousness of the health condition, namely, 'How serious is HIV and AIDS?'
- The perceived benefits of specific behaviour, for example, regarding HAART adherence – 'is it effective?'
- Clues to action, namely, witnessing the illness or death of a close family member due to HIV and AIDS.
- The barriers to taking action, for example, "I don't like taking HAART."

Proponents of this model argue that the belief elements produce in an individual some psychological readiness to act in the face of perceived threat to one's health (Becker, 1974). Specific factors are known that seem to influence psychological readiness, for example, peer pressure, which may be relevant in the case of adolescents. HIV and AIDS education, therefore, must build a sense of personal susceptibility to harm when educating adolescents about unsafe behaviour. It is believed based on this model that educational efforts must produce in recipients the belief that it is indeed in their best interest to change their ways of behaving, including adherence to HAART (Ayopo, 2009).

The Health Belief Model is a framework for motivating people to take positive health actions that use the desire to avoid negative consequences as the prime motivation. The underlying concept of the original Health Belief Model is that health behaviour is determined by personal beliefs or perceptions about disease and strategies to decrease its occurrence. Personal perception is influenced by a whole range of intrapersonal factors affecting health behaviour (Hochbaum, 1958). The Health Belief Model can be applied to a variety of health behaviours. Interventions using this model usually aim to influence the 'perceived threat of disease' variable and hence change the susceptibility/severity balance. The main way of

doing this tends to be directing information that has emotional appeal or contains a strong fear or emotional response (Corcoran, 2013).

The Health Belief Model may be applied in many psychological and medical fields in order to help determine and come to an overall understanding of one's health thoughts, behaviours, and his or her wellness as a conclusion of these. Applying this model can provide context to many socially spread illnesses such as Influenza, STDs, and other contagions. The model also provides individual context of health behaviours and the perceived need or presence of health screenings, risky behaviours, and compliance to medication that also serve as preventative measures.

The Health Belief Model, developed by researchers at the U.S. Public Health Service in the 1950s, was inspired by a study of why people sought X-ray examinations for tuberculosis. The original model included these four constructs:

- Perceived susceptibility (an individual's assessment of their risk of getting the condition). The greater the risk is of getting a certain medical condition, the more a person will engage in behaviours to decrease the risk. That is why people get vaccinations to prevent disease, brush their teeth to prevent gum disease, and work out to stay healthy.
- Perceived severity (an individual's assessment of the seriousness of the condition and its potential consequences). For example, getting the flu seems like a fairly minor thing for most people, just bed rest for a few days and one is all better again. However, for people who cannot afford to take a few days off work or for people who already have a severity, the perceived severity will vary greatly between them.
- Perceived barriers are the most influential construct because they determine if someone will adopt a new behaviour or not, depending on whether the benefits of the behaviour outweigh the consequences.
- Perceived benefits (an individual's assessment of the positive consequences of adopting the behaviour). This is why people eat fruits and vegetables, use sunscreen, or get health screenings. Perceived benefits are opinion-based; not everyone adopts the same behaviours. A person only adopts behaviours that they

think will decrease the chance of getting a disease that they think they are more susceptible to (Rosenstock et al., 1994).

Subsequent constructs include the following:

- Underlying medical condition such as getting the flu could be a very serious thing. Kip (2008) presents a variant of the model as inclusive of the perceived costs of adhering to prescribed intervention as one of the core beliefs. Constructs of mediating factors were later added to connect the various types of perceptions with the predicted health behaviour.
- Demographic variables (such as age, gender, ethnicity, occupation).
- Socio-psychological variables (such as socio-economic status, personality, coping strategies).
- Perceived efficacy (an individual's self-assessment of ability to successfully adopt the desired behaviour).
- Cues to action (external influences promoting the desired behaviour may include information provided or sought, reminders by powerful others, persuasive communications, and personal experiences).
- Health motivation (whether an individual is driven to stick to a given health goal).
- Perceived control (a measure of level of self-efficacy).
- Perceived threat (whether the danger imposed by not undertaking a certain health action recommended is great).

The prediction of the model is the likelihood of the individual concerned undertaking recommended health action (such as preventive and curative health actions). Other reasons for this will be shown (Hayden, 2009).

Simultaneous occurrence of three factors in Table 3.1 leads to adherence (Marandu, 2009).

**Table 3.1: Summary of the Concepts of the Health Belief Model Identified for the Study**

These factors are the existence of sufficient motivation (or health concern) to make health issues salient	The belief that one is susceptible to a serious health problem, that is, a sense of a perceived threat	The belief that following a particular health recommendation would be beneficial in reducing the perceived threat at an acceptable cost, that is, the perceived barriers that must be overcome in order to follow the health recommendation
Perceived self-efficacy for adherence to HAART by adolescents	Perceived seriousness or severity of HIV and AIDS	Perceived benefits of HAART by adolescents
Perceived quality of life by adolescents due to HAART		Perceived barriers that interfere with adherence to the treatment regimen

Perceived benefits of adherence to HAART by adolescents are generally associated with higher likelihood of adherence. If patients understand the purpose of the treatment and why they are taking it, they will be more inclined to do better with adherence. Furthermore, patients must perceive that there are threats to their health or believe that their health is at risk and that the events are potentially serious in terms of pain or discomfort, time lost to work, or economic difficulties (Feldman & Elliott, 1990).

The Health Belief Model states that the perceptions of people's health behaviours are influenced by at least three factors. Some of these factors include general health values, which include interests and concerns about health, and beliefs about the consequences of the health problems. Once people perceive a threat to their own health and are simultaneously cued to action, their perceived benefits outweigh perceived barriers. These individuals are more likely to undertake the recommended preventive health actions than people without such perceptions. Thus, individuals must perceive or believe that the benefits of visiting the health care providers outweigh the costs (Kip, 2008).

The Health Belief Model is based on a sequence of events that occur in order for behaviour to change. It attempts to predict health-related behaviours regarding certain belief patterns. This model is used in explaining and predicting preventive health behaviours, as well as sick-role and illness behaviours or clinic use. Preventive health behaviours and sick-role behaviours with recommended medical regimens usually follow professional diagnosis of an illness and clinic use, including physicians' visit for a variety of reasons. People's motivation to undertake health behaviour is divided into three main categories: individual perceptions, modifying behaviours, and the likelihood of action (Kip, 2008).

The Health Belief Model has been frequently used as the major theoretical or organising framework for explaining and predicting adherence to health and medical care recommendations. Knowledge and attitudes about AIDS are predisposing factors for behaviour change. Knowledge is one of the modifying variables mentioned in the Health Belief Model. These frameworks seek to identify the constellation of constructs that influence adherence and the manner in which these constructs coexist and influence one another. The development and evaluation of theoretical models have critical implications for intervention development and clinical practice. In practice, many efforts to understand the dynamics of HAART adherence have involved the application of health behaviour models developed outside of the domain of ARV adherence (Pope et al., 2009).

As with HIV prevention programmes such as condom use, delay of sexual debut, and treatment of STIs, the conventional wisdom associated with the way HAART adherence is currently conceptualised is that given the facts and presented with alternatives, people will adhere to treatment. In large measure, this approach is encapsulated by the Health Belief Model, which states that health-related action depends on the simultaneous occurrence of three factors (Rosenstock et al., 1994). These factors are the existence of sufficient motivation (or health concern) to make health issues salient; the belief that one is susceptible to a serious health problem, that is, a sense of a perceived threat; and the belief that following a particular health recommendation would be beneficial in reducing the perceived threat at an acceptable cost, that is, the perceived barriers that must be overcome in order to follow the health recommendation (Marandu, 2009).

The Health Belief Model is an extensively studied model of health behaviour change. It posits that individuals must perceive themselves to be at risk of the health threat before they take action to reduce risky behaviours or to engage in healthy alternative behaviours. Additionally, the model postulates that an individual's actions are based on beliefs. It underlies main factors for decision-making such as perceived vulnerability or susceptibility, perceived severity of the outcomes or conditions, perceived efficacy or benefits of control measures, and the perceived barriers to prevention. It has been extensively used in behavioural sciences to predict behaviours and to design behavioural prevention programmes. Patients' beliefs about the disease and medications are crucial to their intentional adherence behaviours (Kip, 2008).

### **3.3.1 The Health Belief Model Critique**

#### **3.3.1.1 Strengths of the HBM**

HBM's use of simplified health-related constructs results in easier implementation, application and testing (Conner, 2010). The HBM provides a useful theoretical framework for investigating the cognitive determinants of a wide range of behaviors. It focuses researchers' and health care professionals' attention on variables that are prerequisites for health behavior. Hence, it has formed a basis for many practical interventions across a range of behaviors (Jones, Jones & Katz, 1987). HBM's flexibility makes the HBM adaptable and applicable to many health behavior and population groups.

#### **3.3.1.2 Limitations of the HBM**

The health benefit critique has its own limitations, among which are:

- Common-sense framework simplifies health-related representational processes.
- Theoretical components are broadly defined; therefore, different operationalisations may not be strictly comparable.
- Lack of specification of a causal ordering.
- Neglects social factors.

Despite the success of HBM in informing and predicting a range of behaviors with health outcomes, previous research shows that HBM's determinants are insufficient predictors of behavior (Norman & Brain, 2005). On average, HBM's determinants predict approximately

20% of variance in healthy behavior, leaving 80% of the variance unaccounted for (Carpenter, 2010).

The Health Belief Model has been applied to diverse sets of health behaviours. Research reviewed in this study suggests difficulties of the model in predicting future behaviours, especially behaviours related to HIV. Prominent features of adolescence that influence HIV related risk behaviours are discussed: cognitive immaturity, struggle for psychological autonomy, peer influences, and physical development. It is suggested that a model is needed to guide prevention efforts and that these adolescent-specific factors need to be incorporated into any such model (Brown, DiClemente & Reynolds, 1991).

### **3.4 THE BIO-PSYCHOSOCIAL MODEL**

The bio-psycho-social model was developed at Rochester decades ago by Drs. George Engel and John Romano. While traditional biomedical models of clinical medicine focus on pathophysiology and other biological approaches to disease, the bio-psycho-social approach emphasises the importance of understanding human health and illness in their fullest contexts (Engel, 1977). The bio-psycho-social approach systematically considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery (Engel, 1980; Nassir Ghaemi, 2009). Recognition that understanding a patient's beliefs, feelings, thoughts and health behaviour is necessary to aid in understanding that the patient's condition has led to a move from a disease model to a bio-psycho-social model of care, which acknowledges the importance of psychological, social factors, as well as the physical impact of living with a chronic disease (Dogar, 2007; Ryan & Carr, 2010).

The bio-psycho-social model is derived from the general systems theory. The biological system emphasises the anatomical, structural and molecular substrate of disease and its effects on the patient's biological functioning. The psychological system emphasises the effects of psychodynamic factors, motivation and personality on the experience of illness and the reaction to it. The social system emphasises the cultural, environmental and familial influences on the expression and the experience of illness. Psycho-social well-being result from a complex interaction of all these factors (Green & Shellenberger, 1991).

Engel (1977) describes the bio-psychosocial model as a general model or approach, positing that biological, psychological (which entails thoughts, emotions, and behaviours) and social (socio-economical, socio-environmental, and cultural) factors all play a significant role in human functioning in the context of disease or illness. Indeed, health is best understood in terms of a combination of biological, psychological, and social factors rather than purely in biological terms. The bio-psychosocial approach is of the view that well-being is as the result of the interaction of biological, psychological and social factors (Green & Shellenberger, 1991) This is in contrast with the biomedical model of medicine that suggests that every disease process can be explained in terms of an underlying deviation from normal function such as a virus, gene or developmental abnormality, or injury (Engel, 1977).

Engel (1977) submitted that each system affects and is affected by every other system. He further asserts that medical illness is a direct result of a person's psychological or sociocultural makeup, but, rather encourages a comprehensive understanding of disease and treatment. The patient-doctor relationship is a critical component of the bio-psychosocial model. Physicians must have both the working knowledge of the patient's medical status and be familiar with how the patient's individual psychology and sociocultural milieu affect their medical condition (Engel, 1977; Sadock & Sadock, 2007).

The bio-psychosocial model is better established in psychiatry and health care for medically unexplained symptoms. This model emphasises an integration of mind, body and the social context of the illness. The psychological and social factors contribute to disease; therefore, the illness cannot be addressed in isolation without tackling the issues in the social and psychological sphere. HIV and AIDS is a medical condition which is impacted by psychological and social factors. Three types of psychological and social factors relevant to medical disorders can broadly be distinguished. These are adverse life experiences, such as life events and chronic stressors; psychological dispositions or traits, which are either protective or increase vulnerability to stress; and factors in the social environment such as social support and isolation. It is widely acknowledged that there is an interplay between exposure to adversity and psychosocial protective factors, such that the impact of negative experiences may be offset by adequate coping resources (White, 2005). Adolescence and HIV and AIDS form part of adverse life experiences and chronic stressors; that being the case, the interplay of medical illness and psychosocial factors cannot be underestimated.

It is important to note that the bio-psychosocial model does not provide a straightforward, testable model to explain the interactions or causal influences (that is, amount of variance accounted for) by each of the components (biological, psychological, or social). Rather, the model has been a general framework to guide theoretical and empirical exploration, which has amassed a great deal of research since Engel's 1977 article. McLaren (1998) concurs that the bio-psychosocial model enables the physician to extend the application of the scientific method to aspects of everyday practice and patient care heretofore not deemed accessible to a scientific approach. The biomedical model can make provision neither for the person as a whole nor for data of a psychological or social nature.

The bio-psychosocial model is a model that emphasises the biological, psychological and social changes of the adolescent developmental period. Adolescence has historically been a developmental period of relative neglect with respect to research on both mental and physical health intervention and outcome (Williams et al., 2002; Sendangala, 2011). Adolescence is a transitional developmental period between childhood and adulthood that is characterised by more biological, psychological, and social role changes than any other stage of life except infancy (Holmbeck & Kendall, 2002). Other authors (Feldman & Elliot, 1990; Fargher & Dooley, 2010) go on to describe adolescence as encompassing physical and social changes that occur during puberty as maturation begins and social interactions become increasingly centred on members of the opposite sex.

The fundamental assumption of the bio-psychosocial model is that any health or illness outcome is a consequence of the interplay of biological, psychological and social factors. Naidoo (2011) agrees that this approach enables those with HIV and AIDS to develop strategies for coping; it helps to improve adherence to treatment, and it helps to prevent transmission of the disease and suicide. In adolescence, just as there is a burgeoning of sexuality given the changing body, so there may be an increase of aggressive feelings. It is during this period that adolescents begin questioning what medication they are taking and why they have to take such medication. General rebellion towards authority might include rebelling against taking such medication, thereby affecting adherence levels and subsequently compromising their health. Throughout peoples' lives, they have to deal with feelings of aggression and how to engage with them; however, during adolescence, such levels of aggression might be detrimental to the adolescent (Fargher & Dooley, 2010).

Moreover, there are two transition points during this single developmental period: the transition early adolescence from childhood and the transition to adulthood from late adolescence (Williams et al., 2002; Steinberg, 2008). Given the magnitude of such changes, it is not surprising that there are also significant changes in the types and frequency of health problems and psychological disorders during this developmental period, as compared to during childhood (Williams et al., 2002).

During adolescence, a multifaceted developmental transition is set in motion; biological, psychological and social forces intersect as the individual advances from childhood towards adulthood. This transition is rarely smooth or straightforward; adolescence is perplexing and disquieting for many young people (Feldman & Elliott, 1990), without throwing in the challenge of coping with HIV and AIDS. While no single model has taken precedence, a large body of empirical literature has identified socio-cognitive (the psycho-social aspect of Engel's model) variables that appear to influence engagement in healthy behaviours and adhere to prescribed medical regimens, such as self-efficacy in chronic diseases such as type 2 diabetes, cardiovascular disease. By default, this could be applied to understanding adherence to HAART in adolescents living with HIV and AIDS (Williams et al., 2002).

Some thinkers see the bio-psychosocial model in terms of causation. With this understanding, the biological component of the bio-psychosocial model seeks to understand how the cause of the illness stems from the functioning of the individual's body. The psychological component of the bio-psychosocial model looks for potential psychological causes for a health problem such as lack of self-control, emotional turmoil, and negative thinking. The social part of the bio-psychosocial model investigates how different social factors such as socio-economic status, culture, poverty, technology, and religion can influence health (Dogar, 2007). HAART is essential in the treatment of HIV and AIDS; however, a holistic approach to HIV and AIDS management is necessary. With that said, applying the bio-psychosocial approach provides a global view of the experiences of adolescents as far as HAART is concerned.

Bio-psychosocial approach can be seen as the multi-pronged approach applied when it comes to HIV and AIDS and HAART management. Naidoo (2011) is of the same mind that all doctors, regardless of where they practice, have an essential role to play in the treatment and management of HIV and AIDS-infected patients. This management requires that both the doctor and patient have accurate knowledge and positive attitudes regarding the

disease; a multidisciplinary holistic approach can be considered and both pharmacological and non-pharmacological management can be instituted (Naidoo, 2011).

Some of the non-pharmacological types of management include counselling on adherence to treatment, nutrition, side effects of medication, psychosocial issues, family and support systems. Counselling in HIV and AIDS has become a core element in a holistic model of health care with psychological and emotional support recognised as being integral to patient management and being essential at all stages of the HIV and AIDS infection. Despite the enormous benefits derived from HAART, the issue of non-adherence to treatment still remains unresolved. Adherence to medication and treatment is vital because it is one of the most important patient-enabling factors that is related to virological failure and drug resistance. Many factors seem to impact negatively on adherence such as the treatment regimen (complexity, heavy pill burden and food requirements), difficulty in taking medication, access to medication, side effects, stigma, forgetting to take pills, psychosocial issues, the disease itself, and concomitant substance abuse (Naidoo, 2011).

Another important aspect in HIV and AIDS management is nutrition; as a result, the role of the dietician is important. Critical questions such as how well the antiretroviral drugs work in people who do not have access to adequate nutrition and the role of vitamins and other supplements in HIV and AIDS management are emerging as HIV and AIDS treatment becomes increasingly available in the poorest parts of the world. The role of micronutrients in immune function and infectious disease is well established. Researchers have found that people with HIV and AIDS are more likely to show signs of micronutrient deficiencies as compared to uninfected people. Various micronutrients have been linked to changes in the rate at which HIV infection progresses to AIDS. Without adequate food or the right nutrition, taking ARV drugs can be painful, causing people simply not to take the drugs (Pontali, Feasi, Toscanini, Bassetti, De Gol, Nuzzolese, & Bassetti, 2001; Naidoo, 2011).

When chronic illnesses are congenital or begin in childhood, the manner in which the transition from childhood to adolescence to young adulthood is negotiated has significant implications for disease outcomes throughout the remainder of the lifespan. Given the unique developmental challenges of adolescence, an effective and theoretically sound approach to adolescent health psychology research and treatment must be firmly grounded in a developmental framework. A bio-psychosocial model of adolescent development is one

such framework that can inform primary, secondary, and tertiary prevention research and interventions targeting adolescents (Williams et al., 2002).

Dietary advice should be tailored to individual circumstances; however, in general, the recommendations for people living with asymptomatic HIV and AIDS infection should be to follow a healthy, well-balanced diet. For some, appropriate food required to be taken alongside medication may not be easily affordable. The government has attempted to respond to some of these concerns to a certain extent. Many types of support systems are available in South Africa, ranging from simple availability of food parcels to disability grants, social grants and pension grants. South Africa's social grants target the elderly, disabled people, poor families with children, and citizens who are incapacitated and unable to work due to illness (Kagee, 2007).

The bio-psychosocial model of health is based in part on the social cognitive theory. The model implies that treatment of disease processes requires that the health care team address biological, psychological and social influences upon a patient's functioning. In a philosophical sense, the bio-psychosocial model states that the workings of the body can affect the mind and the workings of the mind can affect the body. This means both a direct interaction between mind and body as well as indirect effects through intermediate factors. The bio-psychosocial model presumes that it is important to handle the three together, as a growing body of empirical literature suggests that patient perceptions of health and threat of disease, as well as barriers in a patient's social or cultural environment, appear to influence the likelihood that a patient will engage in health-promoting or treatment behaviours, such as medication taking, proper diet or nutrition, and engaging in physical activity (DiMatteo, Haskard & Williams, 2007).

### **3.4.1 The Bio-psychosocial Model Critique**

#### ***3.4.1.1 Strength of the BPS Model***

The fundamental assumption of the bio-psychosocial model is that any health or illness outcome is a consequence of the interplay of biological, psychological and social factors. This approach enables people with HIV and AIDS to develop strategies for coping; it helps to improve adherence to treatment and it helps to prevent transmission of the disease and suicide (Naidoo, 2011).

### **3.4.1.2 Limitation of the BPS Model**

Some critics point out that a question of distinction and a question of determination of the roles of illness and disease run against the growing concept of the patient medical tradesperson partnership or patient empowerment, as 'bio-psychosocial' becomes one more disingenuous euphemism for psychosomatic illness. This may be exploited by medical insurance companies or government welfare departments that are eager to limit or deny access to medical and social care. Some psychiatrists see the bio-psychosocial model as flawed, in either formulation or application to de-stigmatise mental health (Epstein & Borrell - Carrio, 2005).

## **3.5 CHAPTER RÉSUMÉ**

The chapter explored the development of HIV and AIDS health promotion based on two of the existing health behaviour theories, namely, the Health Belief Model and the bio-psychosocial model. It then applied it to the description of HAART with respect to adolescence.

Adolescence is a developmentally challenging period, even without adolescents having to deal with adherence to chronic treatment. Adolescents living with HIV and AIDS need to successfully navigate the world of HAART adherence as well as other developmental challenges in order to achieve optimal adulthood. Adolescents find adherence to HAART to be particularly challenging as they enter a stage of life when they become self-aware and want to fit in with their peers.

The Health Belief Model and the bio-psychosocial model jointly applied offer a relatively comprehensive description of adolescents' experiences of HAART, without necessarily overemphasising one area at the expense of another. Such was the focus of this chapter.

The next chapter deals with the research design and methodology deemed appropriate for this study.

## **CHAPTER 4: RESEARCH DESIGN AND METHOD**

### **4.1 INTRODUCTION**

The foregoing chapter discussed the theoretical framework that was seen to be suitable for this study. This chapter presents the research design and methods used in this study. This is basically the research methodology, which is the logical, theoretical analysis of the methods applied to a field of study entailing the conjectural analysis of procedures and doctrines related to a branch of knowledge (Howell, 2013). Usually, it incorporates concepts such as paradigm, theoretical model, phases and quantitative and/or qualitative techniques. It discusses data analysis, ethical considerations and steps taken by the researcher to ensure trustworthiness of the research. Data was collected using semi-structured interviews as well as questionnaires. Data analysis consisted of both quantitative and qualitative methods in order to strengthen the study. The aim of the study was to explore the nature of experiences of adolescents who are on long-term HAART treatment in Tembisa Hospital, Gauteng province.

### **4.2 RESEARCH APPROACH**

Research approach and methodology are often used interchangeably. In this study, the term research approach was selected. Creswell (2014) defines research approach as a plan and procedure for research that span the steps from broad assumptions to detailed methods of data collection, analysis, and interpretation. The overall decision should be the philosophical assumptions the researcher brings to the study, procedures of inquiry (called research designs) and specific research approaches of data collection, analysis and interpretation (Goodman, 2008).

The study primarily applied a qualitative approach to capture the experiences of adolescents who were undertaking HAART as they personally experience it, in line with the aim of the study, which is to explore the experiences of adolescents who are on long-term HAART. This approach is most suitable for addressing the why questions to explain and understand issues or the how questions that describe processes or behaviour (Hennink, Hutter, & Bailey, 2011). Qualitative approaches are also particularly suitable for examining sensitive topics, as the process of rapport building provides a comfortable atmosphere for participant disclosure.

Only profiles of the health care professional participants' (HCPPs) demographic characteristics, work experience, qualifications, specific profession and experience tenure with adolescents on HAART were measured by quantitative approaches. Furthermore, the grades and ages of adolescent participants were also measured by quantitative approaches. The strengths of quantitative approaches are a greater precision of measurement, as they are tied in with explicit theories of psychological measurement and statistics; the ability to make comparisons, both among the HCPPs and across the study; and the ability to test causal hypotheses using experimental designs (Cooper et al., 2012).

For research to be organised and systematic, a researcher needs to punctuate a specific angle from which he or she will study the phenomena of interest, and this punctuating is referred to as research approach (Punch, 2014). This study sets a systematic and organised effort to explore the experiences of adolescents with specific regard to their HAART treatment, how their HAART treatment has impacted and influenced their world view, thus the choice of a qualitative approach. For this study, only the qualitative approach will be discussed.

### **4.3 RESEARCH DESIGN**

The study employed a qualitative methodology, as it was suitable because it needed to find an explanation of experiences in non-numeric form. Qualitative data analysis is a non-mathematical analytical procedure that involves examining the meaning of people's words and actions (Haslam & McGarty, 2003). In this study, qualitative methods assisted in capturing the experiences of adolescents and HAART as the adolescents personally experienced the HAART treatment. Furthermore, the study was an exploratory design using a phenomenological approach. This approach was based on the assumption that to understand humans, it is best to discover their meaning world through interacting directly with them.

Phenomenology is an investigative method that focuses on what individuals have actually experienced, how they personally interpret the situation and the way they narrate it in their own words (Creswell, 1998; Patton, 1990). Its major concern is to explore phenomena. It is also a philosophical effort that deals with human and social sciences such as psychology (and sociology) with regard to attitude, approach, design, strategy, method, or technique with lived experience (Edwards, 2001). Additionally, it facilitates an understanding of lived experiences in daily life. Thus, phenomenology advances the ways in which people make

sense of the social world and its political organisations and affiliations (Gubrium & Holstein, 2000).

Phenomenology reveals the phenomenon and is interventionistic, consciously suspending any assumptions in order to allow original reality to emerge or alternatively empathise with (or enter into) the world of another (as in existential psychotherapy) (Edwards, 2001). People intervene in one another's worlds and influence one another in that, as human beings, individual unique existences are essentially intersubjective and radically social. People continuously change social constructions and continuously influence one another through interpersonal encounters and interventions in one another's worlds.

#### **4.4 RESEARCH SETTING**

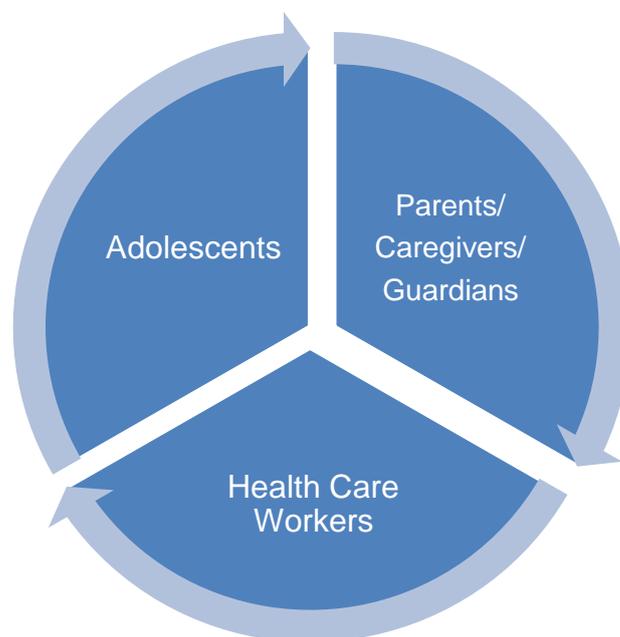
The study took place at a provincial tertiary hospital, in Tembisa, which is a public health facility. The collection of data was done in the field at the site where participants experience some of the issues under study (Polit & Beck, 2006; Creswell, 2014). Furthermore, the interaction entailed an up-close information gathering by actually talking directly to people, through the use of in-depth interviews (Boyce & Neale, 2006; Creswell, 2014).

The area of the study was influenced by the high rate of non-adherence to HAART at the Masakhane Clinic of Tembisa Hospital, in Gauteng, where the researcher is employed as a clinical psychologist. While some adolescents are known to be adherent to their treatment, there is a high percentage of adolescents who struggle with adherence to HAART and as a result were referred to the psychology department for psychological intervention. The rationale for conducting this study in Gauteng was that the study inevitably provides results that may enable the multi-disciplinary team at Masakhane Clinic, Tembisa Hospital, to design suitable interventions to address the specific problems of non-adherence.

##### **4.4.1 Population and Sample Frame**

A population is simply every possible case that could be included in a study as a participant. However, the population is often too large to undertake; therefore, it is often a practice that a representative group, called a sample, needs to be selected (Spata, 2003). Sekaran (2003) defines a population as the entire group of people, events, or things of interest that the researcher wishes to investigate. The study was conducted among adolescents accessing public health facilities within the context of tertiary hospitals in the Gauteng province of South

Africa. The focal area was the Tembisa Provincial Tertiary Hospital in Ekurhuleni Metropolitan Municipality. The main aim of the study was to explore and describe the factors contributing to adherence and non-adherence to prescribed HAART treatment of individuals on treatment. Tembisa Hospital is a designated HAART roll-out hospital. For the purpose of HAART roll-out, the hospital has designated a section of the hospital, called Masakhane Clinic, as their roll-out point. According to Masakhane Clinic, the number of people receiving HAART is increasing significantly per month, ranging from between 2,000 and 3,000 patients – about 600 of these comprise adolescents (Isithembiso, 2011). These adolescents are thus the key focus of this study. Bailey (1994) concurs that a sample must always be viewed as an approximation of the whole rather than as a whole in itself.



**Figure 4.1: Participants and Mutually Influential Relationship**

The population of interest was adolescents who were on HAART treatment. To optimise a complex picture and enhance confidence in the findings of the research problem under study, a report from multiple perspectives was necessary. Participants of mutual influential relationships with the adolescents, as shown in Figure 4.1, in the context of the research study were approached. This process is referred to as triangulation. In this study, data triangulation was applied to collect data through several sampling strategies as well as through a variety of people (Denzin, 1970).

Therefore, identifying the many factors involved in adolescent HAART experiences, it became crucial to include the experiences, impression, and reactions of parents, guardians,

caregivers (PGCPs) as well as HCPPs' expert observations on experiences, so as to arrive at a relatively holistic picture. The sampling frame, which entailed the subgroup from which the sample for this study was drawn (Zikmund & Babin, 2012), consisted of adolescents who were on HAART treatment at the Masakhane Clinic. PGCPs were included to give a broader perspective of the experiences of adolescents' HAART. Furthermore, HCPPs who deal with HAART were included so as to broaden the scope of experiences. Study populations comprising elements involved are too many in number and thus may be impossible to study. By making use of a variety of participants, the possibility of finding underlying constants or themes in the many forms of expression the experience takes was greatly increased.

#### **4.4.2 Inclusion Criteria**

Thinking about sampling requires thinking about inclusion and exclusion criteria for this study's sample. This entails who or what people want to hear from (Braun & Clarke, 2013).

**The inclusion criteria for the sample of adolescent participants were:**

- Adolescent participants must be aged between 12 and 19, inclusive.
- Adolescent participants must have been on HAART for at least two years.

**The inclusion criteria for the sample of PGCPs were:**

- The participant should be a parent, guardian or caregiver to an adolescent on HAART for at least two years.

**The inclusion criteria for the sample of HCPPs were:**

- HCPPs should have received HAART-specific training.
- HCPPs should be employed at the Masakhane Clinic.
- HCPPs must have working experience with adolescents on HAART.

#### **4.4.3 Sampling**

Sampling is the scientific process researchers use to select cases for inclusion in a research study (Zechmeister, Zechmeister, & Shaughnessy, 2000). A sample is a subset of the population. In other words, some, and often not all elements of the population, would form

the sample. A sample is thus a subgroup or a subset of the population. By studying the sample, the researcher can draw conclusions that would provide light about the population of interest. Studying a sample rather than the entire population is less costly and mostly manageable. There is less fatigue and fewer errors in collecting data using a sample (Sekaran, 2003).

Non-probability samples are used when it is difficult to identify all potential cases in the population (De Vos, Strydom, Fouche, & Delport, 2002; Sekaran, 2003). Convenience samples (prominently used in psychological research), purposive samples (selected deliberately to meet an often non-statistical goal), and quota samples (in which interviewers recruit and interview an assigned number of cases from each of several subgroups) were suitable for this study (Cooper et al., 2012). A non-probability sampling method can be used when no convenient sampling frames of the population are available or when time or cost restrictions make the surveying of a widely dispersed population impractical (Mook, 2001).

Purposive or judgemental sampling is an acceptable sampling approach for special situations. It is useful in selecting members that are difficult to reach, such as a specialised population in sole possession of the information, knowledge and/or experience required by virtue of belonging to the targeted population (Cooper et al., 2012). Judgemental sampling involves the choice of participants who are in the best position to provide the information required.

The sample was purposively selected, as the primary participants were patients attending HAART clinic at the hospital, with the secondary participants being the HCPPs and PGCPs. A secondary participant is someone who was not initially designated as a primary participant in a study, but about whom information is gathered from persons who are primary participants. Secondary participants are created when individuals provide information about other people whom they know or to whom they are related (Given & Saumure, 2008). In light of that, the purposive sampling method was the most convenient and appropriate to use. Furthermore, Sekaran (2003) confirms that having gone through the experiences and process of HAART themselves, the adolescent participants (together with PGCPs and HCPPs) were expected to have reliable knowledge and perhaps be able to provide good information to the researcher. Thus, the judgemental sampling design was used because a limited category of people had the information that was sought.

#### **4.4.4 Sample Size**

The study needed to limit the number of cases in a sample or the size of the sample. Sample size explains how large or small the research interviewees should be. In this study, identifying a sample size large enough to gather enough evidence on the target group was sufficient for the study. Since the research study was a qualitative phenomenological method, it was preferable to have in-depth research than a large population. The guide was to interview participants until saturation of data was attained. Bowen (2008) defines saturation as the point when additional data fails to generate new information. The researcher stopped collecting data when the categories of themes were saturated, that is, when gathering fresh data no longer sparked new insights or revealed new properties (Creswell, 2014). Phenomenological study samples typically have fewer than 10 individuals (Polit & Beck, 2006). In this study, data saturation was reached after getting seven individual adolescent participants, a focus group of adolescent participants (FGAPs), three PGCPs and 11 HCPPs.

### **4.5 QUALITATIVE APPROACH**

The main objective of the study was primarily to gain an understanding of adolescents' perspective of being on HAART. The second objective was to gain broader insight of experiences leading to adherence and non-adherence to HAART. A qualitative research approach was thus employed in this study. A qualitative study is an inquiry into a social or human problem, and its objective is to gain a detailed understanding of underlying reasons, beliefs, and motivations of peoples' subjective experiences (Hennink et al., 2011). Qualitative approaches are typically used for providing an in-depth understanding of the research issues that embrace the perspectives of the study population and the context in which they live (Jaeger & Halliday, 1998).

#### **4.5.1 Exploration**

Exploratory research is undertaken when few or no previous studies exist. The aim is to look for patterns, hypotheses or ideas that can be tested and will form the basis for further research (Neville, 2007). Additionally, qualitative research methodology is useful for exploring new topics or understanding complex issues, for explaining cultural norms of a culture or society (Patton & Cochran, 2002). A qualitative research approach was chosen for

this study because of its usefulness as a tool for exploration related to knowledge development. It attempts exploration in a 'naturalistic' way, under uncontrolled conditions. It focuses on behavioural or meaningfully understood action variables only (Shaughnessy, Zechmeister, & Zechmeister, 2012). The qualitative approach gives the texture of the person's responses, meaning one feels much greater acquainted with the participant hearing her words rather than just knowing her scores; in other words, the data is richer.

#### **4.5.2 Hard to Recruit Population**

Qualitative studies tend to have a small sample size and thus may be more appropriate for researchers working on their own or researching a hard-to-recruit population (Cooper et al., 2012). In this study, it is a challenging task to obtain a sample of adolescents who are on HAART. Issues of confidentiality and the adolescents' rights to privacy compound accessibility of the sample, and these were also addressed in the study.

#### **4.5.3 Inductive Nature of Inquiry**

Qualitative research approaches are typically more flexible, that is, they allow greater spontaneity and adaptation of the interaction between the researcher and the study participants. In addition, the relationship between the researcher and the participant is often less formal than in a quantitative research approach (Mack, Woodsong, MacQueen, Guest, & Namey, 2005; Graziano & Raulin, 2013).

Qualitative approach emphasises the uniqueness of individuals or special populations preferring narrative summaries or descriptions. Additionally, it seeks to understand a given research problem or topic from the perspectives of the local population it involves. Qualitative research is specifically effective in obtaining culturally specific information about the values, opinions, behaviours and social contexts of particular populations (Mack et al., 2005; Goodman, 2008). A famous useful method among the qualitative methods is the phenomenological method.

### **4.6 PHENOMENOLOGY**

The origins of phenomenology can be traced back to Kant and Hegel. Husserl is generally viewed as the fountainhead of phenomenology in the 20th century (Groenewald, 2004). The phenomenological paradigm to research has its roots in the work of Edmund Husserl (1859-

1938) at the turn of the 20th century. Husserl developed and named his philosophical method 'phenomenology' – the science of pure 'phenomena' (Hahn, 2010, p246), for use in philosophy and the human sciences. In psychology, this method is a descriptive, qualitative study of human experience. It is used to study and learn about phenomena that are difficult to observe and measure (Wilding & Whiteford, 2005). Eidetic phenomenology aims to determine the form and nature of reality as mediated through and individual experience of it. To arrive at this essential structure, Husserl's method suggests four fundamental processes: intentionality, phenomenological reduction, description, and essence (Wimpenny & Gass, 2000).

#### **4.6.1 Intentionality**

Phenomenological approaches aim to study participants' inner experiences, in other words, how they perceive and make sense of the world. A phenomenological study aims to faithfully conceptualise the processes and structures of mental life, how situations are meaningfully lived through as they are experienced, with nothing added and nothing subtracted (Wertz et al., 2011).

According to Fouche and Delport (2002), when adopting a phenomenological paradigm, the researcher works towards an understanding of an individual's perceptions, perspectives and an understanding of a given situation. The purpose of a phenomenological study is to describe and interpret the experiences of the participants regarding a particular event in order to understand the participants' meaning ascribed to that event (McMillan & Schumacher, 2010). Each individual has a unique position in life, and by joining the environment and reality of the individual, the researcher has the opportunity to experience the actual phenomena and report on it from the individual's perspective (Wilson, 2014).

This study aimed to gain an understanding and describe the experiences of adolescents on HAART. Phenomenology is concerned with the study of experience from the perspective of the individual, 'bracketing' taken-for-granted assumptions and usual ways of perceiving. Epistemologically, phenomenological approaches are based on a paradigm of personal knowledge and subjectivity and emphasise the importance of personal perspective. As such, they are powerful for understanding subjective experience, gaining insights into people's motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom (Wertz et al., 2011). Although phenomenological researchers seek targeted experiences, they also want to explore the diversity of individual experiences (Polit & Beck, 2006; Husserl, 1970).

#### 4.6.2 Consciousness

Merleau-Ponty (1962) describes phenomenology as the study of essences, and according to it, all problems amount to finding definitions of essences: the essence of perception or the essence of consciousness, for example. The lifeworld – Husserl’s *Lebenswelt* – is a key concept and focus of investigation for phenomenology. It can be defined as the world that is lived and experienced – a world that appears meaningfully to consciousness in its qualitative, flowing given-ness; not an objective world out there, but a humanly relational world (Todres, Galvin, & Dahlberg, 2006). The researcher’s project is, in the infamous words of Husserl (1970), to return to the things themselves. The ‘things’ here refer to the world of experience as lived. To return to the things themselves is to return to that world which precedes knowledge, of which knowledge always speaks. In the lifeworld, a person’s consciousness is always directed at something in or about the world. Husserl developed intentional analysis and eidetic analysis. Intentional analysis is the procedure of reflecting on, gaining insight into, and describing the *how* and the *what* of experience, *how* experiential processes proceed, and *what* is experienced through them. Intentionality denotes the transcendental quality of consciousness, which is consciousness of something (Husserl & Heidegger, 1927).

Edmund Husserl rejected the behaviouristic belief that objects in the external world exist independently and that information about objects is reliable. He contended that people can be certain about how things appear in, or present themselves to, their consciousness. To arrive at certainty, anything outside immediate experience must be ignored, and in this way the external world is reduced to the contents of personal consciousness. Realities are thus treated as pure phenomena and the only absolute data from where to begin (Eagleton, 2011).

In the lifeworld, a person’s consciousness is always directed at something in or about the world. In this way, subject and object are joined together in mutual co-constitution. This important phenomenological concept is called intentionality, and it is a key focus for research (Creswell, 2003). In this study, the researcher’s aim was to explicate this intentionality that has to do with the directedness of the participants’ consciousness (what they are experiencing and how).

Put another way, the focus is on the intentional relationship between the person and the meanings of the things they are focusing on and experiencing. Phenomenology asks, “What is this kind of experience like?” “What does the experience mean” and “How does the lived

world present itself to me (or to my participant)?" The challenge for phenomenological researchers is twofold: how to help participants express their world as directly as possible, and how to explicate these dimensions such that the lived world – the lifeworld – is revealed. Meanings uncovered by the researcher emerge out of the researcher's attitude and the way the researcher poses questions (Finlay, 2012, p22).

This important phenomenological concept that is being referred to is called intentionality, and it is a key focus for research, as already indicated (Creswell, 2003). Wertz et al. (2011) go on to describe the phenomenological attitude as reflective. It selectively turns from the existence of objects to the processes and meanings through which they are subjectively given. Phenomenology investigates the person's ways of being-in-the-world by descriptively elaborating the structures of the self, ways of experiencing and the meaningful ways in which the world is experienced (Todres et al., 2006).

#### **4.6.3 Philosophical Existence**

Phenomenology is a philosophy which puts essences back into existence and does not expect to arrive at an understanding of man and the world from any starting point other than that of their 'facticity.' It is a transcendental philosophy which places in abeyance the assertions arising out of the natural attitude, to better understand them. However, it is also a philosophy that the world is always 'already there' before reflection begins, as an inalienable presence, and all its efforts are concentrated on re-achieving a direct and primitive contact with the world and endowing that contact with a philosophical status. It is the search for a philosophy which shall be a rigorous science, but it also offers an account of space, time and the world as people 'live' them. It endeavours to give a direct description of a person's experience as it is, without taking account of its psychological origin and the causal explanations which the scientist, the historian or the sociologist may be able to provide (Merleau-Ponty, 1962).

### **4.7 RESEARCH PROCEDURE**

Qualitative research approaches raise ethical issues, as they encroach on personal spheres of the participants. Ethical issues to consider when conducting qualitative research include consent, protection of rights of institutions, privacy, confidentiality and potential to harm (Ramcharan & Cutcliffe, 2001). Letters of permissions and consent forms have been included as appendices.

#### **4.7.1 Gaining Access to Participants**

Permission to carry out this research was requested and granted by the chief executive officer (CEO) of the Tembisa Hospital. Appendix A, Request Letter and Appendix B, Approval Letter from hospital management, are attached. The initial contact was negotiated with the medical team at Masakhane Clinic, as they are the gatekeepers to the clinic. Since permission was given for research by the hospital authority, the researcher then liaised with the medical personnel to refer willing patients for research.

The referral process was treated with much care to avoid issues of confidentiality being compromised. This also included the power and influence which can be abused by referring sources. As health care providers, they can represent a powerful authority which can make potential participants be submissive and lose their power and right to give informed consent and be discouraged from withdrawing should they want to. Therefore, the medical team provided contact details but did not recommend participation in the study to avoid biasness from their side. Additionally, the health care providers did not have the identity of the adolescents who would be part of the study in order to protect participants from any form of prejudice from the health care system.

As soon as the adolescent arrived at the hospital's psychology department, they were invited to voluntarily take part in the research project. First, the purpose of the research was explained to both the guardians and the adolescents, which is to explore the experiences of adolescents who are on long-term HAART treatment in Tembisa. Secondly, their cooperation was requested to take part in the study. Thereafter, the guardians or parents were requested to complete a consent form for research. The willing participants were then booked in for a follow-up session where the research interview was then conducted.

#### **4.7.2 Privacy and Confidentiality**

Informed consent means that those interviewed or observed should give permission having full knowledge of the purpose of the research and the consequences of them taking part (Flewitt, 2005). A written informed consent form was signed by the parents, guardians and caregivers. The parents, guardians and caregivers of the adolescent participants were requested to complete the consent form on behalf of their children. The participants were given time to discuss the consent between parent/guardian and the adolescent. It was further explained in their own home language so that they could not miss any information.

Participants were also made aware that their participation in the study will not automatically carry any treatment benefit. This was done to ensure that participation is open, transparent and under no false intent. Following the consultation between parent/guardian and participant regarding the processes and procedure the study would follow, the parent was requested to wait outside so as to allow the interview between the researcher and participant to take place in a private environment. The researcher then consulted with the adolescent participant to find out if they understood the research, and their willingness to participate was verified once more. Each and every participant during the interviews was constantly reminded that the research was not a therapy or counselling session.

According to the Children's Act (2005), the parent or guardian of a child under the age of 18 years can give consent to the performance of a surgical operation and any other medical treatment; therefore, parental consent formed the initial consent for this study. The researcher made it clear to participants, their parents and guardians about their rights to decline to participate and reassured them that there would be no negative consequences if they chose not to participate and that they could answer any questions they are able to. It was important to emphasise to the adolescent participants that they could choose whether to take part or not and that if they decided to participate, they were always free to change their minds for a few minutes, for a whole session or forever.

Assent was thus obtained from adolescent participants younger than 18 years. In case of harm or discomfort during the interview or as a result of the interview, debriefing and psychosocial support would be made available by the researcher in her capacity as a psychologist. However, such capacity would emerge outside the interview process.

As regards child consent, Article 12 of the United Nations Convention on the Rights of the Child (UNCRC, 1989) clearly states children's rights to express their views on all matters that affect them. Some researchers prefer to use the term 'assent' rather than 'consent,' arguing that minors are unable to give legal consent. However, as Alderson and Morrow (2004) point out, in English law, 'competent minors' under 16 can give valid consent, with 'competence' defined as having sufficient understanding and intelligence to understand what is proposed (Flewitt, 2005; Rose, Hagemann, Aburto & Shahnazarian, 2013).

Another common assumption in ethical, social research is confidentiality in the process of conducting the research and anonymisation of individuals in reporting. Confidentiality is a principle that allows people not only to talk in confidence but also to refuse to allow publication of material they think might harm them (Health Professions Council of South

Africa [HPCSA], 2006; Wiles & Crow, 2008). All data gathered was treated confidentially. No information was released in a way that permits linking specific individuals to specific responses. The findings of the research will be published in a document, thesis, and submitted to the University of South Africa as well to the hospital authority. The risk of submitting favourable findings to suit the interest of the hospital interest was avoided at all cost. This has also been communicated during the process of seeking permission to study. Seminars and a community workshop were used to disseminate information for the benefit of the participants and the population they represent. The identifying information of the participants will not feature in any research publications. The raw data will be safeguarded and will not be available to any parties except for supervision during the study.

#### **4.7.3 Protection of the Participants**

The parents and guardians of these adolescent participants benefited, albeit indirectly. This is because once the adolescent participants gained a realistic understanding of their illness, they might adhere more to their treatment, thereby improving community participation.

The first interview question was about the general experiences of being on long-term HAART. The participants benefited during this research as they stood a chance to express their personal experience. The adolescent participants dealt with personal pain and trauma of their illness, which might have left them emotionally vulnerable. Therefore, the participants were informed that a counselling session could be arranged with the researcher for debriefing purposes as a result of the emotional impact the research might have on them.

A secondary gain of participating in the study included, but was not limited to, interaction with other adolescent participants who are on HAART. Informal support groups were created by participants once they knew they are not the only ones receiving HAART. Certain misconceptions were cleared during the process, as they gained information relating to the reality of HAART. Some adolescent participants were not told the truth about the reasons for their taking HAART, and during the research, they stood a chance to know the truth about their HIV status.

## **4.8 DATA COLLECTION APPROACH**

All the data collection processes were conducted at Tembisa Hospital. The researcher collected the data herself through the use of individual in-depth one-to-one interviews. This is a one-on-one method of data collection that involves an interviewer and an interviewee discussing specific topics in depth (David & Sutton, 2011). In this study, the researcher followed a flexible interviewing guide (often called an interview schedule or protocol). In addition triangulation of data collection was ensured through the use of a focus group of adolescents and questionnaires for health care professional participants.

Data collection methods are an integral part of the research design. Data collection methods in this study included face-to-face interviews and questionnaires that were personally administered, observation of individuals and events with or without audio recording (Sekaran, 2003; Creswell, 2014). Qualitative research methods have preference for open-ended, unstructured and reactive data collection procedures (Given & Saumure, 2008).

Permission was requested from the interviewees to record the interview. The interviews were tape recorded for some and not for others. Interviews were usually audio recorded to enhance the quality of data collection. Some objected to the recording of the interview, and their rights were thus respected. However, permission was requested to make field notes instead and was granted. The advantage of using a tape recorder is that it allowed a much fuller record than notes taken during the interview. It also allowed for the researcher to concentrate on how the interview proceeded and where it went next. However, the direction and duration of the interview were relatively open. As such, the interviewer needed to be prepared for an interview that may go on for longer than initially expected. The disadvantage of tape recording is that some participants did not feel happy being recorded. In such cases, the tape recording did not take place.

### **4.8.1 Informed Assent and Consent**

The researcher contacted and informed the potential adolescent participants about the nature of the study and the importance of their contributions. She then requested their participation in the study. Informed assent was then obtained (Appendix C) for eight of the adolescent participants younger than 18 years from their PGCPs, and consent forms (Appendix D) were signed by the two participants who are at least 18 of age (Wiles & Crow, 2008; HSRC, 2012). Informed consent was obtained for the PGCPs and HCPPs.

The participants were not forced to participate and could withdraw from the study at any stage without explanation or consequence. They were duly informed of this, and also that they would never be punished or harmed if they withdrew at any stage even if they had already signed a consent or assent form, or verbally agreed. The participants were also informed that they would receive no payment for their participation.

#### **4.8.2 In-depth Individual Semi-structured Interviews**

An in-depth interview is a conversation with a purpose. It is focused, discursive and allows the researcher and participant to explore an issue. It is used to determine an individual's perceptions, opinions, facts, forecasts and reactions to initial findings and potential solutions (DePoy & Gitlin, 1998). Clarifying questions were used in order to focus the interview on the relevant topic.

For the purpose of this study, in-depth interviewing was selected due to its advantages of flexibility in terms of adapting, adopting and changing the questions as the researcher proceeds with the interviews. Qualitative studies typically employ unstructured or semi-structured interviews.

Interviewing is the predominant mode of data collection in qualitative research. The researcher interviews because they are interested in other people's stories. Interviews are interactional events and are deeply and unavoidably implicated in creating meanings that ostensibly reside within participants (De Vos, Strydom, Fouche, & Delpont, 2002). The purpose of the phenomenological paradigm is to illuminate the specific, to identify phenomena through how they are perceived by the actors, in this case, the adolescents, in a situation. In the human sphere, this normally translates into gathering 'deep' information and perceptions through inductive, qualitative methods such as interviews, discussions and participant observation, and representing it from the perspective of the research participants (Creswell, 2003). Since the study is a qualitative phenomenological method, it was preferable to have in-depth research through in-depth interviewing. Open-ended questions were used in a mainly semi-structured questionnaire for data collection from the adolescents and PGCPs, and structured questionnaire for the HCPPs.

In-depth interviews are an attempt to understand the world from the participant's point of view, to unfold the meaning of people's experiences and to uncover their lived world prior to scientific explanations. As Hesse-Biber and Leary (2004) note, an interview is a research gathering approach that seeks to create a listening space where meaning is constructed

through an interexchange or co-creation of verbal viewpoints in the interest of scientific knowledge. Harrell and Bradley (2009) concur that interviews are discussions, usually one on one and between an interviewer and an individual, meant to gather information on a specific set of topics. Interviews can be conducted in person or over the phone. Interviews differ from surveys by the level of structure placed on the interaction. There are one-to-one interviews as well as group interviews, referred to as focus groups.

A researcher who employs an in-depth interview in a study is a human being, with a distinctive personal style. That being the case, a researcher uses their social view to practice in order to conduct an interview that is appropriate to the needs and demands of their research question and methodological approach, the context of the interview and the individual participant (Braun & Clarke, 2013).

In-depth interviews have the advantage insofar as they allow a well-trained interviewer to ask all types of questions. Interviewing allows for complex questions and can use extensive probes. Interviews have the advantage that the interviewers can establish rapport with the people being interviewed. Interviewers may be able to notice when participants seem to misunderstand a question and explain its meaning. Furthermore, an added advantage of one-to-one interviews is that they allow the interviewee an opportunity to describe his experiences without interference. The disadvantage of interviews is the cost implication. Interviews can also be time-consuming.

Interviews involve personal interaction; therefore, cooperation is essential. Interviewees may be unwilling or may be uncomfortable sharing all that the interviewer hopes to explore, or they may be unaware of recurring patterns in their lives. The interviewer may not ask questions that evoke long narratives from participants because of a lack of expertise or familiarity with the local language or because of lack of skill. By the same token, she may not properly comprehend responses to the questions or various elements of the conversation (Marshall & Rossman, 2010).

One-on-one interviews involve one interviewer and one interviewee and more often than not entail face-to-face interaction, although telephonic interviews can also be conducted (Gravetter & Forzano, 2010). An interview is an interactive process of making meaning and co-generating data by means of conversation. Various languages were used for the interviews in this study as preferred by the participant, and these languages included Tsonga, Venda, Sesotho languages (Sepedi, Setswana, and South Sotho), IsiZulu and English. In this study, in particular, in-depth interviews were used to ensure that the study

gave insight into the world of another. The approaches helped in gaining insight into the lives, experiences, beliefs and knowledge of adolescents on HAART. This process was facilitated by the researcher being fluent in speaking and reading the above-mentioned languages.

For adolescent participants, an interview guide was created (Appendix E). A pilot study consisting of three adolescent participants was conducted. The guide was improved and interviews conducted accordingly. The objective of the guide was to explore the experiences of the adolescents of the Masakhane Clinic regarding the experiences of the adolescents who are on HAART treatment. The main questions were open-ended in nature with some profile data included for quantitative analysis. Verbal, face-to-face interviews were conducted by the researcher.

The questions included:

- When did you start taking HAART?
- Do you know what the treatment is for?
- What does taking such medication mean to you?
- What is the meaning of being in HAART treatment for you?
- What are the challenges you face being on HAART?
- What do you think are the challenges that adolescents experience as a result of being on HAART?
- What are the benefits you experience as a result of being on HAART?
- What are the coping mechanisms and strategies you use as a result of being on HAART?

An interview guide (Appendix F) was created for PGCPs. The objective of the guide was to explore the experiences of the parents, guardians and caregivers of adolescents regarding the experiences of the adolescents receiving HAART at Tembisa. The main questions were open-ended in nature, with some profile data included for quantitative analysis. Verbal, face-to-face interviews were also conducted by the researcher with the parents, guardians and caregivers.

The questions posed included:

- As a parent, what has been your experience in dealing with adolescents on HAART?
- How was the information of his or her status delivered to him or her?
- How did he or she respond to the information of his or her status?

- What do you think is the meaning of being in HAART treatment for him or her?
- What are the challenges you face as a result of his or her being on HAART?
- What do you think are the challenges that adolescents experience as a result of being on HAART?
- What do you think are the benefits he or she experience as a result of being on HAART?
- What are the coping mechanisms and strategies he or she uses to cope with being on HAART?
- Would you like to add any other comment that was not addressed by the questionnaire?

#### **4.8.3 Structured Questionnaires for HCPPs**

How did the researcher go about requesting participation from the HCPPs? Self-completion questionnaires, Appendix G, were used for HCPPs. The objective of the questionnaire was to explore the experiences of the multidisciplinary team of the Masakhane Clinic regarding the experiences of the adolescents that are on HAART. The questions were closed-ended (quantitative and profiles) and open-ended in nature. Participants could write as much as they could. They could also make use of an extra page if they wished to.

Questionnaires generally consist of open- or closed-ended questions or items that measure facts, attitudes, or values. Consequently, a standard questionnaire, namely, "Interview Guide for Health Care Professionals," was developed to gather the desired information. Both qualitative and quantitative research use questionnaires to collect data. Closed-ended questions elicit a response, score quickly, and are easy to evaluate. To ensure reliability, inventories often restate the question or item several times. Open-ended questions allow the participant to provide a more complete or comprehensive response (McClure, 2002).

A pretest questionnaire was given to one HCPP in September 2014 to pilot and detect any missing important information. On feedback, the questionnaire was improved and handed out to 15 HCPPs in December 2014. A total of 11 completed questionnaires were returned. This approximately 75% response rate is acceptable (Bailey, 1994). The non-response rate of only 27% was sheltered by the diversity of the HCPPs' different professions.

Open-ended responses often provide specific and meaningful information (Arhar, Holly, & Kasten, 2001; Patton, 2002). Simultaneous administration of questionnaires to multiple

people at various locations is one of many positive advantages associated with this methodology. Anonymity is another benefit of questionnaires that makes them an effective tool for collecting data on sensitive or illegal activities.

Questionnaires generally contain objective items written as multiple-choice, fill in the blank, or short answer items (McClure, 2002). The questions or requests from the participants included:

- What has been your experience in dealing with adolescents on HAART?
- Please explain the challenges faced by the adolescents on HAART.
- Please enlighten on the benefits experienced by the adolescents on HAART.
- Please spell out the coping mechanisms and strategies being used by the adolescents on HAART.
- Please comment on any issues that were not addressed in the questionnaire.

#### **4.9 DATA STORAGE**

Storage of interviews were in the form of tape-recorded conversation, handwritten field notes taken during the session, as well as interview transcripts after the analysis. Interviews were conducted in Sesotho, Tsonga, Venda, IsiZulu and English. The Sesotho, Tsonga, Venda and IsiZulu were then translated into English by the researcher herself. To ensure accuracy of translation, a multi-lingual colleague was requested to check for meaning captured and a second verification process, thereby ensuring efficiency in translation. These interviews were transcribed verbatim in English and stored electronically. As the case with qualitative research approaches, transcription of interview data was time-consuming. This was despite the researcher using a transcribing machine, but the process was very intensive than conducting interviews.

Two of the adolescent participants were reluctant to have the conversation with the interviewer tape recorded; because of that, recording did not take place in the case of these two participants. However, field notes were taken during the interview session, which the researcher used as a point of reference during the transcription of the interview. For HCPPs, returned questionnaires were handwritten. The returned questionnaires were scanned and saved electronically. The data on them was analysed. Pseudonyms were used so as not to disclose the real names of the participants. All information provided was kept confidentially.

#### **4.10 DATA ANALYSIS**

Data analysis is the process of bringing order, structure and meaning to the mass of collected data, thereby transforming data into findings (Somekh & Lewin, 2011). The descriptive phenomenological researcher starts with concrete descriptions of lived experiences and proceeds by reflectively analysing these descriptions (Husserl & Heidegger, 1927). Quantitative data was analysed using descriptive statistics analysis methods. Histograms and bar charts were used in the analysis. Quantitative data was collected solely for biographical information comparison.

Thematic analysis and phenomenological analysis approaches were applied, which share the aim of identifying and describing the central ideas (usually referred to as themes or categories) occurring in data. Thematic analysis attempted to identify themes from the material under study. This material comes from the interview data. The researcher normally analyses the material inductively, that is, the themes are derived from the data rather than derived beforehand (Wertz et al., 2011). Themes were organised in a hierarchical structure, with higher order themes and subthemes. In a true sense, thematic analysis is a qualitative analogue of the statistical approaches of factor analysis or cluster analysis, both of which aim to describe a complex data set in terms of number of dimensions or groupings (Cooper et al., 2012).

Analysis of data in this study was a process of reading and looking for themes and patterns of meaning. The researcher read and reread the transcripts to identify emerging themes and subthemes that reflect the experiences of adolescents on HAART, and a code list was developed which defined the identified themes.

Furthermore, computer program Atlas.ti.7 was co-applied in the creation of codes. It was also used subsequently in the generating of themes.

The steps taken followed the guidelines as stipulated in research. Generally, the most usual data source is verbatim transcripts of audio-taped interviews, but other sources are sometimes used, such as group discussions, written accounts or diaries (Miner-Romanoff, 2012).

Some of the steps taken are as follows:

- Phenomenological reduction and bracketing: No position was taken either for or against either the data or any of the researcher's own presuppositions.
- Delineating units of meaning: Those statements that were seen to illuminate the researched phenomenon were extracted. The researcher was required to use her own judgement while consciously bracketing her own presuppositions. The list of units of relevant meaning extracted from each interview was carefully scrutinised, and those units that were clearly redundant were eliminated.
- Units of meaning were clustered to form themes: Having compiled the list of non-redundant units of meaning, the researcher rigorously examined the lists and tried to elicit the essence of meanings of units within the holistic context. Clusters of themes were formed by grouping units of meaning together, and the researcher identified significant topics, also called units of significance.
- Summarising each interview and validating it: A summary that incorporated all the themes elicited from the data gave a holistic context.
- Extracting general and unique themes from all the interviews and creating a summary: Once the process outlined in the above points had been completed for all the interviews, the researcher looked for the themes common to most or all of the interviews as well as the individual variations. Care was however taken not to cluster common themes when significant differences exist; the unique or minority voices are important counterpoints to bring out regarding the phenomenon researched.

#### **4.11 MEASURES TO ENSURE TRUSTWORTHINESS**

Ethical decisions are the result of weighing up a myriad of factors in a specific complex, social and political situation in which research is conducted. Ethics are about striking the balance between protecting the rights of the participants in research as well as guiding the researcher's actions in the field (Flewitt, 2005). Ethical practice is often defined as 'doing no harm' and aspires to 'do good,' thereby conducting research that benefits participants in positive ways (HPCSA, 2006; Chan, Fung & Chien, 2013).

#### **4.11.1 Trustworthiness in Qualitative Research**

Research findings are valid to the extent that they resonate with the experiences of others who have experienced the phenomenon in question. For the adolescents and the PGCPs, the researcher conducted a 'validity check' by returning to the participants to determine if the essence of the interview had been correctly captured. The study was based on the assumption that young people have the ability to speak about their experiences and are capable of contributing to the worlds in which they reside. In addition to learning about the experiences of adolescents related to HAART from the work of other researchers, this study explored the issue from the perspectives of young people themselves.

Credibility is enhanced by keeping the focus on questions which the participants can answer, that is, on what they experienced rather than why they experienced it. Credibility was also strengthened by reflecting the researcher's understanding back to participants and by repeated interviews. Credibility is the confidence that the study measures what it intends to test and the confidence in the findings (Shenton, 2004). The researcher used the appropriate methodology for the study; this made it possible to get the participants' experiences in detail. These participants took part voluntarily, which promoted genuine responses to the questions, thus giving confidence in the findings.

The participants were engaged until data saturation occurred. While working on the data collection, trustworthiness of the research findings was ensured (Patton, 2002). The researcher used a good quality digital voice recorder during data collection and transcribed verbatim to make sure that interpretation is based on the original participants' responses.

It is important that transferability of the findings forms an element of the research. Shenton (2004) explains transferability as showing that the findings can be generalised and applicable in other settings. A full description of the context and background information about the setting of the study, the population, as well as details on the sample and data collection has been given with precision to enable other researchers to determine transferability to other contexts. The research also purposively selected the participants, given their experiences to conduct the study.

It is crucial that findings in a study are dependable. Dependability generally refers to giving fully detailed processes about the study to allow future researchers to repeat the work. It is showing that the findings are consistent and can be repeated in other settings (Shenton, 2004). A full description of what was planned, what was done and how it was done was

given in detail in the methodology. The methodology explained how participants were recruited, how data collection was done and how the analysis was carried out so that interested future researchers can repeat the study and find similar findings.

An aspect not to be overlooked when conducting research is confirmability. Confirmability is the extent that the findings of the study are objective and neutrally reflect the experiences and ideas of the participants without being influenced by the preferences and interests of the researcher (Shenton, 2004). Voice recordings from the group discussions were listened to timely even after verbatim transcribing and translating so as to ensure that participants are not misinterpreted. Timely debriefing sessions online and face to face were held with the research supervisor who served as the sounding board for the researcher to guide development of the themes as identified from the transcripts and guide honest interpretations.

Furthermore, the method of triangulation was applied. This involved using different data sources of information by examining evidence from the sources and using it to build a coherent justification for themes. If themes are established based on converging several sources of data or perspectives from participants, then this process can be claimed to be adding to the validity of the study (Creswell, 2014).

#### **4.11.2 Credibility of the Interview Guides**

All interview guides were created by the researcher and supervised by the study promoter before use. In the case of HCPPs, participants were given their own space and sufficient time to allow for honesty and a favourable response rate. The same questions were asked to ensure consistency. In the case of the PGCPs and adolescents, similar questions were asked using the interview guides.

#### **4.11.3 Prevention of Bias**

When a researcher suspends their own presuppositions and judgements, this is referred to as bracketing. From the Husserlian philosophical stance, only from a point of suspended judgement can inquiry proceed unencumbered from masked assumptions about the nature of the phenomena and conditions observed (Simon, 2011). Bracketing is a method used by some researchers to mitigate the potentially deleterious effects of unacknowledged preconceptions related to the research and thereby to increase the rigour of the project. Given the sometimes close relationship between the researcher and the research topic that

may both precede and develop during the process of qualitative research, bracketing is also a method to protect the researcher from the cumulative effects of examining what may be emotionally challenging material (Tufford & Newman, 2010).

#### **4.12 ETHICAL CONSIDERATIONS**

The researcher ensured strict compliance with ethical standards. These included standards which were relevant to protecting the rights of the participants as well as institutions where data was collected and scientific integrity maintained throughout the study. Approval was sought and obtained from both the Tembisa Tertiary Provincial Hospital as well as the Unisa Ethics Committee before data collection commenced, see Appendix B and Appendix J respectively.

#### **4.13 CHAPTER RÉSUMÉ**

This chapter explained the methodology used in this study and justified its use and the approaches employed. The population was explained, and the sample selected was also described. Phenomenology of qualitative methods of research was given special attention because it forms an integral part of the methodology. Data analysis was also described, as well as the informed consent approach used in dealing with the participants.

The next chapter presents the findings of the study.

## **CHAPTER 5:PRESENTATION AND DISCUSSION OF FINDINGS**

### **5.1 INTRODUCTION**

The previous chapter explained the methodology that was employed in this study. This penultimate chapter presents the interview results of the research section of the study, that is, research findings. The adolescent participants who participated in the study had been on HAART for at least two years, since the study intended to understand the long-term experiences of taking the treatment.

The study findings cover the negative and positive experiences and the perceived role of HAART treatment over a long period of time. The PGCPs were also requested to describe the role they play in the treatment and support of the adolescents under study. Furthermore, the PGCPs' views about the experiences and coping mechanisms of the adolescent participants taking HAART treatment were also included in order to obtain a broader understanding.

The various stakeholders involved in the treatment of the adolescent participants on HAART treatment were also requested to provide information on their experiences of being involved with the HAART treatment for the adolescent under their care at the hospital. These collective contributions were required to provide important information on improving practices in HAART treatment of the HIV and AIDS adolescent participants.

Pseudonyms were used in capturing the responses in order to ensure anonymity of the participants. The findings cover:

- (a) experiences of adolescent participants under HAART treatment at Tembisa Hospital;
- (b) experiences of the FGAPs on HAART treatment,
- (c) experiences of PGCPs of adolescents; and
- (d) experiences of HCPPs involved with these adolescents.

For the demographic data (profiles) of all the four categories, descriptive statistics analysis was used to best describe the data. According to Terre Blanche and Durrheim (1999), descriptive analysis aims to describe the data by investigating the distribution of scores on each variable and by determining whether the scores of different variables are related to one another.

The interview questions included closed-ended and open-ended questions. This chapter presents personal experiences of the adolescent participants under HAART treatment, impressions and reactions of the parents, guardians and caregivers of these adolescent participants. It also considers the expert inputs of the various professionals involved with the adolescent participants.

## **5.2 PROFILES AND NARRATIVES OF THE ADOLESCENT PARTICIPANTS**

This section presents the experiences of the adolescent participants who were taking HAART treatment at the Tembisa Hospital at the time of the study. The main critical aspect of this section is that the people who were directly involved and who had first-hand experiences were the ones sharing their experiences. The HCPPs and PGCPs have shared their impressions about these adolescent participants. The consolidated impressions from the involved parties were thought to be necessary to enable the parties to understand what they could be doing to one another during the treatment, with the hope that there can be interventions found that will allow them to cherish all the challenges involved.

### **5.2.1 Profiles of Adolescent Participants**

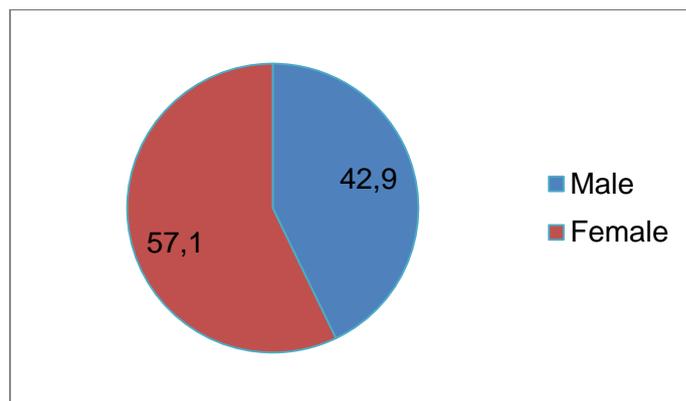
Seven adolescents who were taking HAART treatment at the Tembisa Hospital participated in the study. Significant characteristics among participants included gender, age, education level or school grade, and length of time on HAART treatment. The male (43%) and female (57%) adolescent participants were distributed almost identically (but this is not clear, as the sample sizes used were small); their ages ranged from 13 to 19 years; their school grades were from six to nine, and one was at tertiary level; and they had been on HAART treatment for periods ranging from five to about eight years.

### 5.2.1.1 Gender Distribution of Adolescent Participants

Table 5.1 and Figure 5.1 show how the gender of participants was distributed.

**Table 5.1: Adolescent Participants' Gender Distribution**

	Male	Female
Frequencies	3	4



**Figure 5.1: Adolescent Participants' Gender Distribution**

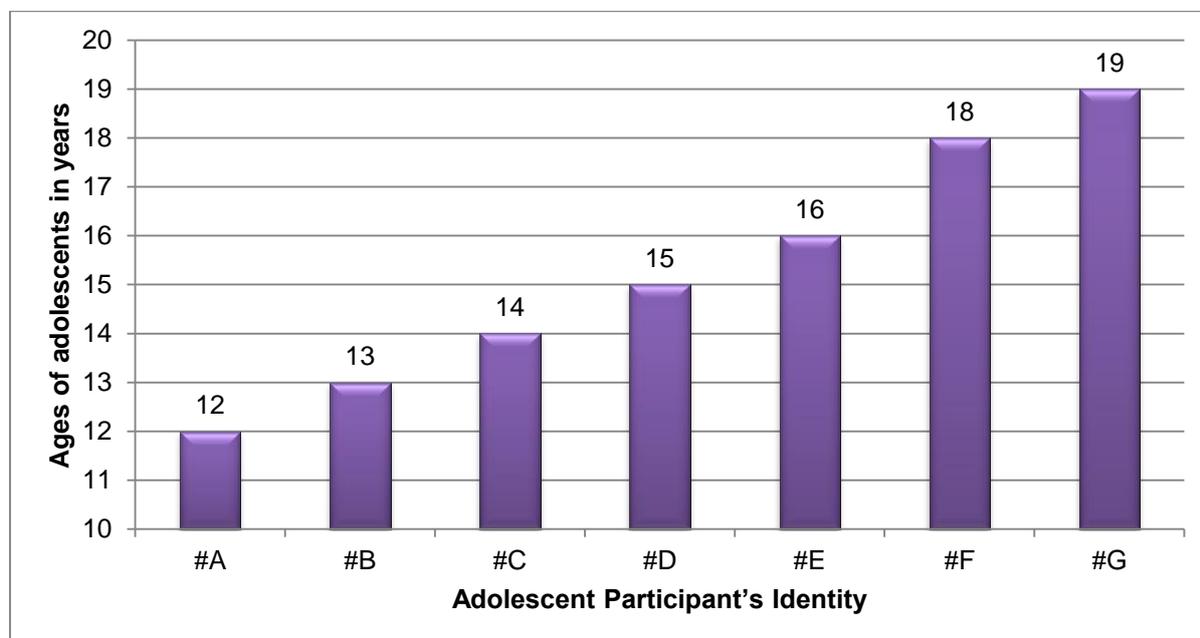
The type of graph used for the distribution of the adolescent participants into gender categories is a pie chart (Figure 5.1), which can easily display categories of adolescent participants in few categories. Table 5.1 and Figure 5.1 show the gender distribution of the adolescent participants to have been 42.9% male and 57.1% females. Both the table and figure indicate that there were more female participants than male participants.

### 5.2.1.2 Adolescent Participants' Ages

In Table 5.2 and Figure 5.2, how the adolescent participants' ages were distributed is shown.

**Table 5.2: Adolescent Participants' Ages**

Adolescent #	A	B	C	D	E	F	G
Ages of adolescents	12	13	14	15	16	18	19



**Figure 5.2: Adolescent Participants' Ages**

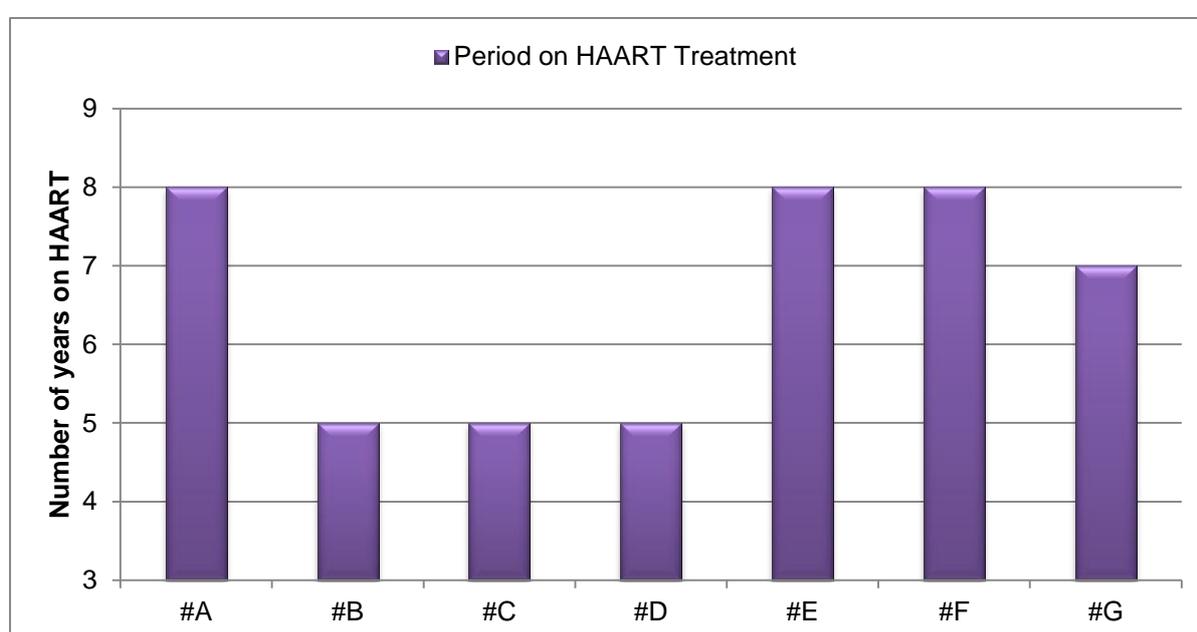
From Figure 5.2, it can be deduced that the average age of the adolescent participants on HAART treatment was 15.3 years. The adolescent participants' ages are equally distributed between ages 12 and 19 inclusive, with the exception of age 17.

### 5.2.1.3 Adolescent Participants' Length of Time on HAART

The adolescent participants' length of time on HAART treatment is revealed in Table 5.3 and Figure 5.3.

**Table 5.3: Adolescent Participants' Length of Time on HAART Treatment**

Adolescent #	A	B	C	D	E	F	G
Period on HAART	8	5	5	5	8	8	7



**Figure 5.3: Adolescent Participants' Length of Time on HAART Treatment**

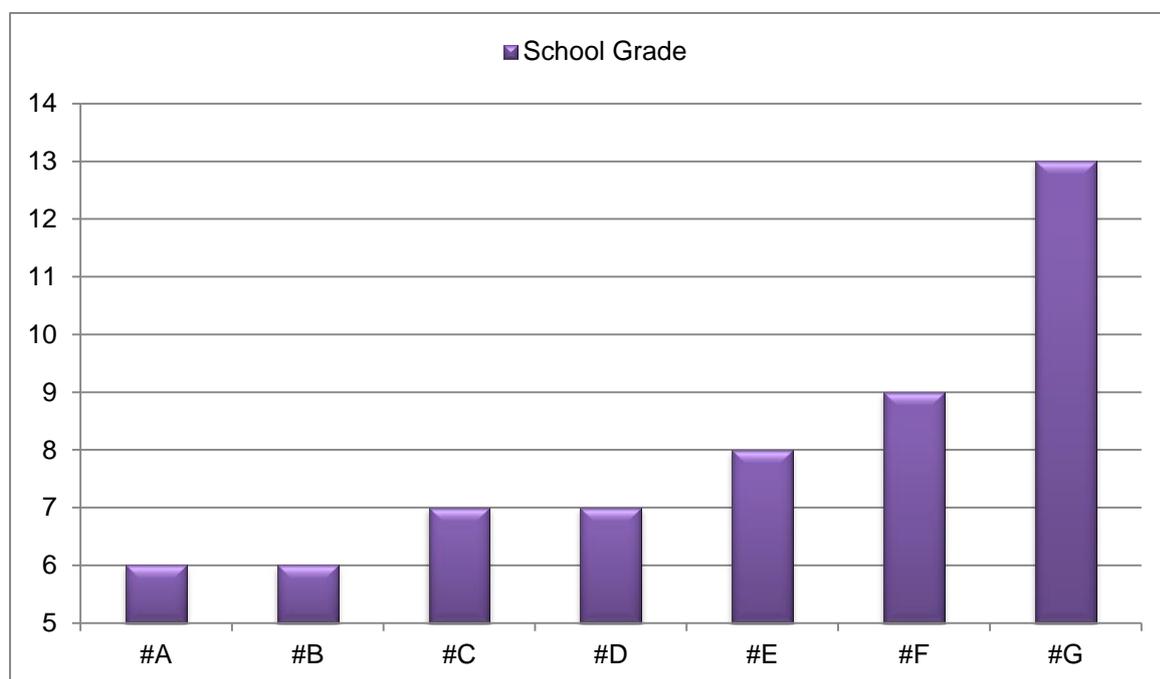
The mean or average length of use of HAART treatment by the adolescent participants was about 6.6 years. Table 5.3 and Figure 5.3 highlight that the longest usage was eight years, and the shortest was five years. The modal lengths of use were both eight and five years, coincidentally the longest and the shortest lengths of using HAART treatment. From the above subsection, the oldest adolescent participant at the time of the study was 19 years, and the youngest was 12 years. This shows that in 2010, when some of them started to take HAART treatment and others were already on the programme, four of them were still below 10 years of age.

### 5.2.1.4 Adolescent Participants' School Grades

With regard to school grades, the participants' school grades are reflected in Table 5.4 and Figure 5.4.

**Table 5.4: Adolescent Participants' School Grades**

Adolescent #	A	B	C	D	E	F	G
School Grade	6	6	7	7	8	9	Tertiary



**Figure 5.4: Adolescent Participants' School Grades**

In Table 5.4 and Figure 5.4, it is illustrated that the lowest grade attended by the bulk of these adolescent participants at the time of the study was grade 7, and the highest was grade 9. There was an exception of an outlier one who was already at tertiary education level. The two modal classes were grade 6 and grade 7, since they appeared more than the rest.

### 5.3 PROFILES AND NARRATIVES OF THE FOCUS GROUP OF ADOLESCENT PARTICIPANTS

In this section, the experiences of the FGAPs who were taking HAART medication at the Tembisa Hospital at the time of the study will be presented. The main importance of the section was to consolidate impressions of another set of adolescents who were directly involved and had first-hand experiences, in a group setting.

#### 5.3.1 Profiles of Adolescent Focus Group of Adolescent Participants

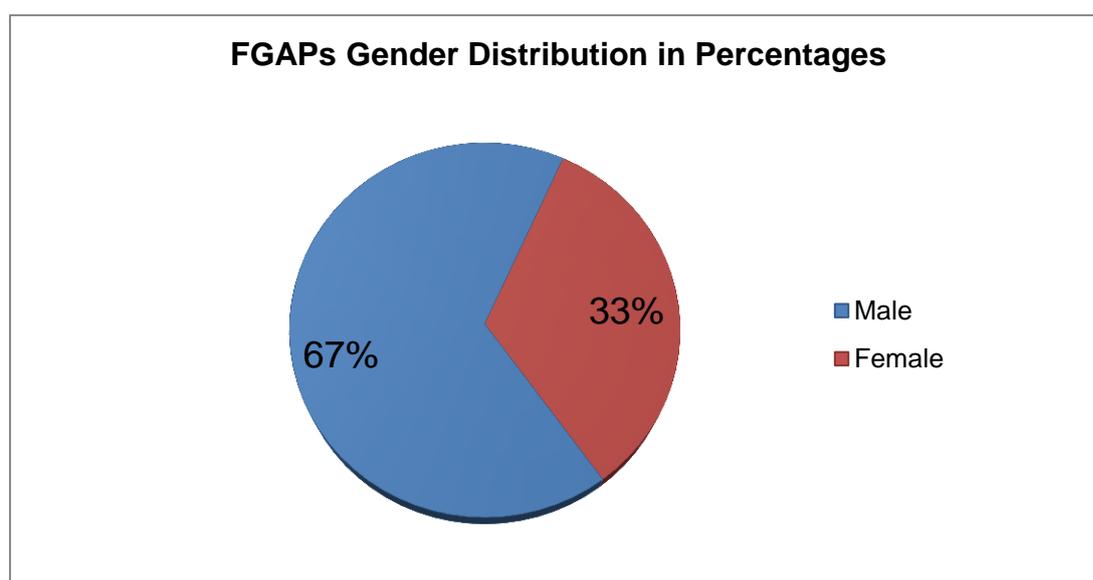
Three adolescents who were taking HAART treatment at the Tembisa Hospital were involved in the focus group. Their other characteristics were gender, age, education level or school grade, and length of time on HAART treatment. There were two males and one female. The adolescents' ages ranged from 14 to 17 years; their school grades were from 7 to 10; and they had been on HAART treatment for periods ranging from 7 to about 10 years.

##### 5.3.1.1 Gender Distribution

The gender distribution of the FGAPs is presented in Table 5.5 and Figure 5.5.

**Table 5.5: Focus Group of Adolescent Participants' Gender Distribution**

	Male	Female
Frequencies	2	1



**Figure 5.5: Focus Group of Adolescent Participants' Gender Distribution**

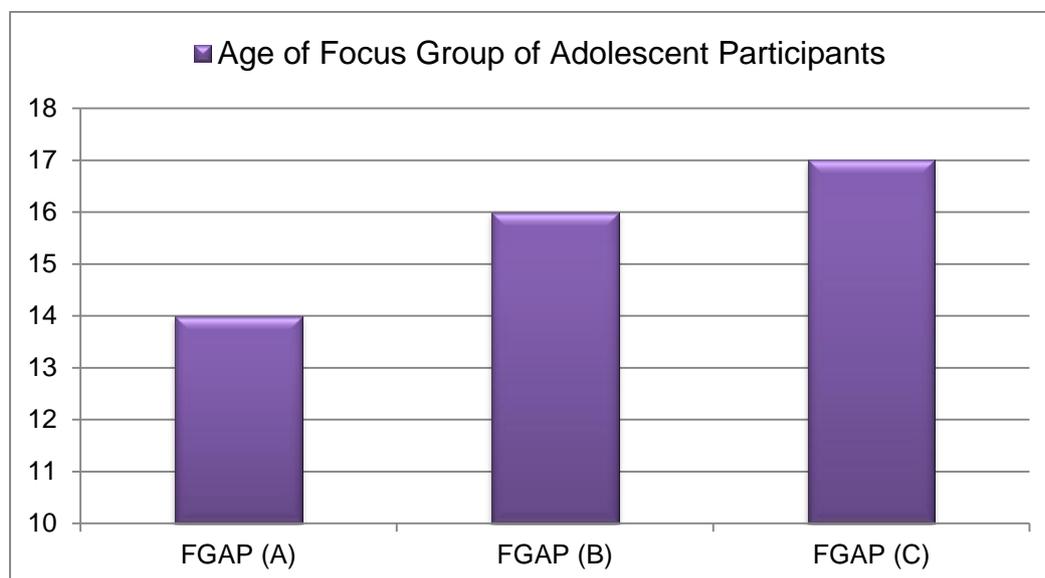
The type of graph used for the distribution of the adolescents into gender categories is a pie chart (Figure 5.5), which can easily display categories of the participants in a few categories. A pie chart is useful when one wants to show relative proportions or contributions to a whole (Walkenbach, 2015). Table 5.5 and Figure 5.5 show the gender distribution of the participants to have been 66.7% male and 33.3% female. In this case, it appears that the number of males participating exceeded that of females.

### 5.3.1.2 Focus Group of Adolescent Participants' Ages

The participants' ages were distributed as shown in Table 5.6 and Figure 5.6.

**Table 5.6: Focus Group of Adolescent Participants' Ages**

FGAP #	FGAP (A)	FGAP (B)	FGAP (C)
Ages in Years	14	16	17



**Figure 5.6: Focus Group of Adolescent Participants' Ages**

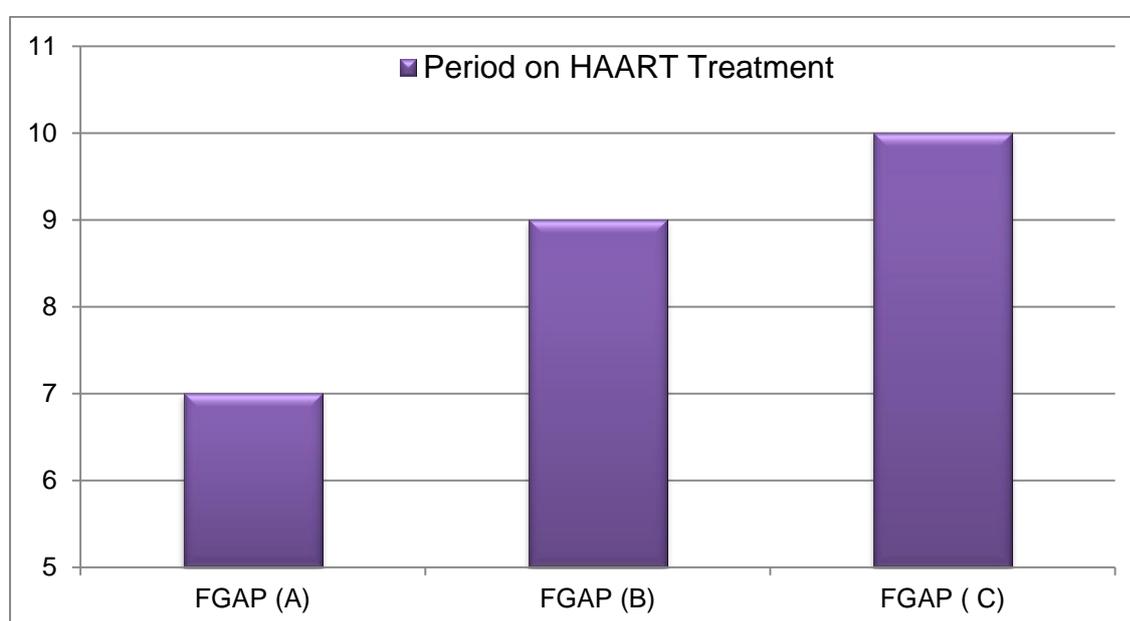
According to the statistics in Table 5.6 and Figure 5.6, the average age of the adolescents on HAART treatment was worked out to be 15.7 years. The adolescents' ages are equally distributed between age 14 and 17 inclusive, with the exception of age 15.

### 5.3.1.3 Focus Group of Adolescent Participants' Length of Time on HAART Treatment

The length of time that the FGAPs have been on HAART treatment is depicted in Table 5.7 and Figure 5.7.

**Table 5.7: Focus Group of Adolescent Participants' Length of Time on HAART Treatment**

FGAP #	FGAP (A)	FGAP (B)	FGAP (C)
Length of Use	7	9	10



**Figure 5.7: Focus Group of Adolescent Participants' Length of Time on HAART Treatment**

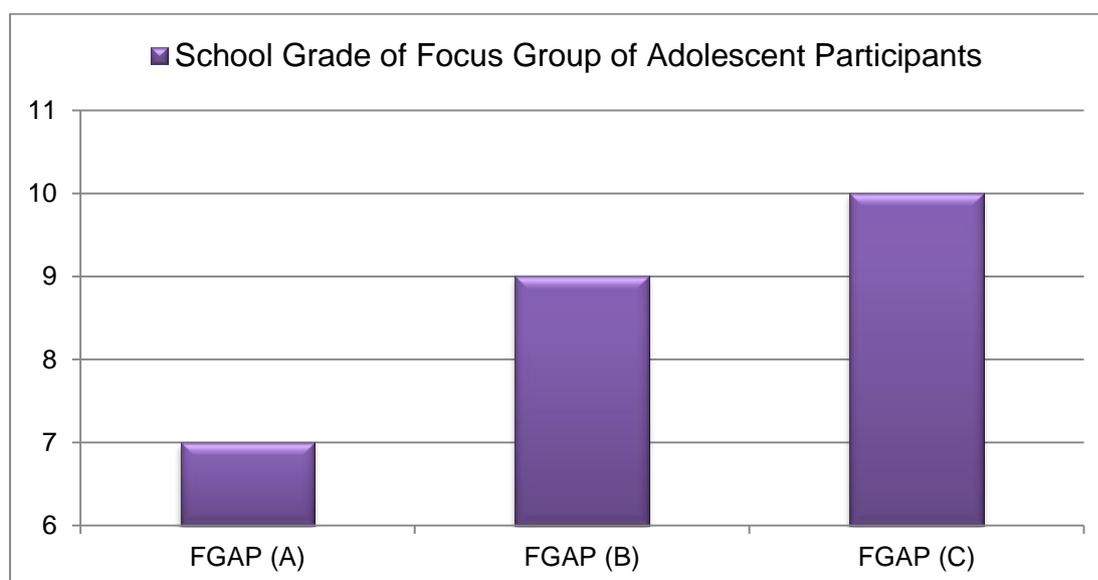
The average length of use of HAART treatment by the adolescents was about 8.7 years. Table 5.7 and Figure 5.7 indicated that the longest usage was 10 years, and the shortest was 7 years. The length of period is equally distributed. From the above subsection, the oldest participant in the focus group was 17 years, and the youngest was 14 years of age. This shows that in 2008, when some of them started to take HAART treatment and others were already on the programme, all of them were still below the age of seven.

### 5.3.1.4 Focus Group Adolescent Participants' School Grades

The FGAPs' school grades were distributed as reflected in Table 5.8 and Figure 5.8.

**Table 5.8: Focus Group Adolescent Participants' School Grades**

FGAP #	FGAP (A)	FGAP (B)	FGAP (C)
School Grade	7	9	10



**Figure 5.8: Focus Group Adolescent Participants' School Grades**

Each FGAP belongs in his or her own grade. Table 5.8 and Figure 5.8 show that the lowest grade that an FGAP was in is grade 7 and the highest is grade 10.

### 5.3.2 Themes Identified From the Focus Group of Adolescent Participants

The subsection that follows presents the themes identified from the focus group session.

#### 5.3.2.1 Access to HAART Treatment

##### 5.3.2.1.1 HAART treatment initiation

The majority of the FGAPs had been on HAART treatment for a long period of time and did not remember from memory when they had initiated the treatment. FGAP (C), after trying to recall, said:

*“... I do not know when I started; I just remember drinking them ...”*

FGAP (B) supported the idea by adding:

*“I also don’t remember exactly the date, but I know I was still small and before I even started school.”*

All FGAPs were still very young at the time of HAART initiation. This is echoed by this comment:

*“I was still very small. But the treatment card will show ...”*

FGAP (A) remembered the specific year he had initiated HAART treatment:

*“I started taking the treatment in 2006.”*

The majority of the FGAPs cannot recall from memory when they initiated the treatment.

#### 5.3.2.1.2 *Experiences with HAART tablets*

The FGAPs’ concern with the tablets was the bitterness of the taste and the difficulty in swallowing them. FGAP (B) started by simply saying:

*“The problem was the swallowing of the bitter tablets.”*

FGAP (A) added:

*... the tablets are hard to swallow, they are bitter when you have to swallow, and it is not nice. I used to drink many tablets, maybe ten tablets two times a day. I had to swallow all of them like that. I used to just put all of them in my mouth at the same time and drink water, but some of them would be stuck on the throat [indicating the throat with her hand], and it was hard to drink but I must drink.*

This is when FGAP (B) continued:

*Me too, 'nami futhi, aya baba lamapilisi' (meaning, me too, I find the tablets to be bitter), so it was difficult but now I don't take as many tablets as before, now I take two tablets at 7 o'clock in the morning and 7 o'clock at night. Now it is easier to take the tablets.*

The transition from multiple tablets to one tablet per day proved to be a pleasant introduction to the participants:

*Now I only have to take one tablet per day, and it does not get stuck on my throat, and it is easier to take the tablets. My weight has increased and the tablet that you take once a day, you must weigh a certain weight before they can give you that tablet, so because I was drinking the many tablets before and I am gaining weight so the doctors at the clinic decided I can start taking the one tablet per day, added FGAP (A).*

#### 5.3.2.1.3 Purpose for HAART treatment

All of the FGAPs knew their purpose for taking treatment. This is exemplified by FGAP (A) who stated:

*"I know I am taking the treatment for HIV ... I respect and I know I am HIV positive."*

FGAP (C) also reported:

*"I know I am HIV positive, and I must take this treatment."*

Furthermore, the remarks of FGAP (B) were:

*"I know I have this illness, HIV, and if I don't take treatment, I will fall sick. I know that I am taking treatment for HIV."*

The FGAPs understood that if they did not take the medication, they would fall sick.

#### 5.3.2.1.4 Significance of HAART treatment

The participants seemed to understand the significance of being on HAART as seen from FGAP (B)'s utterances.

FGAP (B) revealed:

*“The treatment is important because it keeps us healthy. So taking the treatment means we can stay alive.”*

The FGAPs believed that the treatment keeps them healthy and alive. In her words, FGAP (A) stated:

*“I must drink because I want to be alive.”*

The knowledge of family members who had passed on successfully through HIV encouraged the participants to adhere to their treatment. FGAP (A) went on to disclose:

*“... my Mom died because of this disease and so I must take medication so I can stay alive.”*

The benefits of HAART treatment was physically visible to the adolescents, thus giving them encouragement to adhere to treatment.

#### 5.3.2.1.5 Challenges of HAART treatment

HAART treatment seems to get in the way of the adolescents' social life, as adolescent participants must make time to take their medication even when out with friends, which is not always practical.

FGAP (A) put this into words when stating:

*“For me, you see I have friends, and I stay out late hanging with my friends on the streets chilling and sometimes time flies by and I come home and the time for medicine is gone.”*

HAART treatment is a lifelong commitment which is viewed by most of the adolescents as hindering social life. The limited choice to either adhere or fall sick leaves the adolescents with unresolved issues that could lead to poor adherence to the HAART treatment.

#### 5.3.2.1.6 *Benefits of HAART treatment*

The FGAPs understood the benefits of being on HAART treatment.

FGAP (B) shared:

*“I know I am healthy because of the medication, so it helps me a lot.”*

FGAP (C) reported sufficient understanding of the benefits of HAART treatment as seen in the following quote:

*“I am also ok, I know if I was not taking the medication I would not be like this; maybe I would be sick.”*

HAART treatment seemed to give the participants hope and ambitions.

FGAP (A) brought this out when highlighting:

*“I must drink because I want to ... grow up and be a chef.”*

The effects of HAART treatment were visible to the adolescent. Their physical growth was positively linked to HAART treatment, leading to sustained adherence and a sense of hopefulness.

#### **5.3.2.2 Disclosure, Stigma and Denial**

Although it was not easy for the family members to disclose to the FGAPs, the guardians seem to be the ones who were left with the task of disclosing to the FGAPs.

FGAP (B) recalled:

*“... my aunt told me about it.”*

Sometimes health care professionals have to be the messengers, as FGAP (C) narrated:

*My grandmother told me I am HIV positive. I was always sick, attending hospital in and out frequently. Grandmother was told by the doctors about my HIV status and*

*they tried to withhold information from me and I asked them to be honest with me because it is my life after all. I even asked the doctors, though they were reluctant to tell me, but finally I persuaded them to tell me, and they told me.*

Disclosure is of importance to the focus group adolescent participants. Given a choice, the FGAPs would prefer disclosure to be done by someone who would be in a position to answer their follow-up questions.

#### 5.3.2.2.1 *Death of parents*

Some of the parents of the focus group adolescent participants have passed away. The sense of bereavement towards loss of parents is experienced at a young and vulnerable stage of development.

*“My mom passed away,”* responded FGAP (B), when asked about biological parents.

FGAP (A) lamented:

*“My mom died of this illness, and she left me when I was very small. Many people are dying of this illness; that is why I don’t like talking about it.”*

Two of the FGAPs’ biological mothers had passed away. The FGAPs felt a sense of being abandoned by their mothers, whether they had passed on or not. FGAP (C) had a different recollection of her mother:

*... she took me to the hospital one day. When we were at the hospital, she said I must wait for her by the corner; she is coming back; she is going to buy me some sweets. She never came back. I was small, and now I am sixteen and a half years old, and she has not come back from the sweets.*

The only living mother of the FGAPs did not live with her child and was also HIV positive:

*“Mom also has this HIV ... my mom has three other children, and she does not stay with any of her children,”* said FGAP (C).

The topic of biological fathers did not come up in the group discussion. This might suggest that not every adolescent was struggling with the loss of a parent or the father's whereabouts were unknown.

The support from significant family members contributes to enhanced adolescents' adherence to HAART treatment. Support targeted specifically at FGAPs such as emotional and related support encourage adherence to HAART treatment.

#### 5.3.2.2.2 *Parents, guardians and caregivers of adolescent participants on HAART treatment*

All FGAPs were under the care of guardians. The guardians of these FGAPs included an aunt, a grandmother and a house mother in a children's home. The FGAPs narrated, with FGAP (C) initiating:

*"I stay with my aunt."*

FGAP (B), on the other hand, noted: *"I have been staying in a Children's Home."*

The FGAPs spoke fondly of their guardians and recognised the support and encouragement they received from their guardians. FGAP (B) recalled affectionately:

*"The house mother also encourages us and supports us. She makes sure there is food to eat before we take the medication."*

The focus group adolescent participants appreciated the support given by their parents, caregivers and guardians. This support contributed to sustained adherence to HAART treatment with visible health benefits.

#### 5.3.2.2.3 *Coping mechanisms used by FGAPs*

Having peers who are also on HAART treatment was comforting for FGAPs. This idea was supported by the following statement by FGAP (A):

*"At school, I have some friends, and some of them are taking treatment and we are like ok, we don't have problems."*

By supporting one another and reminding one another of their medication was a coping mechanism; that is what FGAP (C) had to say:

*“The other children in the home are also taking medication, so we all come together at 7 o’clock to take medication, and we remind each other when it is time for medication.”*

There have also been indications that friends, in the form of humans and pets, formed an important part of the FGAPs’ network, as FGAP (B) explained:

*“My friend has some dogs next door, so I spend a lot of time with him looking after the dogs and I don’t always remember that I am HIV positive.”*

To the majority of the participants’ friends were found to be supportive and non-judgemental. The fact that the FGAPs knew of other people on HAART treatment, they saw being on HAART treatment as normal, as indicated by FGAP (B):

*“... my friends are nice about my HIV status. You know many people take medication, so it is like it is a normal thing around our street.”*

The FGAPs did not easily disclose their status to their intimate partners. Condom usage was used as a coping strategy to protect each other from reinfection and disclosure avoidance. As explained by FGAP (C):

*“I also have a girlfriend, and we must use the condom, and I must use the condom because I don’t talk about the HIV with her, and I don’t know if she has the HIV or not.”*

Emotional coping is found in different sources. Some of the adolescents found a special bond with pets such as a dog. It appears pets performed a soothing role for some of the adolescents. Still for others, having a human person to talk with was a preferable means of support.

#### 5.3.2.2.4 *Role of religion*

Most of the FGAPs reported that religion was a huge source of support, anchoring them through rough times as demonstrated by FGAP (C):

*“But at the Children’s Home, we do Bible reading, and we each read a verse before we go to sleep, and we go to church on Sundays, so the praying helps a lot.”*

Some adolescents found a connection with a higher being to play a hope-instilling role. As long as they practiced their prayers and went to church from time to time, a sense of purpose and hope was instilled which helped make day-to-day life a lot easier to cope with.

### **5.3.3 Themes Identified from Individual Adolescent Participants’ Interviews**

Thematic analysis of the individual adolescent participants’ interviews resulted in the identification of the categories and themes that follow.

#### **5.3.3.1 Access to HAART Treatment**

The category access to HAART treatment relates to purpose upon which the following themes were developed: purpose of HAART; initiation of HAART; availability of HAART; multiple tablets; multiple times of taking HAART; fixed-dose combination; as well as adherence or non-adherence to HAART.

##### **5.3.3.1.1 HAART treatment initiation**

The majority of adolescent participants in the study raised concerns that serious and continuous sickness, initially unidentified, led them to be taken to the hospital.

This is what participant E said:

*... in the beginning I was sick for a long time, so my aunt took me to the hospital and they took my blood, and they told us I must come back next week. And when we came back, they spoke to us that I am sick, and I must take this treatment.*

Some adolescent participants were still very young at the time of HAART treatment initiation. They claim that blood tests were taken, tests done on them, and that these were used to diagnose them positively with HIV and AIDS. Adolescent participant D brought this out:

*“I was constantly sick and weak and had to be in hospital many times until they tested my blood and told me I had HIV.”*

*“I started taking treatment in October 2007. Initially, I was very sickly and at some point I had to be taken to the hospital ...”*

The initial process of HAART treatment commenced while being inpatients at the hospital. After being discharged, continuing HAART treatment was prescribed. Sometimes the adolescent participants did not know or remember when they started the treatment because it was too long ago and they were very young, as demonstrated by adolescent participant E:

*“I was still very young; my grandmother just told me I must drink medication in the morning and in the evening.”*

Some adolescent participants initiated the HAART treatment at a very early age. Other participants started the treatment as inpatients at the hospital; then they continued the treatment as a prescription.

#### 5.3.3.1.2 *First time experience of HAART tablets*

The adolescent participants' first time experience of prolonged HAART treatment included the pressure to terminate sporting activities because of being weak and having to concentrate on the treatment as adolescent participant F explained:

*“HIV frustrates my life plans. I love playing soccer and sometimes when I am weak I must stop playing soccer and take medication.”*

The HAART treatment tablets were also considered to be too many and taken too many times.

Adolescent participant G reported his experience as follows:

*“I take my tablets two times a day. I take three tablets in the morning and one tablet in the evening. My aunt reminds me to take my tablets most of the times.”*

The HAART treatment seemed to annoy these adolescents because sometimes the time for pills arrived when there was no food or thick meal to eat, as adolescent participant E noted:

*“... sometimes, I take my pills before I eat because the food is not ready, sometimes there is no bread to eat.”*

Taking the medication before eating would make the pill uncomfortable in the adolescent's stomach such as feeling like vomiting, and sometimes it led to dizziness, as noted by adolescent participant F:

*“... sometimes, the pills make me vomit.”*

The sentiment was shared by adolescent participant A, who stated:

*“... sometimes I must take my pills, and there is no food. So I take pills, but I feel dizzy, like I vomit.”*

The majority of the adolescents reported that in the initial introduction of HAART treatment, the treatment was viewed with disgust, especially the taste of the tablets. Furthermore, the many tablets that had to be swallowed were experienced as traumatic and discouraging towards adherence.

#### 5.3.3.1.3 Purpose for HAART treatment

Some of these adolescent participants reported that they were told or instructed in a harsh manner to drink the prescribed medication, while others experienced it as polite. The purpose of taking HAART treatment was initially not disclosed to the majority of the adolescents. This is exemplified by adolescent participant A, who indicated:

*“... the doctors told me I must take treatment because I am HIV positive.”*

The foregoing suggests that the negative attitude towards following HAART treatment was influenced by the manner in which they were introduced to the process. The harshness might have instilled fear and a feeling of hopelessness. As a result, they felt discouraged from the onset of the treatment process. The human element, therefore, is at the centre stage when adolescents resume their HAART treatment. Adolescent participant B also reported:

*“I know I must take this treatment because I am HIV positive, and the treatment will help to improve my life so that I am not ill.”*

The medication helped to improve their health, as noted by adolescent participant A:

*“I now feel that the treatment helps a lot; maybe if there was no treatment, I would have passed away like my mother.”*

When the participants took the treatment as prescribed, they stayed healthy or did not fall sick. Adolescent participant D noted:

*“I understand I must take my pills to keep well, otherwise I will die.”*

She also went on to say:

*“... before, I was not happy about the treatment. I was scared I would die like my parents. I used to receive a grant, but now the grant has stopped because my viral load is high.”*

The medication was only not working well when it was not taken regularly. Some of the adolescent participants knew that the reason for taking treatment earlier is that they are HIV positive. Apparently if they all knew beforehand, many would have acknowledged their HIV positive status. They drank the medication mainly because they were told to do so. In the earlier years of taking the medication, they always remembered to drink the medication. As time passed, the prolonged taking of the medication upsets the adolescent participant users. Drinking twice often felt like it was too many times. The information that they were HIV positive reached adolescent participants when they read their hospital file.

Drinking HAART treatment evidently helped these adolescent participants. Because of the medication, the adolescent participants sometimes felt as if they were no longer sick.

#### 5.3.3.1.4 *Challenges of HAART treatment*

Most of the adolescent participants reported that drinking times of the medication proved to be a boundless challenge for most of these adolescent participants. The times of drinking were believed to be fixed, and the adolescents used to miss them due to other commitments and drank them later. Sometimes because of forgetting, or being in a rush to go somewhere, the adolescent would also miss a dose. Missing the medication can be dangerous.

As already expressed, many of these adolescent participants sometimes forgot to drink their medication. Adolescent participant A expressed it this way:

*“I set the alarm on my phone, and I usually remember to take medication; when I am late, I am late by 10 minutes.”*

While there was the challenge that the adolescents hated to take the treatment, these adolescents also hated to be sick. Adolescent participant E describes the challenges he has with HAART treatment as follows:

*I don't like this treatment. It is a burden to take treatment. Sometimes when I have to go somewhere, I must take my treatment with me. Sometimes I go somewhere, and I don't come back on time, and I must worry about the treatment, it is not nice.*

The problem experienced by these adolescent participants with HAART treatment was mostly when many tablets had to be taken many times. However, when one tablet a day was used, the adolescents seemed a little more comfortable. Adolescent participant 4 explained:

*“I used to forget to take my pills, and we went to the hospital, and the doctors gave me pills that I must take only once a day, so it helps now.”*

The adolescent participants have largely realised that the treatment was helpful.

#### 5.3.3.1.5 *Negative approach to HAART treatment*

Some adolescent participants felt inconvenienced or burdened by the treatment, but they had to live with it because it kept them alive. Adolescent participant F commented on his dissatisfaction when frankly stating:

*"I don't like this treatment."*

Adolescent participant E reiterated similar sentiments:

*"... it is a burden to take treatment."*

Taking treatment sometimes made them sad. When these adolescents had to travel, they needed to take the medication along. Adolescent participant E went to mention:

*"Sometimes when I have to go somewhere, I must take my treatment with me."*

Some of the problems experienced included forgetting medication at home when they travelled:

*"Sometimes I go somewhere, and I don't come back on time, and I must worry about the treatment."*

Adolescent participant E concludes:

*"It is a burden to take treatment. Sometimes when I have to go somewhere, I must take my treatment with me."*

FGAP (C) remarked that it is easier to take treatment at home where there is support:

*The other children in the home are also taking medication so we all come together at 7 o'clock to take medication, and we remind each other when it is time for medication. The house Mother also encourages us and support us; she makes sure there is food to eat before we take the medication.*

The treatment reminds the adolescents that they are sick, and that reminder depresses them. As 19-year-old adolescent participant G stated:

*"Sometimes, when I take the medication, it reminds me I am sick, but I just have to take the medication."*

The burden of medication versus maintaining wellness is the ultimate point of consideration. The consequences of not adhering to treatment need to be emphasised so the adolescent participants may understand the value of HAART.

### **5.3.3.2 Disclosure, Stigma and Denial**

The issue of disclosure, be it partial or full disclosure, was identified by most of the adolescent participants.

#### **5.3.3.2.1 Death of parents**

Some adolescent participants' parents in the same condition had passed away when many of the ones who participated in the study were still very young. This expression highlights that fact:

*“My mother passed away when I was small; my mom passed away in 2003, she was sick for a long time.”*

Furthermore, another adolescent participant G stated:

*“My dad also died of HIV illness in 2001.”*

Some of those who lived with their parents were also on HIV treatment. Adolescent participant E described it this way:

*“My mom had to go back to Zimbabwe because she was so sick. My father stays in Limpopo, and he does not take treatment.”*

The causes of the parents' deaths were sometimes unknown, but in some cases, it was believed to have been caused by AIDS. This is evidenced through the conversation with adolescent participant D:

*I believe I got my illness from my mom because I was sick long time before I started having a girlfriend. In 2003, my mother died because she was sick of HIV. My dad also died of HIV illness in 2001.*

The feeling that participants had that other children were able to speak to their biological parents while they could not speak to theirs also caused them some frustration. Adolescent participant D remarked:

*“Sometimes I wish my mother was alive, at least I would know certain things unlike now.”*

Some of the adolescent participants expressed missing their biological parents. They wished that their biological parents were alive, and maybe their lives would have turned out differently.

#### 5.3.3.2.2 *Effect on interpersonal life*

There were those who were scared to play with peers. Adolescent participant D states regarding sharing their information about HIV and AIDS and treatment:

*“I was reluctant to play with other kids before; I was scared of their reactions.”*

The thought of telling friends scared them because they felt they may be laughed at. Some adolescent participants did not trust their friends and did not tell them about their status or treatment, as they did not want them to know. Adolescent participant C captures this experience as follows:

*“my friends, I don’t tell them about my HIV status because I am scared they will laugh at me when I tell them.”*

Also, some of the adolescent participants did not trust their friends mainly because when they talked, they seemed to be judgemental, and especially about people who are HIV positive. For example, a participant disclosed:

*“I have friends and schoolmates, but they do not know about my HIV status. I don’t feel safe disclosing my status to them because they like criticising this disease.”*

The above is the experience of adolescent participant D. However, some adolescent participants experienced good feedback and support from their peers, as adolescent participant B states:

*“My friends are helpful.”*

In addition, adolescent participant F compares:

*“... when I have problems, I rather speak to my friends than my aunt ...”*

Adolescent participant F found her friends to be informative:

*“... my friend told me the ARVs don't kill, they are to help me with my life and not for dying.”*

Having friends in the same status is a comfort irrespective of whether they used the same treatment or not. Sharing stories was seen as very easy. Adolescent participant D relates her experience as follows:

*“I have two friends, ones takes ARVs like me, and the other does not take ARVs but is also HIV positive. And we share our stories, and so it becomes easier to drink treatment.”*

Relating with friends who are experiencing similar health concerns led them to not feeling alone, thus creating some sense of group support. Adolescent participants preferred to chat with fellow adolescents on health concerns, and this was seen as positive by the adolescent participants.

The professionals at the hospital seemed to have been a common factor in comforting these adolescents. This is the case because those who felt disrespected as well as those who felt treated well at their homes found comfort at the hospital.

Most of the adolescent participants talked and shared with friends as a coping mechanism for the HAART. Adolescent participant D finds talking with friends to be a way of dealing with her HIV status:

*“I have two friends, one takes ARVs like me, and the other does not take ARVs but is also HIV positive. And we share our stories, and so it becomes easier to drink treatment.”*

A female adolescent participant B felt her friends are the only coping mechanisms she has. She frankly mentioned:

*“I just talk to my friends.”*

Some adolescent participants mentioned that they use drugs as a way of dealing with their reality. In this regard, adolescent participant C stated:

*“I use drugs and dagga as a means of coping.”*

The use of drugs and talking with friends was seen as a way of coping with the reality of being HIV positive by some of the adolescent participants.

### **5.3.3.3 Psychosocial Support**

Support systems for the adolescent participants were reported as an important element in ensuring consistent adherence to HAART treatment. The support could come from various areas of their lives, be it from within themselves, or from parents, guardians or caregivers or friends and peers, as well as support systems from the government. There were negative and positive responses to parental support in relation to HAART treatment.

#### **5.3.3.3.1 Parental support for adolescent participants on HAART treatment**

Some participants perceived support from their significant others as hostile. Some of these adolescent participants felt that their guardians and caregivers were too harsh when dealing with them, such as shouting at them discourteously in the presence of other children in the house or friends they interact with in the streets. For example, this comment was made by adolescent participant F:

*“One day, my grandmother was very angry with me because of my carelessness ... during my periods ... she just shouted.”*

Such treatment seemed to confuse the adolescent participants. Adolescent participant F continued:

*“She just shouted at me in front of all my cousins, and I was so shocked. I think I must have been about 15 or 16 years old when this happened; I was angry and wondered why she did not tell me this before.”*

Guardians did not necessarily help, as some are unapproachable. The following comment by adolescent participant F illustrated this point:

*“My aunt is not approachable, and when I have problems, I rather speak to my friends than my aunt. She likes shouting a lot.”*

While others, though helping to take medication, made negative comments that could hurt a young adolescent. In contrast to negative and harsh family support, some participants felt their guardians treated them kindly and were very supportive, as supported by adolescent participant C:

*“I have encouragement and support from grandmother, aunt and my big sister and an older brother.”*

The foregoing was supported by adolescent participant A, who stated:

*“... my paternal aunt treats us well, and she tries her best to provide most of our material needs, like going to school and having food. Today, she accompanied me to the clinic visit.”*

Most of the adolescent participants felt discouraged when their caregivers shouted at them. For the most part, a gentle approach was preferred by the adolescent participants, yet they were not as cooperative when the gentle approach was used and were in opposition to harsh treatment.

The guardians of these adolescent participants included family members such as aunts, grandparents (for example, grandmothers), and step parents, among others. For instance, adolescent participant B reported:

*“I stay with my mom’s mom ...”*

Adolescent participant C and adolescent participant F remarked as follows, respectively:

*“I am under the guardianship of my mother’s older sister.”*

*“I stay with my sister now.”*

There are usually other children in the homes in which the adolescent participants lived.

*“I have encouragement from my grandmother, aunt and big sister who has two kids,”* adolescent participant C emphasised.

She continued to say:

*“I stay with my aunt and her four children.”*

The presence of a loving caregiver seemed to offer emotional support to the adolescent participant who is taking HAART treatment.

#### 5.3.3.3.2 *Sexual relations and condom usage while on HAART treatment*

Even an intimate partner may scare an adolescent from sharing their stories. The use of a condom during sex is sometimes not pursued, as demonstrated by adolescent participant G:

*Having a girlfriend sometimes, it is hard to tell the girlfriend. The doctor told me various ways of getting HIV infection: accident, unprotected sex and from your mother. Sometimes, the condom can work and sometimes it is not so easy you see. I know I must be protected, but sometimes, it does not happen. I had a girlfriend before, and I told her about my HIV status, so she know, and we would use condoms most of the times, but the relationship ended, and now I don't have a girlfriend.*

Pregnancy occurred among this group – who did not use a condom – and without the adolescent participant imagining it would occur. It could also points out that as young HIV-infected people, the adolescents engaged in unprotected sex without a condom. There were some adolescent participants who used protection almost always when they wanted to have sexual intercourse.

#### 5.3.3.3.3 *Role of religion in the adolescent participants' lives*

Some adolescent participants seemed to have started to doubt the ability of religion to intervene. The 16-year-old participant seemed conflicted by the role of religion versus HAART treatment, as quoted from adolescent participant F:

*“I struggle a lot with religion and treatment because I believe in the healing power of prayer and God, and my sister does not understand that, so sometimes we fight about that.”*

Sometimes it was the adolescent disbelieving that religion or God could help, since they had been sick for too long. Adolescent participant B disclosed:

*“I am a Christian, and they teach us to believe in God at church. Sometimes, when I take treatment, it is like I don’t believe that God can heal me.”*

Some of the adolescent participants were left questioning the value and role of religion versus their illness. They questioned the role of God, and this usually led to arguments with close members as well as to poor adherence to HAART treatment.

Still, for other adolescent participants, religion was viewed as important and instilling hope. For the positively inclined adolescent participants, hope was seen, and adherence to HAART treatment was much higher.

#### 5.3.3.3.4 School performance

School attendance generally suffered for most of the adolescent participants. They tended to be more absent from school, having to go to hospital for medical check-up and treatment collection. As a result, some of the adolescents would experience feelings of discouragement and hopelessness about the prospects of their own lives.

Adolescent participant A felt hopeless about life. She felt that she was already behind in her grades, and her life was not an easy one. She expressed her feelings as follows:

*I feel so hopeless, and I just want to give up on my own life. I doubt I will even pass Grade 9. I am 18 years old and in Grade 9. I will fail Grade 9 because I don’t really have a very easy life.*

Adolescent participant C echoed adolescent participant A’s bleak view:

*Because of my sickness when I was younger, one time I stayed in hospital for two months and I missed out so much from school, and I had to repeat Grade 3. I also repeated Grade 5, and I am only doing Grade 9 now, and most people my age are finishing Matric. So I sometimes feel that this sickness makes me slow at school.*

Illness and hospital visits and check-ups lead to disruption in the adolescent participants' school attendance, thus leaving them feeling that they constantly have to play catch-up as far as schooling is concerned.

#### **5.4 PROFILES AND NARRATIVES OF PARENTS, GUARDIANS AND CAREGIVER PARTICIPANTS**

This section presents the profiles and narratives of PGCPs on adolescents' HAART treatment. This entails people who were taking care of the adolescents who were on HAART treatment at the Tembisa Hospital at the time of the study. Three PGCPs participated in the study.

##### **5.4.1 Profiles of the Parents, Guardians and Caregiver Participants**

The PGCPs who participated in the study were distributed across 100% of females. Their employment status was about 33% unemployed (but previously employed) and about 67% employed. All those who were working were in a health facility and consisted of nurses. They also consisted of guardians at homes and children's homes and stepmothers.

The PGCPs needed to have been involved in caring and/or interacting with these adolescents being treated for a long period, preferably over a year to match the required period of the adolescents on which they were expected to narrate. They all indicated so, and others were known to be satisfying the profile specified. However, for this study, it was not necessary to report on the exact period they had been in these roles, as it was only enough to confirm that they had been involved for more than a year.

##### **5.4.2 Themes Identified with the Parents, Guardians and Caregiver Participants**

The PGCPs of adolescents taking HAART treatment were included in the research. Adolescents taking HAART treatment often need the emotional support of their PGCPs in order to ensure adherence. As such, the views of the PGCPs thus became vital in order to attain a relatively complete experience of adolescents as viewed by those who are responsible for their well-being. The next subsection presents adolescents' experiences as seen from the viewpoint of the parents, guardians and caregivers.

### **5.4.2.1 Access to HAART Treatment**

#### *5.4.2.1.1 Durations since initiating HAART treatment*

The adolescents started taking HAART treatment when they were as young as six years old. Some started in 2006, while others in 2010. Some started six to eight years ago. Some came to the orphanage after being dropped by a parent.

#### *5.4.2.1.2 Adolescents' knowledge of the HAART treatment*

The narratives of PGCPs highlighted the fact that adolescents seemed to know the reasons for being on HAART treatment, as they had been informed by the hospital professionals and the caregivers who were looking after them. PGCP (B) stated:

*"... she knows because I personally made sure I inform her. I also brought her to the hospital so that the doctors can talk to her."*

It has been a common experience shared by PGCPs that most adolescents were informed that the treatment was for maintaining good health and preventing sickness deterioration.

#### *5.4.2.1.3 Meaning of being on HAART treatment as understood by adolescents*

The PGCPs' narratives indicated that the adolescents were very sick before they started the treatment. They would frequent the hospital many times. However, at the time of the study, many of the adolescents were showing notable improvement in their health.

Some PGCPs indicated their doubts about the adolescents' understanding of being on HAART treatment. The concern is captured by PGCP (B) as follows:

*"... sometimes I think he understands, but then he turns around and not take treatment; then I wonder if he understands."*

The way the adolescents behaved on treatment discipline made the PGCPs doubt if they understood the purpose of the HAART treatment. The PGCPs' impressions were that these adolescents knew and understood reasons for the treatment. At some point, they were wondering if the adolescent really knew as they were defaulting on treatment. PGCP (C) states her frustration with the adolescent as follows:

*“... she does not seem to be responding well because she refuses to take treatment, and when we ask her does she realise the medication is keeping her healthy, she just shrugs and keeps quiet.”*

There was probably some consolation the adolescent participants derived when they used the medication, and that could in all likelihood be a major incentive for many of them to tolerate the treatment. High CD4 counts bothered the PGCPs. The PGCPs, however, seemed to know the meaning of being on HAART treatment.

#### *5.4.2.1.4 PGCPs' challenges about adolescents on HAART treatment*

PGCPs faced challenges about adolescents on HAART treatment, in addition to the challenges of parenting. Long working hours seem to have prevented regular monitoring of the adolescents taking HAART treatment, as noted in the interview with PGCP (A):

*“I used to work long hours at my previous job. I would not be sure he is taking his medication.”*

Another challenge was that the adolescents would pretend to take the pill through the mouth but immediately threw it down the drain trying to flush it. PGCP (B) reported this when she revealed about the adolescent:

*“she throws away the tablets.”*

The aforementioned was supported by PGCP (C) who reported:

*“sometimes I see her throwing the tablets into the kitchen sink.”*

Consequently, defaulting bothered the PGCPs.

Based on parents and caregivers' perspective, the adolescents also stayed out of the house up to late hours, and medication time often passed without them taking it. The following was PGCP (A)'s assertion:

*“I have to go looking for him, and this makes it hard for me because I have my own children that I have to take care of.”*

There was therefore the challenge of having to look for the adolescent to come and take their HAART treatment. It was hard for the PGCP, as their own children also needed care.

Another challenge was these adolescents' refusal to talk when confronted about their defaulting behaviours. PGCP (C) commented:

*"... and when I talk to her, she just keeps quiet."*

These adolescents under study were said to be unapproachable. As a result, it was extremely difficult to talk to them.

Some of these adolescents seemed to have been in denial, arguing that they were not sick. For example, PGCP (C) indicated:

*"when we remind her it is medication time, she becomes angry, and her facial expression changes, and she is not approachable anymore. She tells us she is not sick, and so she does not have to take tablets."*

Another challenge for the PGCPs was to get the adolescents on HAART treatment to appreciate the treatment for their own health. The adolescents needed to be encouraged to take medication, as stated by PGCP (C):

*When we remind her it is medication time, she becomes angry, and her facial expression changes and she is not approachable. Most of the times, when we insist she takes the medication, she puts it in the mouth and then she spits the tablets out.*

*"I used to work long hours at my previous job. I would not be sure he is taking his medication ok, so I resigned so I can be able to monitor his treatment closely,"* stated PGCP (A).

Behavioural difficulties by the adolescents lead to failure to take treatment at the required time. Sometimes when the adolescents are at home, they pretend to be taking treatment, only to spit out the medication later, thus rendering the treatment ineffective. The PGCPs seemed to get frustrated by the behaviours of these adolescents. They pointed out that these adolescents could help themselves by making it easy for the PGCPs to help them. This was an acknowledgement that the adolescents were not doing enough to help

themselves, and this was confirmed by constant forgetting of the adolescents to take medication.

#### 5.4.2.1.5 *Challenges experienced by adolescents on HAART treatment*

According to PGCPs who took part in the study, peers and friends seemed to bother the adolescents. Adolescents followed patterns of their peers, without knowing if the peers had similar ailment problems. PGCP (A)'s concern is noted in the following statement:

*“he follows peer pressure too much, and he just does what other children do, and he does not know if the other children have the same problem as he does.”*

Peer pressure was mainly a problem identified by PGCPs. The adolescents' lives seemed to have changed for the worse. They found it difficult when observing healthy children around them. They ruled themselves to be different from other children and were perturbed by having to take lifelong medical treatment. They also seemed to have lagged behind with schooling, as reflected by PGCP (C)'s words:

*“... she is 14 years, and only now she is in Grade 4.”*

Some PGCPs indicated that school attendance for adolescents under HAART treatment was also very difficult. They had been sick for too long, leading to falling behind in their grades. HAART treatment has implications for school going, and it becomes a double-edged sword to choose whether to go to school and forfeit medical care or attend to medical care and forfeit school lessons.

#### 5.4.2.1.6 *Benefits experienced by adolescents on HAART treatment*

Based on the experiences of PGCP, the adolescents showed signs of satisfactory recovery health wise for those who were taking medication properly. PGCP (B) thus indicated:

*“I know treatment will keep her healthy and well. Sometimes I look at her, and I see how much well she looks.”*

There were also positive signs that the adolescents who were confirmed to be taking the medication properly had developed physique and had also shown to have gained weight. The remark of PGCP (B) captures this accurately:

*“... look how tall and strong; she looks older than 12 years.”*

The positive effects of HAART treatment on physical growth are seen as evidence of the treatment functioning, therefore encouraging further adherence.

#### **5.4.2.2 Disclosure, Stigma and Denial**

Disclosure, stigma and denial are detrimental to the consistent process of HAART treatment. Some adolescents are told partially about their illness; they are told that they are sick, therefore need to take treatment, without fully disclosing the nature of the illness. For some adolescents, they are fully informed of their HIV positive status and the reasons they should take HAART treatment. The responses to such partial or full disclosure are discussed below.

##### *5.4.2.2.1 Reaction to being told of being HIV positive*

As reflected from the narratives of PGCPs, the majority of adolescents seemed to have been upset by being told of their HIV positive status. Regarding the response to being told of their HIV positive status, the adolescents' response fluctuated from indifference to anger. In the case of PGCP (C)'s experience, she noted:

*“... we told her that she is HIV positive, and she needs to be on treatment so that she does not get sick. In the beginning, she was taking the medication, and now she refuses to take medication.”*

Some of these adolescents seemed to have been refusing to take medication sometimes. These refusals seemed to have angered some parents and also frustrated them. Many of the adolescents seemed to have failed to assist the PGCPs as they refused or got angry arbitrarily.

##### *5.4.2.2.2 Mode of information delivery to adolescent regarding adolescent's status*

In some cases, the information regarding the HIV positive status and their taking of HAART treatment was passed on to the adolescents by PGCPs and hospital professionals. In other cases, the PGCP did not know if the adolescents had been told about their status. PGCP (C) gave this report:

*“the Head Mom is the one who broke the news to her, according to what I hear.”*

*My grandmother told me about my HIV positive status. I was always sick, attending hospital in and out frequently. Grandmother was told by the doctors about my HIV status, and they tried to withhold information from me, and I asked them to be honest with me because it is my life after all. I even asked the doctors, though they were reluctant to tell me, but finally I persuaded them to tell me and they told me.*

The manner of disclosing to the adolescents about their HIV positive status could make or break the extent to which adherence to HAART will play out as the adolescent grows up. Those who were given open and honest disclosure were much more likely to adhere to treatment once developmental conflicts came into play.

### **5.4.2.3 Psychosocial Support**

#### **5.4.2.3.1 Changes of adolescents' homes**

PGCPs pointed out that some previous caregivers of the adolescents who participated in the study (could be as many as four), that is, before them, who were on HAART treatment died. They indicated that the adolescents were staying with their parents (mainly mothers) before and grandparents. PGCP (B) explained:

*“Her mother passed away some six years back, and she stayed with her paternal grandparents, and since last year, she is with us, her dad and I.”*

PGCP (A) also describes the constant movement in terms of the adolescent's living environment:

*He used to stay with his mom who passed away, and then he stayed with his dad, who also passed away. He then had to stay with my mom, and she also passed away last year. So I started staying with him after my mom passed away.*

Judging from the experiences of PGCPs, some adolescents who originally stayed with their parents had to stay with their grandparents after their parents died. Such adolescents would have been cared for by multiple caregivers, and the caregiver at the time of the study was the most recent one. There would also be a child belonging to the family, who was not taking the treatment.

#### 5.4.2.3.2 *Peers on HAART treatment*

The concern raised by most PGCP was that most adolescents were at the time of the study the only ones under HAART treatment in their households. Being the only one taking medication made it hard for them to accept their status. PGCP (C) put it in these words:

*“... at one point, we had another child, same age group who was taking medication, and this child would take tablets so well and even reminded the other to take medication ...”*

When the adolescents used medication alone, they did not find it encouraging. The support of other adolescents who are in the same health condition as them gave them the courage to continue taking HAART treatment.

#### 5.4.2.3.3 *Father involvement in adolescent regarding adolescent's status*

Fathers were found not to be helping in these adolescents' welfares. PGCP (B) frankly revealed:

*“You know how men are. He is not involved at all. He does not even know how many tablets she has to take or where the hospital is.”*

The participating PGCPs were all female, and fathers who were around the environment of treatment did not help in any way. Fathers knew nothing about the adolescents' schooling.

#### 5.4.2.3.4 *Coping mechanisms and strategies*

According to PGCPs' narratives, the only noticeable coping and intervention methods for survival of these adolescent participants were the HAART treatment. For the majority of the adolescent participants, medication is the trusted hope to good health for them. As a result, due to refusals by some to take medication properly, those who defaulted were showing signs of health deterioration. There were rumours of deaths in the past of some who had defaulted, but this was not pursued, as participants did not want to share that sensitive point.

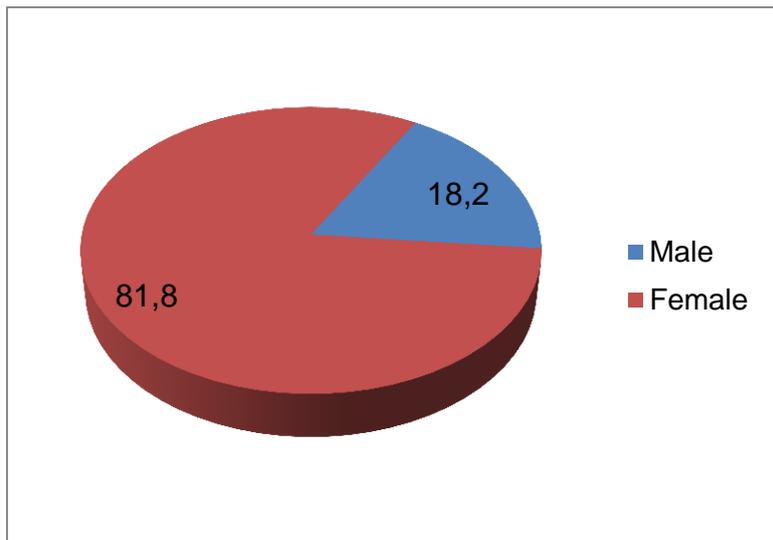
## 5.5 PROFILES AND NARRATIVES OF THE HEALTH CARE PROFESSIONAL PARTICIPANTS

This section describes the profiles of the HCPPs who were giving treatment to the adolescents on HAART treatment at the Tembisa Hospital at the time of the study.

### 5.5.1 Health Care Professional Participants' Demographic Characteristics

**Table 5.9: Genders of Health Care Professional Participants**

	Male	Female
Percentages	18.2	81.8

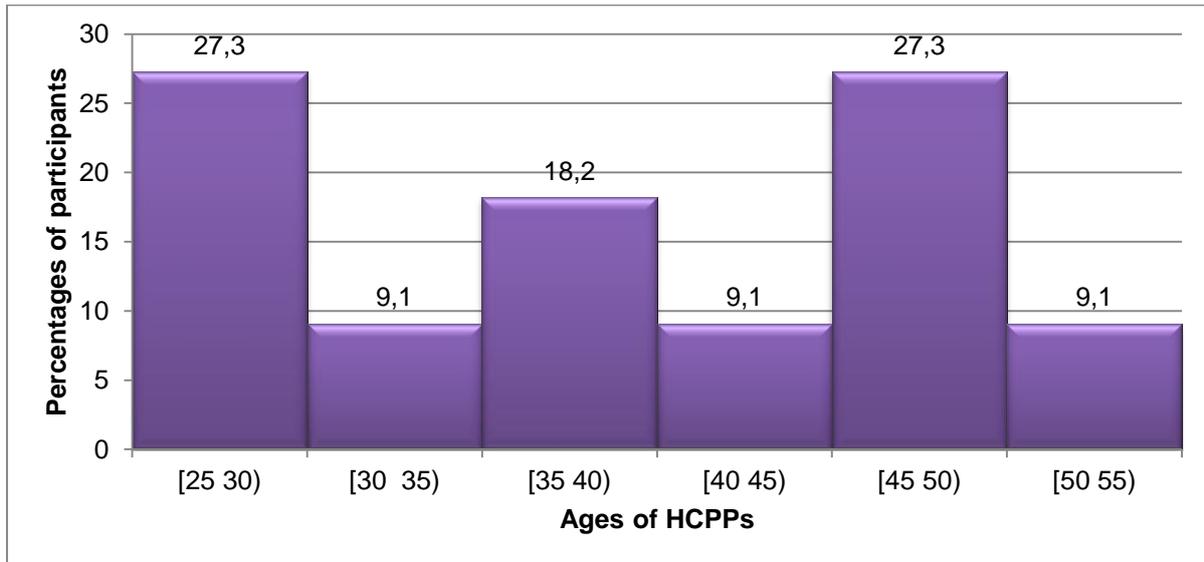


**Figure 5.9: Genders of Health Care Professional Participants in Percentages**

The pie chart used in Figure 5.9 easily displays categories of the participants in few categories. Table 5.9 and Figure 5.9 show the gender distribution of the HCPPs to have been 18% male and 82% females. This highlights that the HCPPs comprised mainly females.

**Table 5.10: Ages of Health Care Professional Participants**

Years	(25-30)	(30-35)	(35-40)	(40-45)	(45-50)	(50-55)
Percentage	27.3	9.1	18.2	9.1	27.3	9.1



**Figure 5.10: Ages of Health Care Professional Participants**

The ages in Figure 5.10 were displayed on a histogram, which is suitable for continuous random variables (Johnson & Wichern, 2002). Table 5.10 and Figure 5.10 depict the ages of the participants. From the table and figure, it is evident that about 27% of HCPPs were between 25 and just below 30 years old. Additionally, about 9% of them were 30 to just below 35 years old, and about 18% of them were 35 to just below 40 years old. It is further indicated that about 9% of the HCPPs were 40 to just below 45 years old, whereas about 27% of them were 45 to just below 50 years old. Finally, about 9% of the HCPPs were 55 to just below 60 years old.

Furthermore, the descriptive statistics on the ages of the HCPPs are calculated from grouped data as follows:

Let  $x_i$  denote the class midpoint of class interval number  $i$ , and  $f_i$  be the corresponding frequency.

### Estimating the mean of grouped age data

According to Newbold, Carlson, and Thorne (2009), an estimate of the mean of the population, denoted by  $m$  from which the data is drawn, can be calculated from the grouped data as:

$$\begin{aligned}m &= \frac{\sum f_i x_i}{\sum f_i} \\&= \frac{27.3(27.5) + 9.1(32.5) + 18.2(37.5) + 9.1(42.5) + 27.3(47.5) + 9.1(52.5)}{100} \\&= \frac{750.75 + 295.75 + 682.5 + 386.75 + 1296.75 + 477.75}{100} \\&= 38.90\end{aligned}$$

### Estimating the standard deviation of grouped age data

An estimate of the standard deviation, according to Ghahramani (2000), is given by:

$$\begin{aligned}s &= \sqrt{\frac{\sum f_i (x_i - m)^2}{\sum f_i}} \\&= \sqrt{\frac{444.76}{100}} \\&= 8.82\end{aligned}$$

### Estimating the coefficient of variation of grouped age data

According to Reed, Lynn, and Meade (2002), the coefficient of variation ( $c_v$ ) is defined as the ratio of the standard deviation  $s$  to the mean  $m$ :

$$c_v = \frac{s}{m}$$

A small coefficient of variation indicates stability. From this data, the coefficient of variation is estimated as:

$$\begin{aligned} c_v &= \frac{s}{m} \\ &= \frac{8.82}{38.90} \\ &= 0.2267 \end{aligned}$$

The ages are not too widespread (according to a small value of the coefficient of variation), even though there are advantages of youth (for future and succession) and notable maturity age.

### Estimating the median from grouped age data

$L$  is the lower class boundary of the class interval containing the median;  $n$  is the total number of data;  $F$  is the cumulative frequency of the class interval before the median class;  $f_m$  is the frequency of the median class; and  $w$  is the class width. According to Harris (2000), an estimate of the median of the population, denoted by  $m_d$  from which the data is drawn, can be calculated from the grouped data as:

$$m_d = L + w \frac{\frac{n}{2} - F}{f_m}$$

The median class is (35-40),  $L = 35$ ,  $n = 100$ ,  $F = 36.4$ ,  $f_m = 18.2$ , and  $w = 5$ . The value of the estimate of the median is:

$$\begin{aligned} m_d &= L + w \left( \frac{\frac{n}{2} - F}{f_m} \right) \\ &= 35 + 5 \left( \frac{50 - 36.4}{18.2} \right) \\ &= 38.74 \end{aligned}$$

### Estimating the mode from grouped age data

$L$  is the lower class boundary of the class interval containing the median;  $f_{m-1}$  is the frequency of the class interval before the modal group;  $f_m$  is the frequency of the median class;  $f_{m+1}$  is the frequency of the class after the modal class; and  $w$  is the class width. According to Albert and Jay (2001), an estimate of the mode of the population, denoted by  $m_o$  from which the data is drawn, can be calculated from the grouped data as:

$$m_o = L + w \frac{f_m - f_{m-1}}{(f_m - f_{m-1}) + (f_m - f_{m+1})}$$

Two modal classes are (25-30) and (45-50). The first modal class values are based on  $L = 25$ ,  $f_m = 27.3$ ,  $f_{m-1} = 0$ ,  $f_{m+1} = 9.1$  and  $w = 5$ . The mode for these is:

$$\begin{aligned} m_o &= 25 + 5 \frac{27.3 - 0}{(27.3 - 0) + (27.3 - 9.1)} \\ &= 28 \end{aligned}$$

For the second modal class,  $L = 45$ ,  $f_m = 27.3$ ,  $f_{m-1} = 9.1$ ,  $f_{m+1} = 9.1$  and  $w = 5$ . The mode for these is:

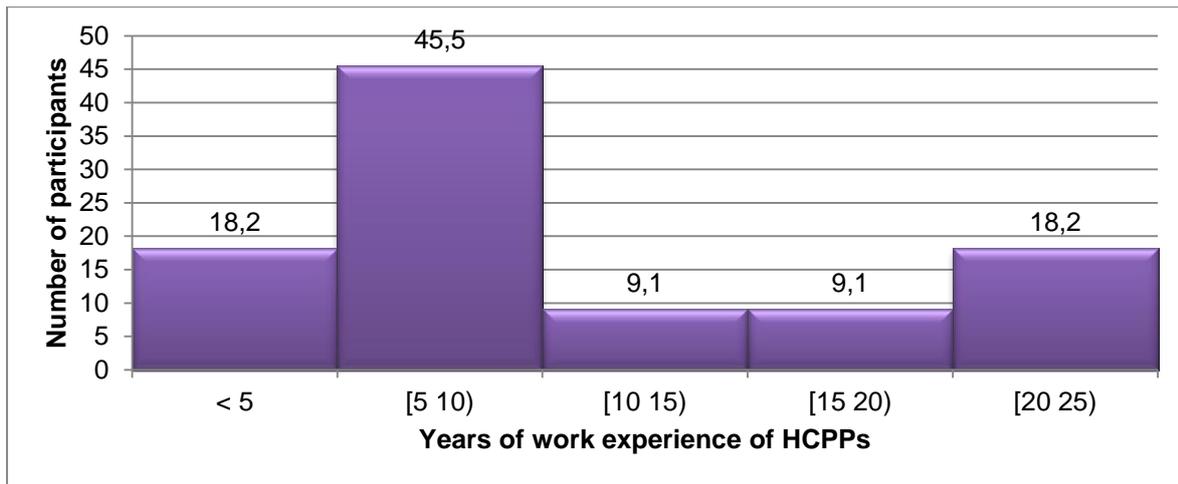
$$\begin{aligned} m_o &= 45 + 5 \frac{27.3 - 9.1}{(27.3 - 9.1) + (27.3 - 9.1)} \\ &= 47.5 \end{aligned}$$

### 5.5.2 Health Care Professional Participants' Work Experiences

The work experiences of the HCPPs are captured in Table 5.11 and Figure 5.11.

**Table 5.11: Health Care Professional Participants' Work Experiences**

Years	< 5	(5-10)	(10-15)	(15-20)	(20-25)
Percentage	18.2	45.5	9.1	9.1	18.2



**Figure 5.11: Health Care Professional Participants' Work Experiences**

The histogram used in Figure 5.11 for the distribution of years of experiences of the health care professionals is applicable in continuous data categories, or class intervals. Table 5.11 and Figure 5.11 indicate the years of experience of the participants. It is noted that 18% of the participants had experience below 5 years, while 46% had 5 to just below 10 years of work experience. In addition, about 9% had from 10 to just below 15 years of experience. Moreover, about 9% had 15 to just below 20 years of experience, whereas about 18% had 20 to just below 25 years of experience.

Furthermore, the descriptive statistics on the work experience of the HCPPs are calculated from grouped data as next indicated.

### Estimating the mean of grouped experience data

$$m = \frac{\sum f_i x_i}{\sum f_i}$$

$$= 10.69$$

### Estimating the standard deviation of grouped experience data

$$\begin{aligned} s &= \sqrt{\frac{\sum f_i(x_i - m)^2}{\sum f_i}} \\ &= \sqrt{\frac{4674.098}{100}} \\ &= 6.84 \end{aligned}$$

### Estimating the coefficient of variation of grouped experience data

$$\begin{aligned} c_v &= \frac{s}{m} \\ &= \frac{6.84}{10.69} \\ &= 0.64 \end{aligned}$$

### Estimating the median from grouped experience data

$$\begin{aligned} m_d &= L + w\left(\frac{\frac{n}{2} - F}{f_m}\right) \\ &= 5 + 5\left(\frac{50 - 18.2}{45.5}\right) \\ &= 8.49 \end{aligned}$$

### Estimating the mode from grouped experience data

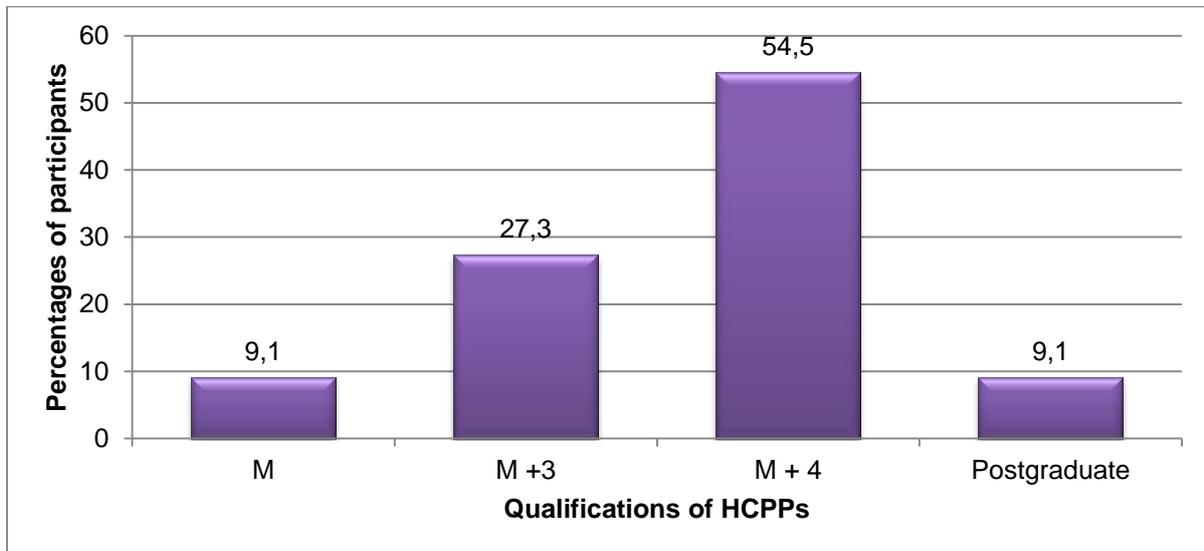
$$\begin{aligned} m_o &= 5 + 5 \frac{45.5 - 18.2}{(45.5 - 18.2) + (45.5 - 9.1)} \\ &= 5.43 \end{aligned}$$

### 5.5.3 Health Care Professional Participants' Qualifications

The qualifications of the HCPPs will be covered in Table 5.12 and Figure 5.12.

**Table 5.12: Qualifications of Health Care Professional Participants**

Qualification	M	M + 3	M + 4	Postgraduate
Percentage	9.1	27.3	54.5	9.1



**Figure 5.12: Qualifications of Health Care Professional Participants**

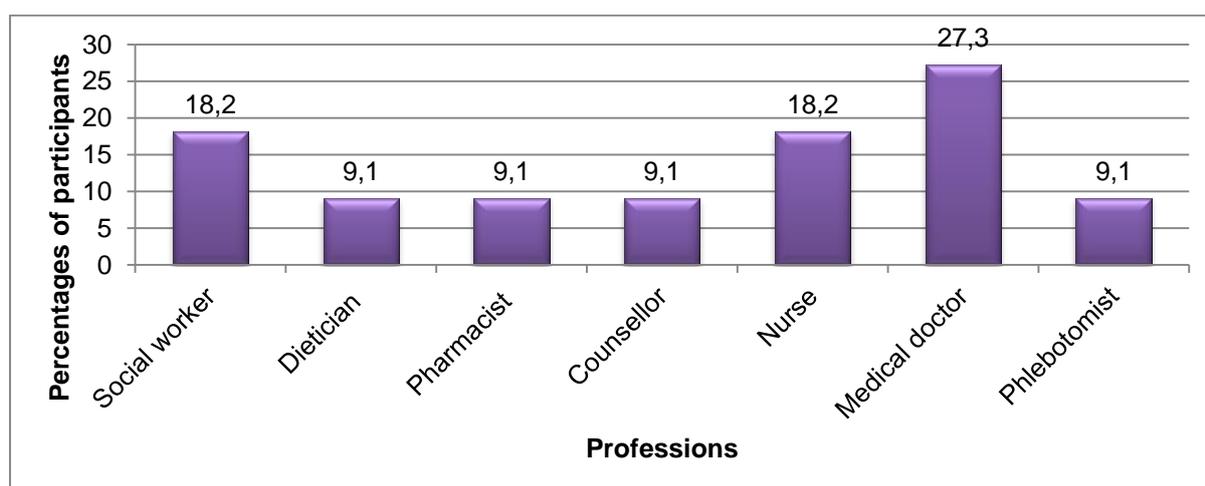
Figure 5.12 used for the distribution of the health care professionals into qualifications is in the form of a bar chart, which is a suitable method for displaying categorical data of nominal random variables (Crowther & Lancaster, 2012). Table 5.12 and Figure 5.12 highlight the distribution of the participants according to their qualifications. The table and figure show that about 9% had matric (M); about 27% had three-year degrees or diplomas (M+3); about 54% had four-year degrees (M+4); while about 9% had postgraduate degrees.

### 5.5.4 Health Care Professional Participants' Specific Professions

To provide a good background of the HCPPs, the specific professions of the HCPPs are shown in Table 5.13 and Figure 5.13.

**Table 5.13: Health Care Professional Participants' Professions**

Profession	Social Worker	Dietician	Pharmacist	Counsellor	Nurse	Medical Doctor	Phlebotomist
Percentage	18.2	9.1	9.1	9.1	18.2	27.3	9.1



**Figure 5.13: Health Care Professional Participants' Professions**

The bar chart used in Figure 5.9 for the distributions of the health care professionals into professions is a suitable method for displaying categorical data of nominal random variables (Creswell, 2009). Table 5.13 and Figure 5.13 illustrate the distribution of the participants according to their professions. The distribution of the HCPPs is as follows: 18% of them are social workers and nurses; 9% of them are dieticians, pharmacists, counsellors and phlebotomists, whereas 27% of the HCPPs are medical doctors.

### 5.5.5 Review on Closed-ended Questions

It was indicated in Table 5.9 and Figure 5.9 that much more female professionals (about 82%) than males participated in the study.

In terms of the ages, there was a balance of experience, with about 27% each for those who were between 25 and 30 years of age and those between 45 and 50 years of age. Furthermore, Table 5.10 and Figure 5.10 showed the balance of experience at about 18% for those between 35 and 40 and fewer of about 9% in the ages of 30 to 35 years, 40 to 45 years and 50 to 55 years each. The modal ages (the ones appearing most compared to others) were therefore 25 to 30 years and 45 to 50 years.

Regarding their experience, most (over 45%) of the participants have between 5 and 10 years' service, about 18% each have experiences of less than 5 years and between 20 and 25 years' experiences. Furthermore, about 9% each have experiences of between 10 and 15 years and between 15 and 20 years' experiences (Table 5.11; Figure 5.11).

Qualifications were also distributed widely. Only about 9% had matric, over 27% had a three-year qualification (national diploma or bachelor's degree) beyond matric. About 55% had four-year degrees, and over 9% had postgraduate qualifications (Table 5.12; Figure 5.12).

The professions were widely distributed across social workers, dieticians, pharmacists, counsellors, medical doctors and phlebotomists (Table 5.13; Figure 5.13). The modal ones were the medical doctors who made up over 27%. Social workers and nurses were the next in highest frequencies at just over 18% frequencies each, while the rest were all equal at about 9% occurrences each.

#### **5.5.6 Themes Identified from HCPPs' Responses**

Themes identified from the HCPPs are provided in this subsection.

##### ***5.5.6.1 Experience on Dealing with Adolescents on HAART Treatment***

According to the HCPPs, the adolescents who have to take HAART treatment for as long as they are alive face a lifelong challenge which tests their sense of commitment to the treatment. HCPP1 stated:

*"For me, I find that adolescents are having a big challenge dealing with issues of adolescence and dealing with the fact of being HIV positive and taking ARTs forever."*

His sentiments were shared by HCPP3 who maintained:

*Usually, what I have seen during counselling is that these kids they do not know why they have to take this treatment of ARVs. It is not easy dealing with adolescents; sometimes I feel it is difficult to have to tell them they are HIV positive.*

HCPP5 also supports the assertion of experiencing difficulties when talking with adolescents on HAART treatment and reports:

*My experience on dealing with adolescents who come here for ARV is mostly not so pleasant. It is hard to have a sensible conversation with these kids. They are mostly unresponsive, and they are forced to come to hospital without even understanding why.*

The conversation about HAART treatment seems to be compounded by developmental changes. Adolescence is an emotionally taxing period, let alone having to deal with issues of chronic treatment.

#### **5.5.6.2 Stigma and Disclosure of HIV positive Status**

According to the majority of HCPPs, the disclosure of HIV positive status to an adolescent is seen as a challenge and everyone hopes everyone would have disclosed to the adolescent. The assumption that having a conversation on disclosure with someone who has been on HAART treatment for over three years that they know they are HIV positive must be replaced by having the conversation and asking the adolescent why they are taking treatment. As highlighted by HCPP3:

*“Most adolescents have an attitude towards taking their medication correctly or even taking the medication; this leads to under or overdosing. The above is led by peer pressure and stigma from family members and friends or even the community.”*

Some difficulties regarding disclosure have been expressed by HCPP8 as follows:

*As a person who draws their blood for testing, I observe parents not informing their children why they are being tested. They tell the adolescent it is for flu, etc. As a professional, I am not allowed to tell the child why I am taking their blood, all I say is that the blood is taken for testing. Partial or no disclosure is the challenge I have observed. These children then become angry when they find out later; it is better to tell them the truth.*

Over and above that, HCPP8 maintains:

*Some parents did not inform their children on why they were tested, and why they had to drink the medication. Some parents told these adolescents that the medication was for flu. Some then became angry and end up being angry even for the medication when they found out at a later stage.*

HCPP3 supports the above assertions as follows:

*“Some of the adolescents seem to be unaware of reasons for taking the medication, apparently because the parents did not explain to them. Others who take medication cannot tell their boyfriends or girlfriends. Others blame their parents.”*

HCPP5 provided this synopsis:

*“One challenge was failure to disclose to girlfriends and boyfriends. Poor adherence was also identified when there was no supervision. Absenteeism from school was also a factor.”*

HCPP7 stated:

*To be on long-term treatment was a challenge to sustain the interest in the medication, and compliance on everyday basis was difficult. These adolescents were also challenged by how to have safe sex without unnatural means. Disclosure was their other worry, and denial was common. Hence, the result would be defaulting on the medication.*

Stigma was a challenge. The adolescents felt they were stigmatised, had peer pressure, late disclosure of status from family or parents, and social problems, as some people had passed away who could have given them support. The issue of disclosure of the reasons why the adolescents come to hospital and the reason they have to take treatment is noted as a potential stumbling block to effective adherence to HAART. Most found it difficult to accept their HIV status, questioned how they were infected with HIV, stigma and discrimination, and difficulty accepting that they were HIV positive.

#### **5.5.6.3 Challenges Experienced by Adolescents on HAART Treatment**

Disputes regarding adherence to HAART treatment arise whereby the adolescents insist they are taking HAART versus the results of blood testing which reveals declining CD4 counts as well as increasing viral load. This brings to question whether the adolescents fully comprehend the meaning of HAART treatment versus their well-being.

HCPP11 made this expression:

*“A mixture of frustration when lack of disclosure led to poor adherence and relief when adherence was confirmed through blood tests. It becomes satisfying seeing a child who was severely sick improve over time.”*

This is supported by HCPP11 who contended:

*It can also be frustrating when your hands are tied by the adolescent and their family themselves when adherence is not as it should be and you know that medically, this child’s life could be much better but cooperation is not forthcoming and there is different stories all the time.*

HCPP4’s observation was:

*Non-compliance is probably due to many psychosocial reasons: such as denial, anger, irresponsibility, lack of insight about complications and prognostics of HIV. Sexual life with no sense of responsibility. Subsequently, virological and treatment failure. Many do not reach age of 25 years.*

HCPP6 revealed:

*Because of the identity crisis, adolescents tend to default on treatment more often. In most cases they have anger issues regarding how they got exposed to HIV because the majority of them got exposed from birth. They often blame their parents for infecting them. Recently there have been challenges of high pregnancy rate among adolescents.*

HCPP9 shared the sentiment this way:

*“The issue of anger and resentment towards the parent who has infected the adolescent. The unresolved anger leads to refusal to take treatment which further puts the health of the adolescent in danger.”*

HCPP5 makes this disclosure:

*Lifestyle barriers, such as being away from home, busy, forgetting and varied schedules, school attendance, watching TV, behavioural and cognitive challenges impact on adherence. When they feel well, they neglect the ART. Poor nutrition increase disease progression and hinder treatment effectiveness.*

HCPP4 identified the following point:

*Non-compliance was one reality about them, probably due to many psychological reasons, such as denial, anger, irresponsibility, lack of insight about complications and prognostics of HIV. Also, one challenge was imagining sexual life with no sense of responsibility. Virology treatment failure and many who did not reach age of 25 years.*

Other challenges such as peer pressure, lack of disclosure from parents, tolerance of side effects, and some chats through social media were sometimes discomforting. To remember to take the medication was also a challenge. The challenge of trying to keep someone healthy without their participation emerges once more as the obstacle to adherence. Adolescence is generally a rough period in one's life. Having to deal with HAART on a chronic basis can be emotionally demanding for the adolescent.

#### **5.5.6.4 Benefits Experienced by Adolescents on HAART Treatment**

There has been a strong assertion by most HCPPs that HAART treatment improves the adolescent's health, and reduces the risk of severe infections and lowers the chances of transmitting HIV to others. HAART treatment programme improves their lives medically, nutritionally, psychologically, and socially.

*"A better lifestyle and improved healthy lifestyle-immune system. Good and quality knowledge in understanding HIV and ART. Reduction in infection – high CD4-count and low viral load."*

HCPP2 and HCPP3 support this respectively as follows:

*"They believe ART is working for them. They think while there's no medication how can they be. Also knowing the ARV prolonged their lifespan. Also, benefit immune system increase instead of decrease."*

*Long-term adherence to treatment lead to CD4 count improving exceedingly and thus viral load being suppressed, hence lifespan increasing accordingly because of less chances of contracting detrimental opportunistic infections, that is, cryptococcal meningitis, pneumonia. The benefits of proper adherence to HAART are highlighted*

*by productivity at school and workplace, and less tendency of absenteeism as individual will be living a healthy lifestyle.*

HCPP9 remarked:

*“Lifespans were increased; health status improved, school attendance improved and they received support from other children and Health Care Professionals.”*

According to the HCPPs, some adolescents on HAART treatment knew that without HAART treatment they would have been long dead. Others also were grateful because they could not imagine how bad they would have been if it was not because of HAART treatment. Some complain, but they realise that their health was showing improvement and good virological response, and good treatment response. The benefit was a healthy lifestyle. Their lifestyles improved and were safer, their health improved, and their immune systems improved. They gained quality knowledge on managing their status and could help to reduce infections. Their viral loads had decreased and immune system improved.

#### **5.5.6.5 Psychosocial Support and Coping Mechanisms**

The big benefit was achieved most of the time through proper support structures with family members, social workers, psychologists, and help groups. HAART treatment assisted in improving life quality and well-being, especially after a serious illness. There was an understanding and knowledge about HIV. Coping mechanisms and strategies relate to actions that an adolescent takes in order to make living with HIV positive diagnosis a little easier. These range from individual actions to group and team action through which participation can lead to a relatively positive life.

In light of the foregoing, HCPP1 stated:

*“They participate in support group activities, set reminder alarms for taking ART, and they improve their treatment knowledge and understanding of the benefits of taking ART.”*

HCPP2 made this observation:

*“Support groups, support camps and counselling are the mechanisms used to cope for most adolescents on HAART.”*

HCPP5 went further to state:

*Mechanisms included support structure provided by family and support groups with fellow adolescents. There was also a lower pill burden because of these mechanisms and strategies. Another effective mechanism to them is knowing that there was privacy about their status.*

HCPP6 pronounced:

*Support groups help to talk about the challenges they were having. They also learned from each other regarding how to cope with side effects of treatment. Adolescents often go on camp trips, just to reassure them that they were like other children of their ages, and to make them feel loved and to educate them more about HAART”*

Along similar lines, HCPP10 commented:

*Mechanisms and strategies for coping included support groups that encouraged them to cope. Disclosing to friends and family, as well as outing for holidays by the support groups were helping. They participated in youth activities such as sport and recreational activities such as playing drama and accepting the status.*

The role of psychosocial support was identified as crucial where HAART treatment adherence is concerned. The more positive the psychosocial support, the higher the likelihood of consistent adherence.

## **5.6 INTEGRATION AND DISCUSSION OF STUDY FINDINGS**

The aim of the study was to explore the nature of experiences of adolescents who are on long-term HAART treatment in Tembisa, Gauteng province.

The objectives of the study are restated as follows:

- to gain an understanding of the adolescents’ perspective of being on HAART treatment;

- to gain broader insight of experiences leading to adherence and non-adherence to HAART treatment;
- to investigate factors contributing to adherence and non-adherence to HAART treatment; and
- to explore the meaning attached to HAART treatment.

This section integrates the findings of the study with recent literature survey on the experiences of adolescence and HIV and AIDS, as well as HAART treatment. The discussion of these themes is used to address the aim and objectives of the research study. The main themes extracted from the findings were classified as access to HAART treatment; disclosure, stigma and denial; and psychosocial support.

The subsection that follows presents an integrated discussion on the experiences of HAART treatment from the viewpoint of adolescent participants, both from the focus group and individual interviews.

#### **5.6.1 Disclosure of HIV Positive Status and Stigma**

The majority of the adolescents who took part in this study expressed their experiences of HAART treatment and HIV positive status openly and freely. A few adolescent participants responded hesitantly and eventually choosing not to participate any further in the interview. This is in line with the 2013 study by the World Health Organization, where it was found that adolescents would prefer to be involved in conversations about their own health, especially relating to HIV and AIDS. Adolescents are the most knowledgeable about their lives. Most adolescents find participating in conversations about their own health to be an empowering experience and therefore prefer talking about their own health (WHO, 2013).

Learning about their HIV positive status, severe health problems and hospitalisations were experienced as traumatic. The majority of the adolescents came to know about their HIV positive status just as they were entering the stage of adolescence. Nabukeera-Barungi et al. (2007) discovered the benefits of full disclosure of the adolescent's HIV positive status in that it allows for ownership of the adherence to HAART treatment. In some cases, access to treatment leads to reduced sense of stigma, thus enhancing the likelihood for adherence (Barrero & Castro, 2005; Ross et al., 2010).

A different study conducted in sub-Saharan Africa reports that HIV-status disclosure enabled adolescents to engage effectively with their HAART treatment and support groups, which, in turn, provided them with a sense of confidence and control over their lives. Although the adolescents in the two studies were still experiencing stigma from peers and community members, most did not internalise these experiences in a negative way but retained hope for the future and felt pity for those untested and uninformed of their own HIV status. The conclusion was that disclosure and good HIV related services provide an important platform for HIV-infected adolescents to resist and cope with HIV stigma (Midtbo et al., 2012).

Furthermore, all the adolescent participants expressed a high sense of difficulty when it came to accepting the news that they were in fact diagnosed as HIV positive. A study conducted in Zimbabwe found that adolescents struggle with being told about their HIV positive status. Shock and denial are generally the initial response to learning about their HIV positive status. Some of the adolescents reported feeling suicidal upon learning of their HIV positive status. However, this initial state of shock and denial progressed into acceptance with the result that the adolescent decided to help other adolescents come to terms with their own HIV positive status through participation in support groups (Kidia et al., 2014). The adolescents hated not to be told about their HIV positive status. However, when told, they got angry with the PGCPs who told them or denied that they were HIV positive.

Although the adolescents preferred being open and fully informed about their HIV positive status, the news came as a shock and a burden to them. Anger was the resultant persistent feeling which unfortunately was generally associated with less chance for adherence with HAART treatment. A Zambian study discovered that disclosure had various outcomes at the individual and interpersonal levels. At the individual level, some adolescents described being anxious, depressed and blaming themselves after being told they had HIV. At the interpersonal level, disclosure created opportunities for adolescents to access adherence support and other forms of psychosocial support from family members and peers. At the same time, it occasionally strained adolescents' sexual relationships, although it did not always lead to rejection (Mburu et al., 2014).

The issue of disclosure of their HIV positive status was seen as even more personal when it came to disclosing to intimate partners. Most of the adolescents preferred not to disclose their HIV positive status to intimate partners, as they feared rejection and being stigmatised. A study conducted in Port Elizabeth revealed that adolescents avoided the use of condoms in sexual intercourse because of fear of being suspected of being HIV positive (Jena, 2014). Adolescents feared being stigmatised. Some of the adolescent participants on HAART

treatment were sexually active and seemingly did not disclose to their partners what their health condition was with reference to HIV, and as a result, they agreed to engage in unprotected sex. The use of protection is part of the counselling that adolescent participants on HAART treatment need to receive on a continuous basis. Regarding adolescents' disclosure to others, a study in Zambia found that adolescents living with HIV and AIDS expressed a desire to control whether and to whom to disclose their HIV status. Disclosure is something that one should choose to do. It is one's choice whether to tell about it or not (Midtbo et al., 2012; Mburu et al., 2014).

The biggest fear for the adolescents was informing peers about their HIV positive status. Fear of stigma and rejection led to the decision not to easily disclose their HIV positive status to people outside of the immediate family. This is in line with a study in Uganda that found that most adolescents do not disclose outside of the family, and even within the family disclosure is limited to one or two trusted members. Among adolescents who know their status, fears surrounding disclosure were high, and few adolescents disclosed to more than one or two people. Friends seem not to be trusted for disclosure, due to fears of gossip (Musisi, Kinyanda, Nakasujja, & Nakigudde, 2007).

The predominant experience of HAART treatment and HIV was one that entailed the issue of disclosure of their HIV positive status and the associated stigma. The most commonly cited reason for non-disclosure among adolescents is stigma. In particular, adolescents report fearing the pointing of fingers by other people and involuntary disclosure, especially in the school environment (Musisi & Kinyanda, 2009). Stigma in the school environment is serious, and it is perpetuated by fellow students and teachers alike. In some cases, access to treatment leads to reduced sense of stigma, thus enhancing the likelihood of adherence (Barrero & Castro, 2005; Ross et al., 2010).

According to Fielden, Chapman, and Cadell (2011), young people living with HIV and AIDS experience isolation, fear and shame as a result of their HIV positive diagnosis. Once they learn about their status, young people living with HIV and AIDS need to make difficult decisions about whether or not to stay silent or disclose to friends, sexual partners, family members and other significant people in their lives. Moreover, a study conducted in Zambia identified fear of HIV stigma and an underlying presumption that adolescents would not understand the consequences of an HIV diagnosis on their lives and relationships. Respecting adolescents' disclosure of their HIV status to their sexual partners, the same study identified fear of rejection as a common barrier. In rare cases, open family

conversations about HIV helped adolescents come to terms with an HIV diagnosis (Mburu et al., 2014).

### **5.6.2 Early Childhood Experience of Parental Death**

Some of the parents of the adolescent participants have passed away. Some adolescents had either one or both of their parents dying of an HIV and AIDS-related illness. Some adolescents get to see their parents sick. When a parent or caregiver approaches the end stages of AIDS, a plan of care must be created for the surviving children. This process is referred to as permanency planning. When this step is not taken, children are left in a state of uncertainty about who will care for them, which can compound the loss felt by the child after a parent's death. The child may be separated from siblings and may experience frequent shifts from place to place in search of a proper home. Children whose parents do not complete permanency planning are at increased risk of developing emotional and behavioural problems. Several things should be considered when creating a permanency plan. It is best to start with the needs expressed by the dying caregiver (Close, 2006).

The suspicion and/or knowledge about the cause of parental death may lead to a hanging burden and awareness on children about their own mortality. Maternal death is considered to have a far more significant negative impact on the well-being of the adolescent (Olsson, 2013). Mothers are far more able to mediate the challenges that their offspring face, thus giving their children and adolescent a fighting chance in life. Trauma from the death of parents and loss of parental guidance and support may lead to the child being unable to perform at school and, in turn, affecting the decision to attend school (Sharma, 2006).

Parental loss due to HIV and AIDS during childhood causes children to experience significant emotional pain. The grieving process starts when the parent or family member who is infected with HIV becomes sick. Adolescents are generally traumatised with the death of a parent. Bereavement of a parent who died in a cloud of secrecy about their illness or after having disclosed to their adolescent becomes complicated and laden with anger and resentment. The death of their parents becomes a shame because of the stigma attached to dying of AIDS and people's lack of knowledge regarding the spread of AIDS, which increases stigma and results in the isolation of orphaned children (UNICEF, 2006).

The loss of a parent in early childhood, at school age and in early or late adolescence affects children differently, both psychologically and developmentally. As a result of the death of a parent or parents, adolescents find themselves having to leave with other relatives or family

members. More often, the adolescents are forced to leave the homes they shared with their parents to join other relatives or family members. Because of the complexities of some families, conflict often arises when an adolescent on HAART treatment, who is not an original member of the family, has to take space of the members of the family. In some cases, the adolescent would come with their own styles and patterns of behaviour which are not tolerated by everyone in the household, thus creating conflict.

The extended family remains as the predominant caring unit for orphans in communities with severe HIV and AIDS epidemics. Extended families involve a large network of connections among people extending through varying degrees of relationship including multiple generations, over a wide geographic area and involving reciprocal obligations (Foster & Williamson, 2000). The adolescents receive support from these relatives pertaining to living with HIV and AIDS at home, mostly in the form of physical support and assistance with adherence to HAART treatment (Pienaar & Visser, 2012).

In light of the foregoing discussion, adolescents find themselves having to deal with some bitter consequences after losing a parent. Adolescents are forced to grow up and get on with the business of living, often forgoing the luxury of bereavement, which generally tends to lead to unresolved emotional issues later on.

### **5.6.3 Challenges of Taking HAART Treatment**

The challenges of taking HAART treatment experienced by adolescent participants are complex. Longstanding HIV infection acquired when the immune system was not developed results in distinctive chronic clinical complications that cause severe morbidity. As well as dealing with chronic illness, HIV-infected adolescents have to confront psychosocial issues, maintain adherence to drugs and learn to negotiate sexual relations while undergoing rapid physical and psychological developments (Lowenthal et al., 2014).

The fact that HAART treatment consisted of many doses a day led to the adolescents missing the taking of the medication. There were complaints that the medication needed to be taken many times and for lengthy periods of time. The adolescent participants were in favour of one dose a day at night. They preferred HAART treatment to be presented as a fixed-dose combination. This would ease the burden of having to take several medications that were not enchanting. A complicated dosing regimen that requires 100% adherence was in itself an introduction to adherence failure. Additionally, side effects compromised adherence and trust in the health care process (Taddeo et al., 2008). Many of them would

have preferred a single tablet containing all the medicine than having to swallow many types of medicine. Prolonged HAART treatment was frustrating for the adolescents.

The majority of adolescents were delayed in schooling as a result of the frequent amount of absenteeism from school to follow up on health checks at hospitals. There were also some indications that these adolescent participants were not passing their grades easily, as they were missing classes reasonably often. Their schooling was disrupted. The impact of the HIV and AIDS pandemic has become an issue of not only health but also of cross-sectional importance affecting other major cornerstones in society such as education (Rosenthal, Waters, & Glaun, 1995; Olsson, 2013).

School absenteeism was common among the adolescents on HAART treatment, since many of them stayed in hospital for long periods. Some adolescent participants were older in their grades than most learners because they had been delayed. However, there were others who did not stay away for too long. These ones were coping well with schooling and were in their normal grades, but they were in the minority.

Adolescents on HAART treatment were at a relatively higher risk of experiencing mental health conditions. Some adolescent participants reported that they had lost hope. Other adolescents were sometimes experiencing feelings of suicide as a result of realising that their lives were going to depend on medication. Living with a long-term chronic condition also leads a patient to experience burnout. With burnout, a patient may feel depressed and isolated. He or she becomes frustrated with the medication regimen and the constant requirement to maintain greater than 95% adherence (Close, 2006). Life was experienced as not easy and not fair. The emotional effects of coping with HIV infection can be severe, and the frequency of psychiatric admissions compounds their already burdened developmental challenges (Rudy, Murphy, Harris, Muenz, & Ellen, 2009; Lowenthal et al., 2014).

Adolescence is an emotionally challenging and confusing period with conflicts between adolescents and their parents or caregivers. Moving towards independence from their parents, adolescents typically want to make their own choices and have a sense of control over their lives. Having a disease may make them feel powerless, and they may try to gain control by not taking their medications, missing appointments or not following dietary restrictions. Sometimes, the parents may have developed an overprotective parenting style, which can delay the teen's ability to take responsibility for his or her treatment or cause frustration for the adolescent. Thus, low adherence can be a way of confronting the authority of parents and professionals (Taddeo et al., 2008).

The adolescent participants reported feeling frustrated by parents, caregivers and guardians. The guardians sometimes shouted at the adolescents for not taking HAART treatment or for being late at taking it. This sometimes made the adolescent feel disliked or undermined, especially when it happened in the presence of other children in the household. Emotional support seemed to be limited though, as they could not discuss their experiences with family members (Pienaar & Visser, 2012). Some of the guardians, according to the adolescent participants, needed to soften up, as they were experienced as being unapproachable wardens. Some adolescents were despondent with the treatment they were receiving from their caregivers to a point that they were contemplating finding other ways of coping outside the home. An adolescent living with HIV and AIDS experienced greater life stressors and family conflict (Wu et al., 2008).

Some adolescent participants experienced a sense of not being trusted by health care providers when it came to their adherence to HAART treatment. The health care workers would remark that judging by the adolescent participants' declining CD4 count and high viral load, it appears that the adolescent participants were not adhering to the HAART treatment. The adolescent participants would insist that they are indeed adhering to HAART treatment. The adolescents identified mistrust, lack of communication and impersonal interactions with health care providers as barriers to disease management (Sanne et al., 2009; Pienaar & Visser, 2012).

All the aforementioned challenges require psychosocial support and patience which most parents or caregivers are not privy to. Adolescents are required to participate in their own self-care in order to enhance the quality of their own lives. The findings created an awareness of the challenges and dilemmas that adolescent participants have to contend with, such as disclosure, adherence to treatment, disease management and lack of support.

#### **5.6.4 Factors Influencing Adherence to HAART Treatment**

Adherence to HAART treatment entails taking all ARV pills in the correctly prescribed doses, at the right time and in the right way, observing any dietary restriction. To achieve effective treatment and realise the benefits of treatment, strict adherence to treatment instructions are very critical (Nyambura, 2009).

Understanding the purpose of taking HAART treatment facilitated adherence in the sense that once they knew what the medication was for, they were less hesitant to adhere. Adolescents regarded their antiretroviral treatment positively, recognising that the pills were

an important and beneficial part of their daily lives (Li, 2009). Adolescents exhibited a better understanding about the importance of their tablets and were aware of the role that they played in attaining and maintaining physical well-being. These participants recognised that antiretroviral treatment helped them to stay strong and healthy. A number of adolescents also demonstrated comprehension about the importance of adherence (Li, 2009).

Fixed-dose combination meant that the adolescent had one tablet to take instead of multiple tablets, which facilitated adherence. The goal of combination ARV therapy is first to suppress HIV viral load in plasma to below the limit of detection and secondly to restore immune function, as demonstrated by an increased number of CD4<sup>+</sup> T-cells (Chen, Hoy & Lewin, 2007). Most of the adolescents in the study reported that it was easier to adhere to HAART treatment when the multiple three times a day tablets were replaced by one tablet once a day. A conjoint study of fixed-dose combination undertaken in Malawi and Zambia presented findings that fixed-dose combination increases the chance of adherence to HAART treatment (Kayitare et al., 2009; German, Warren, West, Hui, & Keaney, 2010).

Parental support played a crucial role in adherence to HAART treatment by adolescents. Li's study described that adolescents recognised the central role that their families played in helping them cope with both their illness and life in general. Many of the participants had lost one or both of their biological parents to AIDS, with only 23% of the adolescents living with both their mother and father, and 42% being cared for by a relative or an institution (Li, 2009). Adolescents who felt supported, cared for and loved were more likely to adhere to HAART treatment, as they felt their lives meant something to someone other than themselves.

### **5.6.5 Factors Influencing Non-adherence to HAART Treatment**

Some adolescent participants felt inconvenienced or burdened by the treatment but had to live with it because it kept them alive. There was interference with normal day-to-day activities. The experience of prolonged HAART treatment included the pressure to terminate sporting activities because of being weak and having to concentrate on the treatment. A study done in Pretoria, South Africa discovered that adolescents had conflicting ideas about antiretroviral therapy and the restrictions it placed on their lives. All of the adolescents battled with the conflict between being normal and being different. All of them tried to live a normal life by having friends and participating in sport, and most described future identities (Pienaar & Visser, 2012).

Poor support from parents, guardians and caregivers led to a sense of isolation. Pienaar and Visser (2012) went on to identify that most of the adolescents assumed primary responsibility for taking their medication. Emotional support seemed to be limited though, as they could not discuss their experiences with family members.

Another factor that led to non-adherence to HAART treatment related to the direct effect of the medication on the adolescent. The study at Brown University points to similar factors. It identified three common themes that arose for non-adherence on a daily basis: regimen complexity (for example, too many pills or taking pills in relationship to meals), toxic side effects, and simply forgetting to take the pills. For many of the adolescents interviewed, these factors were linked. The more complex regimens were often more difficult to remember and had more toxic side effects, thus compounding the tendency towards non-adherence (Pugatch, Bennett, & Patterson, 2009).

#### **5.6.6 The Impact of Religion on HAART Treatment Adherence**

For the majority of the adolescent participants, religion played some role in adherence to treatment or lack thereof. Those with strong religious beliefs were helped to cope with living with HIV and AIDS and adhering to HAART treatment (Naidoo, 2011). However, there was one adolescent participant who believed that his belief in God should be good enough to cure him, and so he struggled with adherence to HAART treatment. He believed that taking medication was an indication of lack of faith and trust in God.

Van Wyngaard (2013) discovered that people with a high believe in God tend to have resilience in times of hardship. He described someone's experience as having feeling accepted by God after his pastor spoke to him about repentance. The feeling that God loves them despite their HIV positive status gave them a sense of acceptance and peace with their HIV positive status, which led to a higher likelihood of adherence to treatment. Some adolescents with HIV were more likely to endorse feeling God's presence; they were more likely to feel that they were part of a larger force, and they were also more likely to feel at times that God had abandoned them. Religion was thus viewed as leading to an increase in spiritual distress (Bernstein et al., 2012). In a different study, spirituality was not associated with the decision to use intensive life-prolonging care. The belief that HIV is a punishment from God was associated with significantly less medication adherence and less spiritual quality of life (Lyon et al., 2011).

Religion can have a mitigating influence in day-to-day decision-making. Some adolescents view religion as helping them stay safe insofar as it preached no sex before marriage, thus protecting them from risky behaviour and further spread of HIV. Furthermore, the burden of HIV and AIDS is viewed as being shifted to a higher being who takes the load over, thus freeing them of guilt, blame and anger feelings (Lyon et al., 2011).

Religion can take the place of psychiatric treatment, thereby helping them cope with issues of depression and improving their mental health. Any method of coping that helps improve the quality of life of adolescents on HAART treatment can be appreciated, as it takes more than one approach to provide health care.

## **5.7 CHAPTER RÉSUMÉ**

This chapter presented the research findings as collated from the collected data. The prolonged use of HAART treatment was a great factor because when it started, before it could prolong, the adolescents seemed to have been happy to take it. They were also not asking much about the treatment, and they did not forget to take the medication. Only when prolonged, all these distresses emerged.

The findings suggest that adolescents who are on HAART treatment over an extended period of time experience drug fatigue. Drug fatigue has far-reaching implications for the health of adolescents, as it has a higher likelihood that poor adherence or even complete refusal to take HAART treatment will occur. Poor adherence or refusal to take HAART treatment will most likely lead to cross infection and further spread of the HIV.

Moreover, the role of psychosocial support was identified as the deal breaker where HAART treatment adherence is concerned. The more positive the psychosocial support, the higher the likelihood of consistent adherence.

The next chapter focuses on conclusions drawn from the research process, themes determined and discussions of the semi-structured interviews, as well as the literature and theoretical review. Recommendations are also based on the research study and findings.

## **CHAPTER 6: CONCLUSION AND RECOMMENDATIONS**

### **6.1 INTRODUCTION**

In the penultimate chapter, discussion and integration of study findings were presented. In this chapter, the conclusions and recommendations that emerged from the deliberations of the research study are presented. The research study was undertaken to explore the nature of experiences of adolescents who are on long-term HAART treatment in Tembisa, Gauteng province.

### **6.2 RESEARCH FINDINGS SUMMARY**

The research findings established that disclosing HIV positive status to an adolescent is the preliminary point and needs to be addressed courteously in order to assist with acceptance of their HIV positive status. Based on the narratives of adolescent participants, the issue of disclosure of their HIV positive status poses a number of challenges. Adherence to HAART treatment depends on how disclosure of HIV and AIDS-positive status has been managed by significant others including health professionals. It is important that family members disclose the HIV positive status of adolescents to adolescents directly and allow for a follow-up discussion with health care workers who can explain the medical perspective of HAART so as to enhance understanding.

Disease knowledge is a crucial element of the management of HAART treatment and self-care. Where adolescents trusted the medication, treatment was taken consistently, leading to relatively good health. They knew the reasons for taking the medications on a regular basis. The only thing they did not know was that they are taking treatment because they have been infected by HIV and AIDS virus. They could only speculate that they had the disease from parents who had died of the disease. However, it was immaterial to them how the HIV and AIDS virus was acquired. All they were focusing on was to get better from the HAART treatment they received.

The main reason adolescents adhere to HAART treatment was the belief that their medical condition would improve. Their problem was more about their HIV positive status; they felt aggrieved by the fact that they were HIV positive. Moreover, most of the adolescent participants reported receiving encouraging support from home. Most guardians took good

care of them. This was not the case in families where there was poverty. However, they did not seem to be humiliated through being stigmatised.

The diagnosis with HIV positive status initially angered and saddened them, but they eventually accepted their HIV positive status. Some of the adolescent participants had delayed schooling due to failure to cope and lack of support. The adolescent participants still had ambitions for the future and were hoping to become helpers through professions in the medical field, such as medical doctors, when they grow up.

The findings of the study also highlighted issues related to coping mechanisms used by adolescent participants after resuming HAART. Coping mechanisms included a company of friends, but dangerous methods such as drugs and dagga use were also mentioned. The adolescent participants reported that they followed treatment. However, sometimes the doctors deduced that the patients had defaulted through blood tests. This angered the adolescent participants, as they were convinced that they honoured the prescriptions. These adolescent participants trusted the treatment and were looking forward to improved health. The treatment gave them hope.

The positive findings of the study relate to the adolescent participants' understanding of the role of sex. Some of them considered the use of a condom as an option when they become sexually active, although in practice it was a completely different situation. They would consider having unprotected sexual intercourse if it meant hiding possible suspicion about their HIV positive status when condom usage was not negotiated. One of the female participants was pregnant at the time of the study, indicating that it is difficult for adolescent females to negotiate safe sex. The sexually active male in the study was already reported to be exercising the concept of condom usage during sexual intercourse. This signifies the extent to which the gender of the adolescent participant influences their ability to negotiate for safe sex. The study reveals that males are in a better position to negotiate the use of condoms, whereas females feel powerless and end up giving into unsafe sex in order to be accepted by their sexual partners.

### **6.3 LIMITATIONS OF THE STUDY**

The context-specific features of the research setting have limited the generalisation of the research study results. The study was based at a clinical unit in Tembisa with a homogeneous population. Therefore, its findings cannot be generalised to other races,

provinces or other diverse biographical populations. However, other areas in South Africa may experience similar characteristics.

A further limitation of the research study is the duration of the study data collection. A longitudinal study would have produced an additional set of results in comparison to the cross-sectional study. Data for the individual adolescents was collected within a period of three months while that of parent, guardian and caregiver participants was within two weeks. HCPPs returned the questionnaire within a period of two weeks, while the focus group met only once.

The sample size for parent, guardian and caregiver participants was limited to three due to poor willingness and withdrawal from participation. This sample was identified based on phenomenological research principles which recommend small sizes of the participants; however, for future research, more participants can be included. The focus group size was planned to be between six and eight participants. However, only three participants arrived for the scheduled interview and were willing and open to participate. Bigger samples would have resulted in more diverse responses and findings.

Conducting the interviews in a mixture of English and the participants' vernacular language and then transcribing and translating into English can be considered as a limitation, as some meaning might have been lost during the process.

#### **6.4 STRENGTHS OF THE STUDY**

Perceptions and experiences were explored from individual adolescent participants; a focus group of adolescent participants; parent, guardian and caregiver participants; and finally the health care professional participants. This multi-dimensional research study gave strength to the findings and results.

The size of the individual adolescent participants was initially planned at 10 participants. However, this number was stopped at seven after reaching saturation point. Although some of the participants who initially agreed eventually did not show up at the agreed interview appointment, resulting in the need to recruit new participants, a sample of seven meant that a varied set of opinions was discovered.

As far as health care professionals were concerned, 15 questionnaires were handed out, and 11 were returned. The hope was that at least eight participants would complete and return the questionnaires, yet a total of 11 questionnaires were returned. The element of optimism was duly noted and considered in the analysis of the responses.

## **6.5 RECOMMENDATIONS FOR PRACTICE AND POLICY**

Based on the findings, the recommendations that follow were put forward.

### **6.5.1 Timely and Developmentally Appropriate Disclosure of HIV positive Status**

Disclosure to an adolescent about their own HIV positive status has implications for long-term HAART adherence. It is therefore important that disclosure is done as early as possible. At the time of HIV positive diagnosis, disclosure should be made using the language and description that the child or adolescent can understand with full disclosure and explanation as they grow and develop. In this way, the knowledge of HIV positive status and AIDS is known from initiation of HAART so as to prevent a sense of betrayal that is experienced when disclosure is only made when the adolescent is older.

It is recommended that strategies to enable earlier disclosure of HIV positive status and AIDS to the concerned children and adolescents be implemented as a matter of urgency. The bio-psychosocial team at the hospital should allocate a designated 'Disclosure Agent,' whose main job is to ensure that every young person diagnosed with HIV positive status is informed of their status at the initial time of diagnosis.

### **6.5.2 Establishment of a Hospital-based Education Unit**

Most adolescent participants reported the fact that they lag behind with their schooling as a result of constant hospital check-ups and hospitalisation. The recommendation for this challenge is the introduction of a hospital-based school. An education unit that focuses on assisting hospitalised learners with catch-up programmes should be set up within the hospital. Dedicated and qualified facilitators who visit the various children's wards to assist with catch-up programmes should be allocated so that students do not miss out on schooling.

### **6.5.3 School Outreach Programmes by Health Care Professionals**

A further recommendation is for the hospital to introduce school outreach programmes whereby health care professionals visit various schools to carry out routine medical check-ups as well as roll out HAART treatment for adolescent learners. It is possible that such school-based outreach programmes will initially experience stigmatisation. Therefore, these outreach programmes should be used for psychoeducation which will, in the long run, desensitise stigma, thus leading to higher HAART treatment adherence.

### **6.5.4 Adolescent-tailored Services**

Considering the findings of this study, there is a need for a welcoming, reassuring and open-minded environment as well as convenient appointment scheduling and confidentiality.

#### ***6.5.4.1 After-hours Appointments and Support Groups***

The Masakhane Clinic should schedule school adolescents' medical doctor and HAART treatment collection appointments after school hours and/or on weekends. Furthermore, instead of the present monthly prescription refill, the adolescent learners should be scheduled for prescription refill and blood works at the hospital quarterly, thereby increasing the likelihood of school attendance. During these days, peer support groups and group activities where adolescents will have an opportunity to share their HAART treatment experiences with people of the same age group should be arranged. In this way, time spent away from the classrooms will be kept at a minimum while maximising disease management education.

#### ***6.5.4.2 Community-based Support Programme***

The practice of group activities and peer education should be incorporated into community-based support programmes for adolescents. Home-based visits are a commonly practiced routine when it comes to most social ills. This system must be introduced for adolescents who are on HAART treatment. The hospital social workers already perform such services for mental health care users, and they could extend their services to cater for the adolescents receiving HAART treatment.

#### **6.5.4.3 Establishment of Adolescent and Youth Centre**

The hospital should create a youth and adolescent-friendly centre whereby a section of the clinic will be designated for adolescents and youth in general for the provision of services that are sensitive to adolescents' various stages of development. Without tailored adolescent services, adolescents are likely to fall through the health care cracks, and when mixed with adults from the same communities, adolescents on HAART treatment are likely to withdraw their participation when adults are present.

#### **6.5.4.4 Use of Technology and Social Media**

Furthermore, use of technology and social media, such as Facebook, WhatsApp groups and Twitter feeds, should be used to interact with adolescents. Social media reminders should be sent to adolescent participants to remind them about follow-up dates for check-ups, treatment follow-ups and any events related to their welfare.

#### **6.5.4.5 Fixed-dose Treatment Roll-out**

Lastly, the hospital should introduce a fixed-dose combination treatment as a prominent treatment modality to encourage adherence and discourage treatment fatigue for adolescents.

### **6.6 RECOMMENDATIONS FOR FURTHER RESEARCH STUDIES**

The following suggestions are made as recommendations for future studies:

- Conduct a closely related or similar research study in other HAART roll-out facilities in and around Tembisa, to explore the perceptions and experiences of adolescents growing up on HAART.
- Replicate this research study to other topographical zones for the generality of these research results to all adolescents.
- Give attention to reproductive health care needs of adolescents who grow up on HAART treatment.

- Carry out a relatively global study that includes a bio-psychosocial approach to research the adolescent phenomenon together as opposed to researching in silos.
- Consider a multilevel research study to explore measures of lessening stigma and discrimination towards HIV and AIDS-positive adolescents.

## **6.7 RESEARCH STUDY CONCLUSION**

This research study explored the experiences of adolescents relating to HAART treatment for at least two years. In-depth interviews, as well as a focus group, were used to collect data, which was analysed using thematic categorisation. The objectives of the research study, those of exploring the experiences of adolescents as far as HAART treatment is concerned, were met.

The research study findings covered the negative and positive experiences, and the perceived role of HAART treatment over a long period of time. Additionally, the PGCPs' views about the experiences and coping mechanisms of the adolescent participants taking HAART were also included in order to obtain a broader understanding. The various health care professionals involved in the treatment of the adolescent participants on HAART provided information on their perceptions of the experiences of the adolescents on HAART under their care at the hospital. These collective contributions were required to provide information regarding the importance of improving practices in HAART of the HIV and AIDS adolescent participants.

The predominant themes identified from adolescent participants were disclosure of HIV positive status and the stigma surrounding a positive status, early childhood experience of parental death, the challenges of taking HAART treatment, the factors influencing adherence and non-adherence to HAART treatment, and lastly, the impact of religion on HAART treatment adherence. Adolescent participants struggle with the disclosure of their HIV positive status. Drug fatigue has far-reaching implications for the health of the adolescents, as it determines adherence to HAART treatment. Poor adherence or refusal to take HAART treatment will most likely lead to cross infection and further spread of HIV and AIDS.

This study has thus contributed to the body of knowledge regarding experiences of long-term HAART treatment by adolescents.

## LIST OF REFERENCES

- Abdool Karim, S. S., & Abdool Karim, Q. (2010). *HIV/AIDS in South Africa*. Durban: Cambridge Publishers.
- Aber, V., & Aboulker, J. P. (1996). Delta: A Randomised Double-Bind Controlled trial comparing combinations of zidovudine plus didanosine or zalcitabine with zidovudine alone in HIV-infected individuals. *Lancet*, *348*(9023), 283-291.
- Adler, M. W. (2001). *ABC of AIDS*. Tavistock Square. London: BML Books. BMJ Publishing Group, BMA House.
- Adler, M. W., Edwards, S. G., Miller, G. S., & Williams, I. G. (2012). *ABC of HIV and AIDS*. Oxford: Wiley-Blackwell.
- Agyarko-Poku, T., Sarkodie, Y. A., & Atakorah-Yeboah, L. (2014). Too bad! Fixed-dose combination antiretroviral drugs. *BMC Infectious Diseases*, *14*(2), 80.
- Albert, J., & Jay, B. (2001). *Curve ball: Baseball, statistics, and the role of chance in the game*. New York: Springer-Verlag.
- Alderson, F., & Morrow, V. (2004). *Ethics, Social Research and Consulting with Children and Young People*. Ilford, United Kingdom.
- Arhar, J. M., Holly, M. L., & Kasten, W. C. (2001). *Action research for teachers: Travelling the yellow brick road*. Mishawaka: Prentice Hall.
- Davies, N. & Kijko, A. (2003). Seismic risk assessment: with an application to the South African insurance industry. *South African Actuarial Journal* *3*: 1–28
- Ayopo, J. M. (2009). *Exploring Nigerian adolescent students' perceptions of HIV/AIDS and their attitudes to prevention methods: A psycho of educational perspective*. Doctor of Education (Psychology in Education) thesis, University of South Africa.
- Badri, M., & Bekker, L. G. (2004). Initiating highly active antiretroviral therapy in sub-Saharan Africa: An assessment of the revised World Health Organization scaling-up guidelines. *AIDS*, *18*(8), 1159-1168.

- Bailey, K. D. (1994). *Methods of social research*. New York: The Free Press.
- Barnett, T., & Whiteside, A. (2002). *AIDS in the twenty-first century: Disease and globalization*. Palgrave MacMillan.
- Barrero, C. E. A., & Castro, A. (2005). Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil. *Social Science and Medicine*, 62(5), 1219-1228. doi:10.1062; Socsimed. 2005.07.006
- Bartlett, J. G., Gallant, J. E., & Conradie, F. M. (2008). *Medical management of HIV infection*. Pretoria: Foundation for Professional Development.
- Beal, J., Orrick, J. J., Lora, M., & Vandokelaar, A. (2011). *ARV therapy in adults and adolescents*. ARV Card.
- Becker, M. H. (1974). The health belief model and personal health behaviour. *Health Education Monographs*, 2, 324-473.
- Bekker, L-G and Hosek, S. (2015). HIV and adolescents: focus on young key populations. *Journal of the International AIDS Society*. Source:PubMed DOI:10.7448/IAS.18.2.20076
- Bell, C., Devarajan, S., & Gersbach, H. (2003). *The long-run economic costs of AIDS: Theory and application to South Africa*. Washington: World Bank.
- Berkow, R., Beers, M. H., Bogin, R. M., & Fletcher, M. B. (1997). *The Merck Manual of Medical Information*. Home Edition. Merck Research Laboratories. Merck and Co., Inc. Whitehouse Station, N.J.
- Bernstein. K., D'Angelo., L. J., & Lyon. M. E. (2012). An Exploratory Study of HIV+ Adolescents' Spirituality: Will You Pray with Me? Original Paper 123. *J Relig Health*. doi:10.1007/s10943-012-9565-1
- Bezuidenhout, C., Elago, H., Kalenga, E., Klazen, S., Nghipondoka, K., & Ashton, D. (2005). *The Psychosocial Impact of HIV/AIDS: People are more than just statistics*. Future Leaders Summit.

- Bikaako-Kajura, W., Luyirika, E., Purcell, D. W., Downing, J., Kaharuzza, F., Malamba, S., & Bunell, R. (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS Behaviour*, 10(Suppl.), S85-S93.
- Bill, R. (2006). The politics of civil society in confronting HIV/AIDS international affairs. *HIV/AIDS-Special*, 82(2), 285-295.
- Blanchardt, C. M., Courneya, K. S., Rodgers, W. M., Fraser, S. N., Murray, T. C., Daub, B., & Black, B. (2003). Is the theory of planned behaviour a useful framework for understanding exercise adherence during phase ii cardiac rehabilitation? *Journal of Cardiopulmonary Rehabilitation*, 23, 29-39.
- Bowen, G. A. (2008). *Naturalistic inquiry and the saturation concept: A research note*. Qualitative Research.
- Boyce, C. B., & Neale, P. (2006). Conducting In-depth Interviews: A Guide for Designing and Conducting In-depth Interviews for Evaluation Input. *Pathfinder International Tool Series*. Monitoring and Evaluation-2.
- Brahmbhatt, H., Kigozi, G., Wabwire-Mangen, F., Serwadda, D., Lutalo, T., Nalugoda, F., Sewankambo, N., Kiduggavu, M., Wawer, M., & Gray, R. (2006). Mortality in HIV-infected and uninfected children of HIV-infected and uninfected mothers in rural Uganda. *J Acquir Immune Defic Syndr*, 41(4), 504-508.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Washington DC: Sage.
- Brown, L. K., DiClemente, R. J. & Reynolds, L. A. (1991). HIV prevention for the adolescent: Utility of the health belief model. *AIDS Education and Prevention*, 3 (1), 50 - 59
- Brown, L. K., Lourie, K. J., & Pao, M. (2000). Children and adolescents living with HIV and AIDS: A review. *J. Child Psychol Psychiatry*, 41(1), 81-96.
- Burns, N., & Grove, S. K. (2005). *The practice of nursing research: Conduct, critique and utilisation*. Philadelphia: WB Saunders.

- Carpenter, C. J. (2010). A meta-analysis of the effectiveness of health belief model variables in predicting behavior. *HealthCommun*, 25, 661–669.
- Chan, Z.C.Y, Fung, Y-L. & Chien, W-T. (2013). Bracketing in Phenomenology: Only Undertaken in the Data Collection and Analysis Process? *The Qualitative Report*, 18(59), 1-9.
- Chen, L. F., Hoy, J., & Lewin, S. R. (2007). Ten years of Highly Active Antiretroviral Therapy for HIV infection. *MJA*, 2007(3), 146-151.
- Children’s Act 38 of 2005. Consolidated Regulations Pertaining to the Children’s Act, 2005.
- Claxton, R., & Harrison, T. (1991). *Caring for children with HIV and AIDS*. London Melbourne-Auckland: Hodder and Stoughton.
- Close, K. L. (2006). Psychosocial aspects of HIV/AIDS: children and adolescents. In: HIV Curriculum for the Health Professionals. Baylor College of Medicine, USA.
- Cluver, L., & Gardner, F. (2000). Psychological Distress Amongst AIDS-orphaned Children in Urban South Africa. *Journal of Child Psychology and Psychiatry*, 48(8), 755-763. doi:10. 1111/j, 469-760.2007.01757.x
- Colby, D. G., & Baker, D. G. (1988). State policy responses to the AIDS epidemic. Oxford Journals-Social Sciences. *Publius*, 18(3), 113-130.
- Conner, M. (2010) *Cognitive Determinants of Health Behavior. Handbook of Behavioral Medicine Methods and Applications*. Ed Steptoe A XXIV: 1073.
- Cooper, H., Camic, P. M., Long, D. L., Panter, A. T., Rindskopf, D., & Sher, K. J. (2012). APA Handbook of Research Methods in Psychology. Volume 2: Research Designs; Quantitative, Qualitative, Neuropsychological and Biological. American Psychological Association. Washington, DC.
- Cooper, S. E., Risley, C. L., Drake, L. J., & Bundy, D. A. (2007). HIV as part of children and youth, as life expectancy increases: Implications for education. *Journal of International Cooperation in Education*.

- Corcoran, N. (2013). *Communicating health strategies for health promotion*. Los Angeles. London. New Delhi. Singapore. Washington DC: Sage.
- Cotton, S., Puchalski, C. M., Sheraman, S. N., Mrus, J. M., Peterman, A. H., Feinberg, J., Pargament, K. I., Justice, A. C., & Tsevat, J. (2006). Spirituality and religion in patients with HIV/AIDS. *J Gen Intern Med*, 24(8), 994.
- Creswell, J. W. (1998). *Qualitative research design: choosing among five traditions*. Thousand Oaks: Sage.
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative and mixed methods approaches* (International Student ed.). University of Nebraska, Lincoln: Sage Publications.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative and mixed methods approaches*. University of Nebraska, Lincoln: Sage Publications.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative and mixed methods approaches*. University of Nebraska, Lincoln: Sage Publications.
- Crowther, D., & Lancaster, G. (2012). *Research methods: A concise introduction to research in management and business consultancy*. Oxford: Routledge.
- Dabis, F., & Ekpini, E. R. (2006). HIV-1/Aids and maternal and child health in Africa. *Lancet*, 359(9323), 2097-2104.
- Dagneu, Y. W. (2009). *Factors influencing antiretroviral therapy adherence in Ethiopia*. Master of Public Health dissertation, University of South Africa.
- David, M., & Sutton, C. D. (2011). *Social research: An introduction*. Sage Publications.
- De Baets, A. J., Sifovo, S., Parsons, R., & Pazvakavambwa, I. F. (2007). HIV disclosure and discussions about grief with Shona children: A comparison between health care workers and community members in Eastern Zimbabwe. *Social Science and Medicine*, 66, 479-491.

- De Vos, A. S., Strydom, H., Fouche, H. C. B., & Delport, C. S. L. (2002). *Research at grass roots. For the social sciences and human service professions*. Hatfield, Pretoria.
- DePoy, E and Gittlin, L.N. 1998. *Multiple Strategies for Health and Human Sciences* 2<sup>nd</sup> ed
- Denzin, N. K. (1970). *The Research Act in Sociology*. Chicago: Aldine.
- DiMatteo M.R., Haskard K.B., Williams S. L. (2007). Health beliefs, disease severity, and patient adherence: A meta-analysis. *Medical Care* 45: 521–528.
- Dogar, I. A. (2007). Bio-psychosocial Model. *A.P.M.C.*, 1(1). Department of Psychiatry and Behavioural Sciences.
- DoH. (2008). Department of Health, South Africa. *Trainer's Manual for the Psychosocial Care of Babies and Young Children Living with HIV and AIDS*.
- DoH. (2014). *National Consolidated Guidelines for the preventions of mother-to-child transmission of HIV (PMTCT) and the management of HIV in Children, adolescents and adults*. Department of Health. Republic of South Africa.
- Dohertey, J., & Colvin, P. (2004). HIV/AIDS in South Africa, the prevalence of infection, risk factors and social context. *South African health review*. Durban, South Africa. *Health System Trust*, 13(2), 25-27.
- Durham, J. D., & Lashley, F. R. (2010). *The persons with HIV/AIDS: Nursing perspectives*. New York: Springer Publishing Company.
- Edwards, S. D. (2001). A phenomenological investigation into the experience of being fit: community implications. In A. Papaioannou, M. Goudas & Y. Theodorakis (Eds.), *In the dawn of the new millennium*. Proceedings of the 10th World Congress of Sport Psychology. 1. 105-107. Thessaloniki: Christodoulidi.
- Eagleton, T. (2011). *Literary theory: An introduction*. Oxford: Wiley.
- Ehman, J. W., Ott, B. B., Short, T. H., Ciampa, R. C., & Hansen-Flaschen, J. (1999). Do Patients want physicians to enquire about their spiritual or religious beliefs if they become gravely ill? *Arch Internal Medicine*, 159(15), 1803-1806.

- Engel, G. L. (1977). The need for a new medical model: A challenge for Biomedicine. *SCIENCE*, 196(4286), 129-135.
- Engel, G. L. (1980). American Journal of Psychiatry Clinical application of the biopsychosocial model. *Am J Psychiatry*, 137, 535-544.
- Epstein, R. M. and Borrell - Carrio, F. (2005). The biopsychosocial model: exploring six impossible things. *Families, Systems & Health*
- Fair, C. D., Osherow, J., Albright, J., & McKeone, D. (2014). Medication adherence among adolescents with HIV: A case study of social work interventions. *Journal of HIV/AIDS and Social Services*, 13, 26-45.
- Fair, C. D., Wiener. L., Sima Zadeh, S., Albright, J., Mellins, C. A., Mancilla, M., Vicki Tepper, V., Trexler, C., Julia Purdy, J. P., Lovelace, S., & Kapetanovic, S. (2013). Reproductive health decision-making in perinatally HIV-infected adolescents and young adults. Methodological Notes 123. *Matern Child Health J*, 17, 797-808. doi:10.1007/s10995-012-1070-3
- Fargher, M., & Dooley, H. (2010). *The adolescent storm: A handbook for parents*. South Africa: Penguin Books.
- Feldman, S. S., & Elliot, G. R. (1990). *At the threshold: The developing adolescent*. Cambridge, Massachusetts, and London, England: Harvard University Press.
- Fielden, S. J., Chapman, G. E., and Cadell, S. (2011). Managing stigma in adolescent HIV: silence, secrets and sanctioned spaces, culture, health and sexuality. *An International Journal for Research, Intervention and Care*, 13(03), 267-281. doi:10.1080/13691058.2010.525665
- Finlay, L. (2012). Debating phenomenological methods. *Hermeneutic Phenomenology in Education*, 17-37. Sense Publishers.
- Flewitt, R. (2005). Conducting research with young children: Some ethical considerations. *Early Childhood Development and Care*, 175(6), 553-565.

- Foster, G., & Williamson, J. (2000). A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS 2000*, 14(Suppl. 3), S275-S284.
- Fouche, C. B., & Delpont, C. S. L. (2002). The place of theory and the literature review in the qualitative approach to research. In A. S. De Vos, *Research at grass roots: For the social sciences and human service professions*. Pretoria: Van Schaik.
- Garvie, P. A., He, J., Wang, J., D'Angelo, L. J., & Lyon, M. (2012). An exploratory survey of end-of-life attitudes, beliefs and experiences of adolescents with HIV/AIDS and their families. *J Pain Symptom Manage*, 44(3), 373-385.
- Gaughan, D. M., Hughes, M. D., Oleske, J. M., Malee, K., Gore, C. A., & Nachman, S. (2004). Psychiatric hospitalizations among children and youths with human immunodeficiency virus infection. *Pediatrics*, 113(6), 544-551.
- Geffen, N. (2010). *Debunking delusions: The inside story of Treatment Action Campaign*. Auckland Park: Jacana Media Publishing.
- German, P., Warren, D., West, S., Hui, J., & Keaney, P. (2010). Pharmacokinetics and Bioavailability of an Integrase and Novel Pharmaco-enhancer-Containing Single-Tablet Fixed-Dose Combination Regimen for the Treatment of HIV. *J Acquir Immune Defic Syndr*, 55, 323-329.
- Ghahramani, S. (2000). *Fundamentals of probability*. New Jersey: Prentice Hall.
- Given, L. M., & Saumure, K. (2008). *The Sage Encyclopaedia of Qualitative Research Methods*. Volumes 1 + 2. A Sage Reference Publication. SAGE. London.
- Goodman, C. J. (2008). *Research in psychology: Methods and design*. London, UK: Wiley
- Gravetter, F. J., & Forzano, L. B. (2010). *Research methods for the behavioral sciences*. Wadsworth: Cengage Learning.
- Graziano, A. M., & Raulin, M. L. (2013). *Research methods: A Process of Inquiry* (Pearson International ed.). Always Learning.

- Green, J. A. and Shellenberger, R. (1991) *The Dynamics Of Health And Wellness: A Biopsychosocial Approach*. Fort Worth, TX: Holt and Rinehart and Winston.
- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3(1), 4.
- Gubrium, J. F., & Hostein, J. A. (2000). Analyzing interpretive practice. In N.Y. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 487-508). Thousand Oaks, CA: Sage.
- Guilfoile, P. G. (2011). *Deadly diseases and epidemics: HIV/AIDS*. Chelsea House: An Infobase Learning Company.
- Hahn, C. J. (2010). *Edmund Husserl, The Basic Problems of Phenomenology: From the Lectures, Winter Semester, 1910-1911*. Springer, Dordrecht,
- Hall, J. C., Hall, B. J., & Cockerell, C. J. (2011). *HIV/AIDS in the post-HAART era: Manifestations, treatment and epidemiology*. USA Shelton, Connecticut: People's Medical Publishing House.
- Hans, M. L., Spiegel, M. D., Donna, C., & Futterman, M. D. (2009). *Adolescents and HIV: Prevention and clinical care*. Albert Einstein College of Medicine, Adolescent AIDS Program, Montefiore Medical Center.
- Harper, G. W., & Riplinger, A. J. (2012). HIV prevention interventions for adolescents and young adults: What about the needs of gay and bisexual males? *AIDS Behav*, 17, 1082-1095. doi:10.1007/s10461-012-0178-1
- Harper, G. W., Fernandez, I. M., Bruce, D., Sybil, G., Hosek, S. G., & Jacobs, R. J. (2011). The Role of Multiple Identities in Adherence to Medical Appointments Among Gay/Bisexual Male Adolescents Living with HIV 123. *AIDS Behav*, 17, 213-223. doi:10.1007/s10461-011-0071-3
- Harrell, M. C., & Bradley, M. A. (2009). *Data Collection Methods: Semi-Structured Interviews and Focus Groups. Training Manual*. Prepared for the U.S. Government approved for public release; distribution unlimited National Defense Research Institute.

- Harris, R. (2000). *Information graphics: A comprehensive illustrated reference*. New York: Oxford University Press.
- Haslam, S. A., & McGarty, C. (2003). *Research methods and statistics in psychology*. London: Sage Publications.
- Hayden, J. (2009). *Introduction to Health Behaviour Theory*. Department of Public Health William Paterson University. Sudbury. Massachusetts. Boston. Toronto. London. Singapore: Jones and Bartlett Publishers.
- Haynes, R. B. (1979). Introduction. In R. B. Haynes, D. W. Taylor & D. L. Sackett (Eds.), *Compliance in health care* (pp. 1-7). Baltimore: John Hopkins.
- Health Policy Project. (2013). *Basics of Health Policy*.
- Hennink, M., Hutter, I., & Bailey, A. (2011). *Qualitative research methods*. Sage Publications Ltd.
- Hesse-Biber, S. N., & Leavy, P. (2004). *Approaches to qualitative research: A reader on theory and practice*. New York, Oxford: Oxford University Press.
- Hochbaum, G. M. (1958). Public Participation in Medical Screening Programs: A Socio-Psychological Study. Department of Health Education and Welfare, PHS Publ no. 572. Washington, DC: US Government Printing Office.
- Holmbeck, G. N., and Kendall, P. C. (2002). Introduction to the special section on clinical adolescent psychology: Developmental psychopathology and treatment. *Journal of Consulting and Clinical Psychology*, 70(1), 3–5.
- Howell, K. E. (2013). *Introduction to the philosophy of methodology*. London: Sage Publications.
- HPCSA, (2006). Professional Board for Psychology: Roles of Conduct Pertaining Specifically to the Profession of Psychology. Pretoria: HPCSA.
- HSRC. (2009). The HIV and AIDS epidemic in South Africa: Where are we?

- HSRC. (2012). Human Sciences Research Council. Informed Consent Guidelines re Minors (including orphans and vulnerable children OVC) and Parental Substitutes.
- Husserl, E. (1970). *The crisis of European sciences and transcendental phenomenology: An introduction to phenomenological philosophy*. Northwestern University Press.
- Husserl, E., & Heidegger, M. (1927). Phenomenology. In *Encyclopedia of Britannica*.
- Ijadunola, K. T., Abiona, T. C., Odu, O. O., & Ijadunola, M. Y. (2007). College students in Nigeria underestimate their risk of contracting HIV/AIDS infection. *Eur J Contracept Reprod Health Care*, 12(2), 1, 31-37.
- Isithembiso. (2011). Official Newsletter of Tembisa Hospital, July. Tembisa, Ekurhuleni: Department of Health.
- Jaeger, R. A., & Halliday, T. R. (1998). On Confirmatory versus Exploratory Research. *Herpetologica*, 54(Suppl.), S64-S66. The Herpetologists' League, Inc.
- Jaspan, H. B., Li, R., Johnson, L., & Becker, L. G. (2009). *The emerging need for adolescent-focused HIV care in South Africa*. Desmond Tutu HIV Centre, Institute of Infectious Diseases and Molecular Medicine, University of Cape Town.
- Jena, P. P. (2014). *Exploring the lived experiences of adolescents living with vertically acquired HIV*. Masters dissertation, Department of Social and Behavioural Sciences, University of South Africa, Pretoria.
- Jones, P. K., Jones, S. L. & Katz, J. (1987). Improving compliance for asthma patients visiting the emergency department using a health belief model intervention. *Journal of Asthma* 24, 199–206.
- Kagee, A. (2007). Adherence to Antiretroviral Therapy in the context of the national roll-out in South Africa: Defining a research agenda for Psychology. Psychological Society of South Africa. *South African Journal of Psychology*, 38(2), 413-428.

- Kalichman, S. C. (2013). HIV Treatments as Prevention (TasP): Primer for Behaviour-Based Implementation. Springer Briefs in Public Health. Centre for HIV Intervention and Prevention, University of Connecticut, Storrs, CT USA.
- Kambale, H. N. (2013). *Factors that affect adherence to antiretroviral therapy among adolescent patients at selected Palapye Clinics*. Masters dissertation, Faculty of Economic and Management Sciences, University of Stellenbosch.
- Karamagi, Y. E. M. (2007). Outcome of Highly Active Antiretroviral Therapy (HAART) among HAART naive HIV-infected children under 6 years at the Mildmay Centre, Uganda. M.A. Public Health dissertation, University of Limpopo (Medunsa Campus).
- Kasedde, S., Luo, C., McClure, C., & Chandan, U. (2013). Reducing HIV and AIDS in adolescents: Opportunities and challenges. *Current HIV/AIDS*.
- Kayitare, E., Vervaet, V., Ntawukulilyayo, J. D., Seminega, B., Bortel, V & Remon, J. P. (2009). Development of fixed-dose combination tablets containing zidovudine and lamivudine for paediatric application. *International Journal of Pharmaceutics*, 370(1-2), 41-46.
- Keller, D. M. (2011). Adolescents with HIV Have More Neurocognitive Disorders. Medscape Medical News Paper presented at the 13th European AIDS Conference of the European AIDS Clinical Society (EACS): Abstract PS4/2. Presented October 13, 2011.
- Kidia, K. K., Mupambireyi, Z., Cluver, L., Ndhlovu, C. E., Borok, M., & Ferrand, R. A. (2014). *HIV status disclosure to perinatally-infected adolescents in Zimbabwe: A qualitative study of adolescent and healthcare worker perspectives*. PloS one 9:e87322. doi:10.1371/journal.pone.0087322147
- Kip, E. (2008). *Factors Influencing patients' adherence to Antiretroviral Therapy in four selected health facilities in Botswana*. Doctor of Literature and Philosophy (Health Studies) thesis, University of South Africa, Pretoria.

- Krauss, B. J., Letteney, S., Da Baets, A. J, Baggaley, R. & Okro, A. (2013). Disclosure of HIV status to HIV positive children 12 and under: A systematic cross-national review of implications for health and well-being. *Vulnerable Children and Youth Studies: An International Interdisciplinary Journal for Research, Policy and Care*.
- LaGreca, A. M. (1990). Issues in adherence with pediatric regimens. *J Pediatric Psych*, 15(4):423-436.
- Lam, D., Seekings, J., & Sparks, M. (2006). *The Cape Area Panel Study: Overview and Technical Documentation for Waves 1-2-3*. Cape Town: University of Cape Town.
- Lerner, R. M., & Steinberg, L. (2009). *Muus, 1990 Handbook of Adolescent Psychology*. 1: Individual Bases of Adolescent Development. John Wiley and Sons, Inc.
- Leshem, S., & Vernon Trafford, V. (2007). Oranim Academic College of Education, Israel; Anglia Ruskin University, UK. *Innovations in Education and Teaching International*, 44(1): 93-105.
- Levine, A. (1998). Antiretroviral therapy: Adherence. *Medscape HIV/AIDS eJournal*, (4)2.
- Li, R. (2009). Growing up on HAART: The Experiences and Needs of HIV Positive adolescents in care and treatment in the Western Cape Province of South Africa. CSSR Working Paper No. 249.
- Lippman, I. H., & McIntosh, H. (2010). The Demographics of Spirituality and Religiosity Among Youth: International and US Patterns Child Trends. Research Brief. Publication #2010-21 4301 Connecticut Avenue, NW, Suite 350, Washington, DC.
- Lizewski, L. (2010). The Health Belief Model. Wayne State University. Communication Theory.
- Lowenthal, E.D., Bareeka-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K., & Ferrand, R. A. (2014). *Perinatally Acquired HIV infection in Adolescents from sub-Saharan Africa: A review of emerging challenges*. *The Lancet Infectious Diseases*, 14(7), 627-639.

- Lyon, M. E., Garvie, P., He, J., Malow, R., McCarter, R., & D'Angelo, L. J. (2012). Spiritual well-being among HIV-infected adolescents and their families. *Journal of Religious Health*. doi:10.1007/s10946-012-9657-y
- Lyon, M. E., Garvie, P., Kao, E., Briggs, L., He, J., Malow, R., McCarter, R., & D'Angelo, L. J. (2011). An exploratory study of spirituality in HIV-infected adolescents and their families: FAmily CEntered Advance Care Planning and Medication Adherence J Adolesc Health. *J Adolesc Health*, 48(6), 633-636. doi:10.1016/j.jadohealth.2010.09.006
- Maartens, G., Cotton, M., Wilson, D., Venter, F., Meyers, T., & Bekker, L. G. (2012). *Handbook of HIV Medicine*. Oxford University Press.
- Machi, L. A., & McEvoy, B. T. (2012). *The literature review: Six steps to success*. Corwin, California: Sage.
- Machtinger, E. L., & Bangsberg, D. R. (2006). Adherence to HIV Antiretroviral Therapy. HIV In Site Knowledge Base Chapter. San Francisco: University of California. Retrieved from <http://hivinsite.ucsf.edu/InSite?page=kb-03-02-09>
- Mack, N., Woodsong, C., MacQueen, K., Guest, G., & Namey, E. (2005). *Qualitative research methods: A data collector's field guide*. Family Health International. Research Triangle Park, North Carolina. USA. USAID.
- Maggiolo, F., Airoldi, M., Trotta, M. P., Sette, P., Bisi, L., Mussini, C., Bai, F., Bini, T., Orofino, G., & Gori, A. (2008). Effect of a fixed-dose combination of emtricitabine, tenofovir and efavirenz on adherence and treatment acceptability (ADONE study). *Journal of the International AIDS Society*, 11, 167.
- Marandu, E. E. (2009). Testing The Theory of Reasoned Action and its Extensions: Predicting Intention To Use Condoms. Organisation for Social Science Research in Eastern and Southern Africa.
- Marshall, C., & Rossman, G. B. (2010). *Designing qualitative research*. California: SAGE Publications.

- Masokoane, K. Q. (2009). Adherence and non-adherence to AntiRetroviral Treatment in HIV positive people in Port Elizabeth. Masters dissertation, Nelson Mandela Metropolitan University, Port Elizabeth.
- Mayer, C. (2007). *Non-adherence to treatment: A psychological and communications perspective.*
- Mburu, G., Hodson, I., Kalibala, S., Haamujompa, C., Cataldo, F., Lowenthal, E. D., & Ross, D. (2014). Adolescent HIV disclosure in Zambia: Barriers, facilitators and outcomes. *Journal of the International AIDS Society, 17*, 18866.
- Mburu, G., Ram, M., Oxeham, D., Haamujompa, C., Iorpenda, K., & Ferguson, L. (2001). *Responding to adolescents living with HIV in Zambia: A social-ecological approach.*
- McCleary-Sills, J., Anjala, K, Brakarsh, J & Browky, S. (2013). Foundation for the Future: Meeting the Psychosocial Needs of Children Living With HIV in South Africa and Uganda. Article in *Journal of HIV/AIDS & Social Services* 12(1)
- McClure, R. D. (2002). Common Data Collection Strategies Effective in Qualitative Studies Using Action Research in Technical/Operational Training Programs.
- McCree, D. H., Wingood, G. M., DiClemente, R., Davies, S., & Harrington, K. F. (2002). Religiosity and risky sexual behavior in African-American adolescent females. *Journal of Adolescent Health, 33*(1), 2-8.
- McLaren, N. (1998). A critical review of the Bio-psychosocial Model. *Australian and New Zealand Journal of Psychiatry, 32*, 86-92.
- McMillan, J. H., & Schumacher, S. (2010). *Research in education: Evidence-based inquiry.* Boston: Pearson Education.
- McNeely, C. & Blanchard, J. (2009). The teen years explained: a guide to healthy adolescent development. Johns Hopkins University. Bloomberg School of Public Health, Baltimore.

- Merchant, R. H., & Lala, M. M. (2012). Common clinical problems in children living with HIV/AIDS: Systemic approach. Symposium of Pediatric HIV/AIDS. *Indian J Pediatr*, 79(11), 1506-1513.
- Merleau-Ponty, M. (1962). *Phenomenology of perception*. London and New York: Routledge.
- Midtbo, V., Shirima, V., Skodval, M., & Daniel, M. (2012). How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma. *African Journal of AIDS Research*, 11(3), 261-271.
- Mills, E. J., Nachega, J. B., & Buchan, I. (2009). Adherence to Antiretroviral Therapy in sub-Saharan Africa and North America: A Meta-analysis. *JAMA*.
- Miner-Romanoff. (2012). Interpretive and critical phenomenological crime studies: A model design. *The Qualitative Report 2012*, 17(54), 1-32.
- Mofenson, L. M., & Cotton, M. (2013). The challenges of success: Adolescents with perinatal HIV infection. *Journal of the International AIDS Society*, 16, 18650.
- Mook, D. G. (2001). *Psychological research: The ideas behind the methods*. New York, London: W.W. Norton and Company.
- Mothi, S. N., Swamy, V. H. T., Mamatha, M. Lala., Karpagam, S., & Gangakhedkar, R. R. (2012). Adolescents living with HIV in India: The clock is ticking. Symposium on Pediatric HIV/AIDS. *Indian J Pediatr*, 79(12), 1642-1647. doi:10.1007/s12098-012-0902-x
- Munro, S, Lewin, S, Swart, T & Volmink, J. 2007. A review of health behaviour theories: how useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS?
- Murphy, D. A., Belzer, M., Durako, S. J., Sarr, M., Wilson, C. M., & Muenz, L. R. (2005). Longitudinal antiretroviral adherence among adolescents infected with Human Immunodeficiency Virus. *Arch Pediatr Adolesc Med*, 159(8), 764-770.

- Musisi, S., & Kinyanda, E. (2009). *Psychiatric problems of HIV/AIDS and their management in Africa*. Kampala, Uganda: Fountain Publishers.
- Musisi, S., Kinyanda, E., Nakasujja, N., & Nakigudde, J. (2007). A comparison of the behavioral and emotional disorders of primary school-going orphans and non-orphans in Uganda. *Africa Health Science*, 7, 202-213.
- Nabukeera-Barungi, N., Kaylesubula, I., Kekitjinwa, A., Byakika-Tusiime, L., & Musoke, P. (2007). Adherence to antiretroviral therapy in children attending Mulago Hospital, Kampala. *Annals of Tropical Paediatrics*, 27(2), 123-133.
- Naidoo, P. (2011). Focus group discussion with private sector doctors in the eThekweni Metro of KwaZulu-Natal on the management of HIV/AIDS patients (Pharmacology) School of Pharmacy and Pharmacology, College of Health Sciences, University of KwaZulu-Natal, South Africa. *S Afr Fam Pract*, 53(2).
- Nassir Ghaemi, S. (2009). The rise and fall of the bio-psychosocial model. *British Journal of Psychiatry BJP*, 195, 3-4.
- Nattrass, N. (2007). *Mortal combat AIDS and the struggle for antiretrovirals in South Africa*. Durban: University of KwaZulu-Natal Press.
- Ndubuka, N. O. (2008). *Factors Influencing Treatment Adherence among Adult Patients Receiving Antiretroviral Therapy at Extension 15 Clinic, Gaborone, Botswana*. Master of Public Health. Pretoria: University of South Africa.
- Neville, C. (2007). *Effective learning service: Introduction to Research and research methods*. Bradford University School of Management.
- Newbold, P., Carlson, W., & Thorne, B. (2009). *Statistics for business and economics*. Pearson Education.
- Nichols, S. (2013). *Neuropsychology of HIV in children and adolescents*. American Psychological Association.

- Norman, P. & Brain, K. (2005). An application of an extended health belief model to the prediction of breast self-examination among women with a family history of breast cancer. *Br J Health Psychol.* 10(1):1-16.
- Nyambura, A. W. (2009). *Factors that influence non-adherence to antiretroviral therapy among HIV and AIDS patients in Central Province, Kenya.* Masters of Public Health (Epidemiology and Disease Control) thesis, School of Health Sciences of Kenyatta University.
- Ojikvth, B. O., & Zheng, H. (2008). Predictors of mortality in patients initiating antiretroviral therapy in Durban. *South African Medical Journal*, 98(30), 204-208.
- Olsson, F. (2013). *The Impact of Orphanhood and HIV/AIDS on school enrolment: Evidence from Zambia.* School of Business, Economics and Law. Sweden: University of Gothenburg.
- Palmer, A. (2011). HIV-infected adolescents have multiple risk factors for mental illness. *HIV Clinician*, 23(3), 1-4.
- Parsons, R. (2012). *Growing up with HIV in Zimbabwe: One day this will all be over.* James Currey Weaver Press.
- Paterson, D. L., Swindells, S., Mohr, J., Brester, M., Vergis, E. N., Squier, C., Wagener, M. M., & Singh, N. (2000). Adherence to Protease Inhibitor Therapy and Outcomes in Patients with HIV infection. *Ann Intern Med*, 133, 21-30.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods.* Newbury Park CA: Sage.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods.* London: Sage Publication.
- Patton, M. Q., & Cochran, M. (2002). *A guide to using qualitative research methodology.* UK: Medecins Sans Frontiers

- Petersen, I., Bhana, A., Myeza, A., Alicea, S., John, S., Holst, H., McKay, M., & Mellins, C. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 22(8), 970-978.
- Pettifor, A. E., Rees, H. V., Kleinschmidt, I., Steffenson, A. E., MacPhail, C., Hlongwa-Madikizela, L., Vermaak, K., & Padian, N. S. (2005). Young People's sexual health in South Africa: HIV prevalence and sexual behaviours from a nationally representative household survey. *AIDS*, 19(14), 1525-1534.
- Pharoah, R. (2004). A generation at risk? HIV/AIDS, vulnerable children and security in Southern Africa. *ISS Monograph Series 109*.
- Phiri, S., & Webb, D. (2002). The Impact of HIV/AIDS on orphans and program and policy responses. In G. A. Cornia (Ed.), *AIDS, public policy and child well-being*.
- Pienaar, L., & Visser, M. J. (2012). Exploration of the experience of adolescents living with HIV. *Children and Youth Studies. An International Interdisciplinary Journal for Research, Policy and Care*, 7(1), 66-74. doi:10.1080/17450128.2011.647731
- Polit, D. F., & Beck, C. T. (2006). *Essentials of nursing research: Methods, appraisals, and utilization*. Philadelphia: JB Lippincott.
- Pontali, E., Feasi, M., Toscanini, F., Bassetti, M., De Gol, P., Nuzzolese, A., & Bassetti, D. (2001). Adherence to Combination Antiretroviral Treatment in Children. *HIV Clin Trials*, 2(6), 466-473.
- Pope, C., White, R. T., & Malow, R. (2009). *HIV/AIDS: Global frontiers in prevention/intervention*. New York: Routledge Taylor & Francis Group.
- Preda, A. (2005). *AIDS, rhetoric, and medical knowledge*. University of Edinburgh: Cambridge University Press.
- Pressley, M., & McCormick, C. B. (2007). *Child and adolescent development for educators*. New York: The Guilford Press.

- Pugatch, D., Bennett, L., & Patterson, D. (2009). HIV medication adherence in adolescents: A qualitative study. *Journal of HIV/AIDS Prevention and Education for Adolescents and Children*, 5, 1-2, 9-29. doi: 10.1300/J129v05n01\_02
- Pujari, S., Dravid, A., Gupte, N., Joshi, K., & Belle, V. (2008). Effectiveness and Safety of Generic Fixed-Dose Combination of Tenofovir / Emtricitabine / Efavirenz in HIV-1-Infected Patients in Western India. *Journal of the International AIDS Society*, 10, 196.
- Punch, K. F. (2014). *Introduction to social research: Quantitative and qualitative approaches*. London: Sage Publications.
- Ramcharan, P., & Cutcliffe, J. R. (2001). Judging the ethics of qualitative research: Considering the 'ethics' as process model. *Health and Social Care in the Community*, 9(6), 358-366.
- Reed, J. F., Lynn, F., & Meade, B. D. (2002). Use of coefficient of variation in assessing variability of quantitative assays. *Clin Diagn Lab Immunol.*, 9(6), 1235-1239.
- Reeves, J. D., & Derdeyn, C. A. (2007). *Entry Inhibitors in HIV Therapy: Milestones in Drug Therapy (MDT)*. Birkhauser Verlag. Basel. Boston. Berlin.
- Regnerus, M., Smith, C., & Smith, B. (2004). Social context in the development of adolescent religiosity. *Applied Developmental Science*, 8, 27-38.
- Rice, F. P., & Dolgin, K. G. (2008). *The adolescent: Development, relationships, and culture*. Boston: Allyn and Bacon.
- Richter, L. (2001). *A generation at risk? HIV/AIDS, vulnerable children and security in Southern Africa*.
- Rolando, M. V., Peralta, L., Aldrovandi, G., Kapogiannis, B. G., Mitchell, R., Spector, S. A., Lie, Y. S., Weidler, J. M., Bates, M. P., & Liu, N. (2016). Prevalence of Primary HIV-1 Drug Resistance among Recently Infected Adolescents: A Multicenter Adolescent Medicine Trials Network for HIV/AIDS Interventions Study. *The Journal of Infectious Diseases*, 194(11), 1505-1509.

- Rose, L., Hagemann, J., Aburto, M & Shahnazarian, D. (2013). Student Handbook: Making Sense of Human Subjects Research. University of Southern California
- Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1994). The Health Belief Model and HIV Risk Behaviour Model. *AIDS Prevention and Mental Health*, 5-24.
- Rosenthal, D., Waters, L., & Glaun, D. (1995). What do pre-adolescents and adolescents understand about HIV/AIDS? *Psychology and Health*, 10, 507-522.
- Ross, A. C., Camacha-Gonzalez, A., Henderson, S., Abanyie, F., & Chakraborty, R. (2010). *The HIV-infected adolescent*. Springer Science and Business Media, LLC.
- Rotheram-Borus, M. J., Stein, J., & Lester, P. (2006). Adolescent adjustment over 6 years in HIV-affected families. *Journal of Adolescent Health*, 39, 174-182.
- Rudy, B. J., Murphy, D. A., Harris, D. R., Muenz, L., & Ellen, J. (2009). Patient-related risks for nonadherence to Antiretroviral Therapy among HIV-infected youth in the United States: A study of prevalence and interactions. *AIDS Patient Care and STDs*, 23(9), 185-194. doi:10.1089=apc.2008.0162
- Ryan, S., & Carr, A. (2010). *Applying the bio-psychosocial model to the management of rheumatic disease*. Elsevier Ltd. doi: 10.1016/B978-0-443-06934-5.00005-X 2
- Sadock, B. J., & Sadock, V. A. (2007). *Kaplan 7 Sadock's Synopsis of Psychiatry: Behavioural Sciences / Clinical Psychiatry*. Philadelphia: Wolters Kluwer.
- SAJHIVMED. (2013). South African Journal of HIV Medicine. *Advice Document: Fixed-dose combination for adults accessing antiretroviral therapy*, 14(1)(Suppl.).
- Sande, M. A., & Volberding, P. A. (1999). *The medical management of AIDS*. London: W.B. Saunders Company.
- Sanne, I. M., Westreich, D., Macphail, A., Rubel, D., Majuba, P., & Van Rie, A. (2009). Long term outcomes of antiretroviral therapy in a large HIV/AIDS care clinic in urban South Africa: A prospective cohort study. *Journal of the International AIDS Society*. doi:10.1186/1758-2652-12-38

- Sarno, J.E. (2007). *The mind body prescription: healing the body, healing the pain*. New York, NYC: Little, Brown and Company
- Schietinger, H., Sawyer, M., Futterman, D., & Rudy, D. (1999). *Helping adolescents with HIV adhere to HAART*. Adolescent HIV Initiative, Children's Hospital Philadelphia.
- Sekaran, U. (2003). *Research methods for business: A skills building approach*. New York, NY: John Wiley.
- Sendangala, S. (2011). *Factors affecting the adherence to anti-retroviral therapy by HIV positive patients treated in a community-based HIV/AIDS Care Programme in rural Uganda. A Case of Tororo*. Master of Public Health thesis, University of South Africa.
- Sharma, M. P. (2006). Orphanhood and Schooling Outcomes in Malawi. *American Journal of Agricultural Economics*, 88(5), 1273-1278.
- Shaughnessy, J. J., Zechmeister, E. B., & Zechmeister, J. S. (2012). *Research methods in psychology*. McGraw-Hill International.
- Shearer, W. T., & Hanson, I. C. (2003). *Medical management of AIDS in children*. Saunders: An Imprint of Elsevier Science.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63-75.
- Shisana, O., Rehle, T., Simbayi L. C., Zuma, K., Jooste, S., Zungu N., Labadarios, D., Onoya, D. & the Team (2014) South African National HIV Prevalence, Incidence and Behaviour Survey, 2012. Cape Town, HSRC Press.
- Shrestha, S., Sudenga, S. L., Smith, J. S., Bachmann, L. H., Wilson, C. M., & Kemp, M. C. (2010). The impact of highly active antiretroviral therapy on prevalence and incidence of cervical human papillomavirus infections in HIV positive adolescents. Bio-Medical Central. *Journal of Infectious Disease*, 10, 295.

- Sieleunou, I., & Souleymanou, M. (2009). Determinants of survival in AIDS patients on antiretroviral therapy. *Tropical Medicine and International Health*, 14(1), 36-43.
- Sigelman, C., & Rider, E. (2009). *Life-Span Human Development*. UK: Cengage Learning.
- Simon, M. (2011). *Dissertation and scholarly research recipe: Recipe for success*. Seattle, WA: Dissertation Success, LLC.
- Simons-Morton, B. (2007). Social influences on adolescent substance use. *Am J Health Behav*, 672-684.
- Sinclair, M. (2007). Editorial: A guide to understanding theoretical and conceptual frameworks. *Evidence Based Midwifery*, 5(2), 39.
- Sneed, S.D. 2008. Adolescent Communication About Sex: The Impact of Content and Comfort on Adolescent Sexual Behaviour. *Journal of HIV/AIDS Prevention in Children & Youth*, 9;1, 70-83.
- Soloway, B., & Friedland, G. (2000). Antiretroviral Failure: A Bio-psychosocial Approach NEJM Journal Watch HIV/AIDS Clinical Care.
- Somekh, B., & Lewin, C. (2011). *Theory and methods in social research*. London: Sage Publications.
- Spata, A. V. (2003). *Research methods: Science and diversity*. John Wiley and Sons, Inc.
- Steele, R. G., Nelson, T. D., & Cole, B. P. (2007). Psychosocial functioning of children with AIDS and HIV infection: Review of the literature from a socioecological framework. *J. Dev Behav Pediatr*, 28(1), 58-69.
- Steinberg, L. (2008). *Adolescence*. New York, NY: McGraw-Hill.
- Steinberg, L. (2011). *You and your adolescent: The essential guide for ages 10 to 20*. New York: Simon and Schuster.
- Taddeo, D., Egedy, M., & Frappier, J. Y. (2008). Adherence to treatment in adolescents. *Paediatr Child Health*, 13(1), 19-24.

- Tashima, K. T., & Mitty, J. A. (2006). Once-daily therapies for the treatment of HIV infection. *Current HIV/AIDS Reports 2006*, 3, 86-92. Current Science Inc.
- Terre Blanche, M., & Durrheim, K. (1999). *Research in Practice*. Cape Town: University of Cape Town Press.
- Todres, L., Galvin, K., & Dahlberg, K. (2006). Scientific Contribution. Lifeworld-led healthcare: Revisiting a humanising philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy*, 10, 53-63. doi:10.1007/s11019-006-9012-8
- Treisman, G. J., & Angelino, A. F. (2004). *The Psychiatry of AIDS: A Guide to Diagnosis and Treatment*. Department of Psychiatry and Behavioral Sciences. The John Hopkins School of Medicine, Baltimore, Maryland and London.
- Trochim, W.M.K. (2001). *Research methods knowledge base*. Cincinnati, OH : Atomic Dog Publishing.
- Tucker, J. D., Bien, C. H., Easterbrook, P. J., Doherty, M. C., Penazzato, M., Victorai, M., & Peeling, R. W. (2014). Optimal strategies for monitoring response to antiretroviral in HIV-infected adults, adolescents, children and pregnant women: A systemic review. *AIDS*, 28(Suppl. 2), S151-S160.
- Tufford, L., & Newman, P. (2010). Bracketing in Qualitative Research. *Qualitative Social Work*, 11(1), 80-96. doi: 10.1177/1473325010368316
- Turner, B. J. (2002). Adherence to Antiretroviral Therapy by Human Immunodeficiency Virus-Infected Patients. *The Journal of Infectious Diseases*, 185(Suppl. 2), S143-S151. Human Immunodeficiency Challenges; New Directions.
- UNCRC, (1989). United Nations Conventions on the Rights of the Child.
- UNAIDS. (1997). The case for expanding access to highly active antiretroviral therapy to curb the growth of the HIV epidemic. *UNAIDS point of view: October 1997*.
- UNAIDS. (2007). *AIDS Epidemic Update*

UNICEF. (2004). The framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS.

UNICEF. (2006). *Caring for children affected by HIV and AIDS*. New York, NY: UNICEF.

USC LibGuide (2014). *Organising your social science research paper: Theoretical Framework*. Guide information 2014. University of South California. <http://libguides.usc.edu/c.php?g=235034&p=1561763>

Van Dyk, A. (1999). *AIDS care and counselling*. Pinelands Cape Town: Maskew Miller Longman.

Van Dyk, A. (2012). *HIV and AIDS: Education, care and counselling: A multidisciplinary approach*. Pinelands, Cape Town: Pearson Education SA.

Van Sighem, A. I., Van de Wiel, M. A., Ghani, A. C., Jambroes, M., Reiss, P., Gyssens, I. C., Brinkman, K., Lange, J., & De Wolf, F. (2003). Mortality and progression to AIDS after starting highly active antiretroviral therapy. *AIDS*, 17, 2227-2236.

Van Wyngaard, A. (2013). Addressing the spiritual needs of people infected and affected by HIV and AIDS in Swaziland. *Journal of Social Work in End-of-Life and Palliative Care*, 9, 226-240.

Velasco-Hernandez, J. X. (2002). Could widespread use of combination antiretroviral therapy eradicate HIV epidemics? *The Lancet*, 2(8), 451-508.

Venter, F. (2006). *AIDS in Our Lives*. Treatment Action Campaign: A handbook for people living with HIV and treatment advocates in support groups, clinics and communities.

Walkenbach, J. (2015). *Excel 2016 Bible*. City, State: Wiley and Sons.

Wanjohi, N. A. (2009). *Factors influencing non-adherence to antiretroviral therapy among HIV and AIDS patients in Central Province, Kenya*. Masters dissertation, Department of Public Health, Kenyatta University.

- Wertz, F., Charmaz, K., McMullen, L. M., Josselson, R., Anderson, R., & McSpadden, E. (2011). *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research and intuitive inquiry*. New York, London: The Guilford Press.
- White, P. (2005). *Biopsychosocial medicine: An integrated approach to understanding illness*. New York: Oxford University Press.
- WHO. (2004). World Health Organization Standards for Quality HIV Care: A Tool for Quality Assessment, Improvement and Accreditation. Report of a WHO Consultation Meeting on the Accreditation of Health Service Facilities for HIV Care, 10-11 May 2004, Geneva, Switzerland.
- WHO. (2007a). World Health Organization mental health: Strengthening mental health promotion. Retrieved from <http://www.who.int/mediacentre/factsheets/fs220/en/>
- WHO. (2007b). World Health Report, 2007 – A Safer Future: Global Public Health in the 21st century.
- WHO. (2010). World Health Organization Global Report: UNAIDS report on the global AIDS epidemic, 2010. Geneva, Switzerland: World Health Organization.
- WHO. (2013a). The Voices, Values and Preference of Adolescent on HIV Testing and Counselling: Consultation for the Development of World Health Organization HIV Testing and Counselling.
- WHO. (2013b). World Health Organization HIV and Adolescents: Guidance for Testing and Counselling and Care for Adolescents Living with HIV. Recommendations for a Public Health Approach and Considerations for Policy Makers and Managers. Geneva, Switzerland.
- WHO. (2013c). Guidelines: Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for Public Health Approach. Geneva.
- Wilding, C., & Whiteford, G. (2005). Phenomenological research an exploration of conceptual, theoretical, and practical issues. *OTJR*, 25(3).

- Wiles, R. & Crow, G. (2008). Managing Anonymity and Confidentiality in Social Research: The Case of Visual Data in Community Research. ESRC National Centre for Research Methods: NCRM Working Paper Series 8/08.
- Williams, P. G., Holbeck, G. N., & Greenley, R. N. (2002). Adolescent health psychology. *J Consult Clin Psychology, 70*(3), 828-842.
- Wilson, A. M. E. (2014). Mentoring student nurses and the educational use of self: A hermeneutic phenomenological study. *Nurse Education Today, 34*, 313-318.
- Wimpenny, P. & Gass, J. (2000). Interviewing in Phenomenology and Grounded Theory: Is there a Difference? *Journal of Advanced Nursing, 2000, 31*(6), 1485-1492.
- Wu, N., Slocum, S., Comulada, S., Lester, P., Semaan, A., & Rotheram-Borus, M. J. (2008). Adjustment of adolescents of parents living with HIV. *Journal of HIV/AIDS Prevention in Children and Youth, 9*(1), 34-51. doi:10.1080/10698370802124076
- Zechmeister, J., Zechmeister, E., & Shaugnessey, J. (2000). *Essentials of research methods in psychology*. New York, NY: McGraw-Hill Education.
- Zikmund, W., & Babin, B. (2012). *Essentials of marketing research*. New York: Cengage Learning.
- Zuurmond, M. (2008). *Adherence to ARVs – challenges and successes: A consultation with CAFOD partners and members of the Catholic HIV and AIDS Network (CHAN), Nigeria*. Zambia.

## APPENDIX A: REQUEST FOR PERMISSION TO HOSPITAL



**health and  
social development**  
Department: Health and Social Development  
GAUTENG PROVINCE

Tembisa Hospital  
Clinical Psychology Department  
011 923 2210

03 July 2012

The Chief Executive Officer, Dr S Mfenyana  
The Cluster Allied Clinical Executive; Dr N Socikwa  
The Manager Masakhane Clinic, Sr Violet Ramalapa  
Private Bag X7  
Olifantsfontein  
1665

### REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY AT TEMBISA HOSPITAL

I hereby request your permission to conduct a qualitative research study at your premise.

The title of my study is:

***A STUDY OF THE IMPACT OF LONG-TERM HIGHLY ACTIVE ANTIRETROVITAL TREATMENT ON THE QUALITY OF LIFE OF ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE***

The method of data collection will be individual interviews conducted by myself. Considering the high levels of non-adherence on treatment by adolescents at Masakhane, I am hoping this research will add value to the overall treatment adherence, thereby reducing drug resistance and early fatalities as a result of non-adherence.

This research is for my Doctoral Studies at the University of South Africa. This research is a long term project and will take place over a five year period. I will require support from the Hospital in terms of time off, one half day off once per month for Supervision purposes at the university. Furthermore, I will require confidential access to some patients' files and interviews with such patients as part of the research. Consent from identified patients will be sought at all times.

This research will not interfere too much with my work as I study over the weekends and after hours.

Hoping my application will receive favourable consideration.

Kind Regards,

Submitted by : Ms Musa MaseTshaba  
Clinical Psychologist

Date 02 July 2012

## APPENDIX B: PERMISSION GRANTED TO CONDUCT RESEARCH



DEPARTMENT OF HEALTH  
TEMBISA PROVINCIAL TERTIARY HOSPITAL

Enq. : Dr TN Socikwa  
☎ : 011 923 2053 / 2171  
☎ : 011 926 2719  
E-mail: [Nontobeko.Socikwa@gauteng.gov.za](mailto:Nontobeko.Socikwa@gauteng.gov.za)

Date: 03 July 2012

### TO WHOM IT MAY CONCERN

This serves to confirm that permission is granted for Ms Musa MaseTshaba to conduct a research study at Tembisa Provincial Tertiary Hospital, pending approval of the actual research proposal by the UNISA's ethics committee.

Thank you.

  
Dr TN Socikwa  
Senior Clinical Executive- Allieds  
Tembisa Provincial Tertiary Hospital

Postal Address: HEALTH REGION B: EKURHULENI AND SEDIBENG  
PRIVATE BAG X7, OLIFANTSFONTEIN, 1665  
Physical Address: CORNER OF FLINT MAZIBUKO AND NAMANE DRIVE TEMBISA

## APPENDIX C: ASSENT FORM

### RESEARCH PARTICIPANT ASSENT FORM

#### TEMBISA HOSPITAL

I, \_\_\_\_\_, the **client/patient**, hereby give assent to **Musa MaseTshaba**, who is a Clinical Psychologist, to conduct personal interview with me.

This interview is for the purpose of a Research Study for Doctoral Studies titled: **EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE**

- I will provide my personal experiences to the best of my knowledge relating to HAART.
- I have the right to terminate my involvement in this research as I may so desire.
- The Researcher will treat this information as confidential and your names will not be published.
- The outcome of the research will be in a form of Thesis which will be submitted to the University of South Africa.
- I further acknowledge that I was duly informed that the interview will be recorded for research purpose.

I, \_\_\_\_\_, understand and accept the above conditions.  
**Client/Patient**

\_\_\_\_\_  
**Musa MaseTshaba (Researcher)**

Date (DD) \_\_\_\_\_ (MMM) \_\_\_\_\_ (YYYY) \_\_\_\_\_

## APPENDIX D: CONSENT FORM

### RESEARCH PARTICIPANT CONSENT FORM

#### TEMBISA HOSPITAL

I, \_\_\_\_\_, the **client/patient**, hereby give consent to **Musa MaseTshaba**, who is a Clinical Psychologist, to conduct personal interview with me.

This interview is for the purpose of a Research Study for Doctoral Studies titled:

#### **EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE**

- I will provide my personal experiences to the best of my knowledge relating to HAART.
- I have the right to terminate my involvement in this research as I may so desire.
- The Researcher will treat this information as confidential and your names will not be published.
- The outcome of the research will be in a form of Thesis which will be submitted to the University of South Africa.
- I further acknowledge that I was duly informed that the interview will be recorded for research purpose.

I, \_\_\_\_\_, understand and accept the above conditions.  
**Client/Parent**

\_\_\_\_\_  
**Musa MaseTshaba (Researcher)**

Date (DD) \_\_\_\_\_ (MMM) \_\_\_\_\_ (YYYY) \_\_\_\_\_

## APPENDIX E: INTERVIEW GUIDE FOR INDIVIDUAL ADOLESCENTS

### EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

**Objective:** To explore the experiences of the adolescents of the Masakhane Clinic regarding the experiences of the adolescents who are on HAART.

**Method:** The questions are open ended in nature. Verbal, face-to-face interviews conducted.

**Gender:** \_\_\_\_\_ **Age:** \_\_\_\_\_  
**School Grade:** \_\_\_\_\_ **Place:** \_\_\_\_\_  
**Period on HAART:** \_\_\_\_\_

**Interviewer:** Duration since HAART was started.

**Interviewer:** When did you start taking HAART?

**Interviewer:** The treatment you are taking, what is it for?

**Interviewer:** Do you know what the treatment is for?

**Interviewer:** What does taking such medication mean to you?

**Interviewer:** What is the meaning of being in HAART treatment for you?

**Interviewer:** Who have you disclosed your status to?

**Interviewer:** What are the challenges you face being on HAART?

**Interviewer:** What do you think are the challenges that adolescents experience as a result of being on HAART?

**Interviewer:** What do you think are the benefits you experience as a result of being on HAART?

**Interviewer:** What are the coping mechanisms and strategies you use as a result of being on HAART?

**Interviewer:** Would you like to add any other comment that was not addressed by the questionnaire?

**THANK YOU**

# APPENDIX F: INTERVIEW GUIDE FOR PARENTS, GUARDIANS AND CAREGIVERS

## EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

**Objective:** To explore the experiences of the parents, guardians and caregivers of adolescents receiving HAART at Tembisa.

**Method:** The questions are open ended in nature. Verbal, face-to-face interviews conducted.

**Gender:**\_\_\_\_\_ **Age:** \_\_\_\_\_ **Employment :**\_\_\_\_\_

**Relationship to Adolescent:**\_\_\_\_\_ **Place:** \_\_\_\_\_

**Interviewer:** Duration since HAART was started.

**Interviewer:** When did the adolescent start taking HAART?

**Interviewer:** Does the adolescent know what the treatment he or she is taking is for?

**Interviewer:** As a parent, what has been your experience on dealing with adolescents on HAART?

**Interviewer:** How was the information of his or her status delivered to her/her?

**Interviewer:** How did he or she respond to the information of her/her status?

**Interviewer:** What do you think the meaning of being in HAART treatment for her/him?

**Interviewer:** What are the challenges you face as a result of his or her being on HAART?

**Interviewer:** What do you think are the challenges that adolescents experience as a result of being on HAART?

**Interviewer:** What do you think are the benefits he or she experience as a result of being on HAART?

**Interviewer:** What are the coping mechanisms and strategies he or she uses to cope with being on HAART?

**Interviewer:** Would you like to add any other comment that was not addressed by the questionnaire?

THANK YOU

# APPENDIX G: INTERVIEW GUIDE FOR FOCUS GROUP OF ADOLESCENT PARTICIPANTS

## EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

**Objective:** To explore the experiences of the adolescents in a focus group at the Masakhane Clinic regarding the experiences of the adolescents who are on HAART.

**Method:** The questions are open ended in nature. Verbal, face-to-face interviews conducted.

Focus group interview with adolescents attending HAART Clinic at Masakhane Clinic, Tembisa Hospital, Tembisa Township (ages between 12 and 19 years old).

### **Group Members Biographical Details:**

Gender: \_\_\_\_\_ Age: \_\_\_\_\_ School Grade: \_\_\_\_\_  
Period on HAART: \_\_\_\_\_ Place: \_\_\_\_\_  
Number in a Group: \_\_\_\_\_ Duration of session: \_\_\_\_\_

### **Focus Group Introduction and Welcome Message**

Thanks for agreeing to be part of the focus group. We/I appreciate your willingness to participate.

### **INTRODUCTIONS:** Moderator

**PURPOSE OF FOCUS GROUPS** .We/I have been asked by \_\_\_\_\_to conduct the focus groups. The reason we are having these focus groups is to find out\_\_\_\_\_. We/I need your input and want you to share your honest and open thoughts with us/me.

### **SETTING OF GROUND RULES**

1. WE/I WOULD LIKE YOU TO DO THE TALKING: We/I would like everyone to participate. I may call on you if I haven't heard from you in a while.

2. THERE ARE NO RIGHT OR WRONG ANSWERS: Every person's experiences and opinions are important. Speak up whether you agree or disagree. We/I want to hear a wide range of opinions.

3. WHAT IS SAID IN THIS ROOM STAYS HERE: We/I want folks to feel comfortable sharing when sensitive issues come up.

4. WE WILL BE TAPE RECORDING THE GROUP We/I want to capture everything you have to say. We/I don't identify anyone by name in our report. You will remain anonymous.

**Group Member 1:**

**Group Member 5:**

**Group Member 2:**

**Group Member 6:**

**Group Member 3:**

**Group Member 7:**

**Group Member 4:**

**Group Member 8:**

(depending on number of group members)

**Interviewer:** When did you start taking HAART?

**Interviewer:** The treatment you are taking, what is it for?

**Interviewer:** Do you know what the treatment is for?

**Interviewer:** What does taking such medication mean to you?

**Interviewer:** How has your experience been on HAART?

**Interviewer:** What is the meaning of being in HAART treatment for you?

**Interviewer:** Who have you disclosed your status to?

**Interviewer:** What are the challenges you face being on HAART?

**Interviewer:** What do you think are the challenges that adolescents experience as a result of being on HAART?

**Interviewer:** What are the benefits you experience as a result of being on HAART?

**Interviewer:** What are the coping mechanisms and strategies you use as a result of being on HAART?

**Interviewer:** Would you like to add any other comment that was not addressed by the questionnaire?

THANK YOU

## APPENDIX H: INTERVIEW GUIDE FOR HEALTH CARE PROFESSIONALS

### EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

**Objective:** To explore the experiences of the multidisciplinary team of the Masakhane Clinic regarding the experiences of the adolescents who are on HAART.

**Method:** The questions are open ended in nature. Participants can write as much as they can and make use of an extra page should they wish to.

#### SECTION A: PROFILES OF PARTICIPANTS

1. Gender

	Female	Male

2. Age

Years	<25	25 to 30	30 to 35	35 to 40	40 to 45	45 to 50	55 to 60	60 to 65	≥65

3. Qualification (Please tick highest you have)

	Matric	M + 3	M + 4	Postgraduate qualification (Please specify)

4. Profession of the person filling the form

	Soc Worker	Med Doctor	Dietician	Nurse	Physiotherapist	Other (please specify)

5. Experience in the profession (in years):

Years	<5	5 to 10	10 to 15	15 to 20	20 to 25	25 to 30	30 to 35	30 to 35	30 to 35	≥35

6. Length of time since giving services in a HAART roll-out centre:

Years	<5	5 to 10	10 to 15	15 to 20	20 to 25	25 to 30	30 to 35	30 to 35	30 to 35	≥35

7. Length of time since you started at the Masakhane Clinic:

Years	<5	5 to 10	10 to 15	15 to 20	20 to 25	25 to 30	30 to 35	30 to 35	30 to 35	≥35

8. Did you receive any HAART- specific specialised training?

	Yes	No

If 'Yes':

8.1 what training? \_\_\_\_\_

8.2 at which institution? \_\_\_\_\_

If 'No', please explain how you obtained the skill and/or knowledge you are applying in your work in this environment.

\_\_\_\_\_

**SECTION B: OPEN-ENDED QUESTIONS**

- What has been your experience on dealing with adolescents on HAART?

\_\_\_\_\_  
\_\_\_\_\_

- Please explain the challenges faced by the adolescents on HAART

\_\_\_\_\_  
\_\_\_\_\_

- Please enlighten on the benefits experienced by the adolescents on HAART

\_\_\_\_\_  
\_\_\_\_\_

- Please spell out the coping mechanisms and strategies being used by the adolescents on HAART

\_\_\_\_\_  
\_\_\_\_\_

- Please comment on any issues that were not addressed in the questionnaire

\_\_\_\_\_  
\_\_\_\_\_

THANK YOU

# APPENDIX I: SAMPLE INTERVIEWS

## HEALTH CARE PROFESSIONAL PARTICIPANT 11

### EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

#### Objective:

To explore the experiences of the multidisciplinary team of the Masakhane Clinic regarding the experiences of the adolescents who are on HAART.

#### Method:

The questions are open ended in nature. Participants can write as much as they can and make use of an extra page should they wish to.

### SECTION A: PROFILES OF PARTICIPANTS

#### 1. Gender

	Female	Male
		X

#### 2. Age

Years	<25	25 to 30	30 to 35	35 to 40	40 to 45	45 to 50	55 to 60	60 to 65	≥65
		X							

#### 3. Qualification (Please tick highest you have)

	Matric	M + 3	M + 4	Postgraduate qualification (Please specify)
		X		NURSING DIPLOMA

#### 4. Profession of the person filling the form

	Soc Worker	Med Doctor	Dietician	Nurse	Physiotherapist	Other (please specify)
				X		

#### 5. Experience in the profession (in years):

Years	<5	5 to 10	10 to 15	15 to 20	20 to 25	25 to 30	30 to 35	30 to 35	30 to 35	≥35
	X									

#### 6. Length of time since giving services in a HAART roll-out centre:

Years	<5	5 to 10	10 to 15	15 to 20	20 to 25	25 to 30	30 to 35	30 to 35	30 to 35	≥35
	X									

#### 7. Length of time since you started at the Masakhane Clinic:

Years	<5	5 to 10	10 to 15	15 to 20	20 to 25	25 to 30	30 to 35	30 to 35	30 to 35	≥35
	X									

#### 8. Did you receive any HAART- specific specialised training?

	Yes	No
	X	

If 'Yes':

8.1 what training?

8.2 at which institution?

If 'No', please explain how you obtained the skill and/or knowledge you are applying in your work in this environment.

I went for HIV course- Basic HIV training; Adherence Counselling; Management of HIV; Guidelines on PMTCT- Prevention of mother to child transmission. Pre-post counselling and debriefing.

## **SECTION B: OPEN-ENDED QUESTIONS**

- **What has been your experience on dealing with adolescents on HAART?**

Dealing with adolescents taking ARVs can be both a positive and negative. It is positive when you see the adolescent who was so sick improving and even gaining weight. You somehow feel that you have made a difference in the life of this child. It can also be frustrating when your hands are tied by the adolescent and their family themselves when adherence is not as it should be and you know that medically, this child's life could be much better but cooperation is not forthcoming and there are different stories all the time.

- **Please explain the challenges faced by the adolescents on HAART**

Most adolescents find it difficult to accept their statuses due to lack of understanding how they contracted HIV. Most parents find it hard to explain to their children about HIV and treatment. Stigma and discrimination affect them because their peers don't understand and how one can contract HIV, so it is hard for them to accept their statuses.

- **Please enlighten on the benefits experienced by the adolescents on HAART**

A better lifestyle and improved healthy lifestyle-immune system. Good and quality knowledge in understanding HIV and ART. Reduction in infection-High CD4-count and low viral load.

- **Please spell out the coping mechanisms and strategies being used by the adolescents on HAART**

Through continuation of sessions on counselling and support through support groups, they learn to accept and understand HIV and how to live with HIV and adhere to treatment. Changes are observed through the outcomes brought forward by adolescents on HAART through activities done by them, eg. drama, poems and singing.

- **Please comment on any issues that were not addressed in the questionnaire**

Most adolescents who default treatment are those who don't attend support groups and they have not been told why they take treatment. At an early stage, anger of 9-12 child and to be told about their statuses and by then they learn to accept and know about their health.

**END**

## HEALTH CARE PROFESSIONAL PARTICIPANT 8

### EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

**Objective:** To explore the experiences of the multidisciplinary team of the Masakhane Clinic regarding the experiences of the adolescents who are on HAART.

**Method:** The questions are open ended in nature. Participants can write as much as they can and make use of an extra page should they wish to.

#### SECTION A: PROFILES OF PARTICIPANTS

##### 1. Gender

	Female	Male
	X	

##### 2. Age

Years	<25	25 to 30	30 to 35	35 to 40	40 to 45	45 to 50	55 to 60	60 to 65	≥65
						X			

##### 3. Qualification (Please tick highest you have)

	Matric	M + 3	M + 4	Postgraduate qualification (Please specify)
			X	Registered Nurse and Phlebotomist

##### 4. Profession of the person filling the form

	Soc Worker	Med Doctor	Dietician	Nurse	Physiotherapist	Other (please specify)
				X		Phlebotomist

##### 5. Experience in the profession (in years):

Years	<5	5 to 10	10 to 15	15 to 20	20 to 25	25 to 30	30 to 35	30 to 35	30 to 35	≥35
			X	X						

##### 6. Length of time since giving services in a HAART roll-out centre:

Years	<5	5 to 10	10 to 15	15 to 20	20 to 25	25 to 30	30 to 35	30 to 35	30 to 35	≥35
		X								

##### 7. Length of time since you started at the Masakhane Clinic:

Years	<5	5 to 10	10 to 15	15 to 20	20 to 25	25 to 30	30 to 35	30 to 35	30 to 35	≥35
		X								

##### 8. Did you receive any HAART- specific specialised training?

	Yes	No
		X

If 'Yes':

8.1 what training?

8.2 at which institution?

If 'No', please explain how you obtained the skill and/or knowledge you are applying in your work in this environment.

I have been working with HIV blood testing for the past 10years; I am now employed by National Health Laboratory Services as a Phlebotomist but I am a professional registered nurse by training. I have been a nurse for over twenty years.

## **SECTION B: OPEN-ENDED QUESTIONS**

- **What has been your experience on dealing with adolescents on HAART?**

Dealing with adolescents on HAART my job is to draw blood from them and so I don't engage so much in conversations with them. Whether the results comes back positive or negative, I don't get to disclose to them because that part of telling them whether they are HIV positive or negative, falls on the shoulders of the Doctors. Sometimes you find adolescent who ask questions about why are you taking my blood and I simply tell them to test their blood and then refer them back to the Doctors. I do see some adolescents who are struggling with their status and I do explain the basics about blood and then refer accordingly for further clarity.

- **Please explain the challenges faced by the adolescents on HAART**

As a person who draws their blood for testing, I observe parents not informing their children why they are being tested. They tell the adolescent it is for flu, etc. As a professional, I am not allowed to tell the child why I am taking their blood, all I say is that the blood is taken for testing. Partial or no disclosure is the challenge I have observed. These children then become angry when they find out later, it is better to tell them the truth.

- **Please enlighten on the benefits experienced by the adolescents on HAART**

Fewer HIV related illnesses.  
CD-4 count rise and remain above the baseline count.  
Viral load become undetectable.  
Support from families, health workers, etc.

- **Please spell out the coping mechanisms and strategies being used by the adolescents on HAART**

I have also seen a few adolescents who know they are HIV positive, and they are better cooperative during the blood test. Some even state they have protected sex. Anger-they fight a lot with parents, especially if they do not inform them accordingly of their HIV status. Playing soccer, and the support group run by the Social Workers, helps the children to accept their status.

- **Please comment on any issues that were not addressed in the questionnaire**

**THANK YOU**

## **PARENTS, GUARDIANS AND CAREGIVERS PARTICIPANT B**

### EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

**Objective:** To explore the experiences of the parents, guardians and caregivers of the Masakhane Clinic regarding the experiences of the adolescents who are on HAART.

**Method:** The questions are open ended in nature. Verbal, face-to-face interviews conducted.

**Gender of adolescent:** Female

**Age of Adolescent:** 14 years

**Employment:** Student-Enrolled Nurse

**Relationship to Adolescent:** Step-mom

**Place:** Tembisa Hospital

**Interviewer:** **Duration since HAART was started.**

**Participant:** She started taking treatment in 2010. I am her step-mom, and I recently, last year, I took her to come and stay with myself and her dad. She did start on treatment in 2010, but she was staying with her paternal grandmother and did not take treatment so well. Her mother passed away in some six years back and she stayed with her paternal grandparents and since last year, she is with us, her dad and I and we have another child.

**Interviewer:** **Does the adolescent know what the treatment he or she is taking is for?**

**Participant:** She knows because I made sure I inform her myself. I also brought her to the hospital so that the doctors can talk to her. She seems to understand the one moment and the next she is something else. She throws away the tablets. I don't know what to do sometimes.

**Interviewer:** **How does her father take part in this treatment?**

**Participant:** You know how men are. He is not involved at all. He does not even know how many tablets she has to take or where the hospital is. I was the one who suggested we take her in to stay with us. She is 14 years and only now she is in grade 4 because she started school late after I insisted she gets registered at school. Her father just left her in the village in Limpopo and would see her once a year and he did not even ask whether she goes to school or not. There is another sister, older to this one, but luckily she is not HIV positive and she is at least in high school.

**Interviewer:** **How was the information of his or her status delivered to her/her?**

**Participant:** She used to be sick a lot. She would be in and out of hospital for many times. It was during one of her hospital visit that she was told she was sick and must take treatment, but I am not sure she was told it was HIV sickness.

**Interviewer:** **How did he or she respond to the information of her/her status?**

It is hard to know how she feels but I suspect she is not ok with it because sometimes she does not take her medication. But now she knows and I am sure because I am the one who takes her to the clinic for blood tests and treatment collection but still she does not drink her

treatment well. Sometimes I see her throwing the tablets into the kitchen sink and when I talk to her she just keeps quiet.

**Interviewer: What do you think is the meaning of being in HAART treatment for her/him?**

**Participant:** I have learnt what HIV is as part of my studies as an Enrolled Nurse, I know treatment will keep her healthy and well. Sometimes I look at her and I see how much well she looks but when we get to hospital and they take her blood and they tell us her CD4 count is very high and I become worried.

**Interviewer: What are the challenges you face as a result of her being on HAART?**

**Participant:** Sometimes when I shout at her she thinks I don't love her because she is not my child. I have a six year old with her father and so we have two children at home, and it becomes difficult to talk with her.

**Interviewer: What do you think are the challenges that adolescents experience as a result of being on HAART?**

**Participant:** Her life is not the same as that of other children. She has to take this treatment every day for the rest of her life, I think that is not so easy especially for children you see. She was sick for a long time and she is behind when it comes to school grades and today she did not go to school because she must come to the hospital, it is not so easy sometimes.

**Interviewer: What do you think are the benefits he or she experience as a result of being on HAART?**

**Participant:** Treatment will help her to not be sick,

**Interviewer: What are the coping mechanisms and strategies he or she uses to cope with being on HAART?**

**Participant:** This one, I am not sure,

**Interviewer: What is your experience regarding your interaction with adolescent on HAART?**

**Participant:** Well, this child has been through so much, losing her mother and not going to school alright. Now I am in her life because I am with her dad, and her dad makes it difficult because he seems like he does not care and I must be the mom and I am not her real mom. Sometimes I feel I am alone on this and if I get tired, she has no one to help her. As a student nurse, I understand medication but it is hard to make the people I live with to help them understand and, ja man.

**Interviewer: Would you like to add any other comment that was not addressed by the questionnaire?**

**Participant:** No.

**THANK YOU**

## FOCUS GROUP OF ADOLESCENT PARTICIPANTS

### EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

**Objective:** To explore the experiences of the adolescents in a focus group at the Masakhane Clinic regarding the experiences of the adolescents who are on HAART.

**Method:** The questions are open ended in nature. Verbal, face-to-face interviews in a group setting were conducted.

#### Focus Group Participants

Three adolescents took part in the focus group

FGAPA	FGAPB	FGAPC
<b>Age</b>	<b>Age</b>	<b>Age</b>
17 years	14 years	16 years
<b>Gender</b>	<b>Gender</b>	<b>Gender</b>
Male	Male	Female
<b>School Grade</b>	<b>School Grade</b>	<b>School Grade</b>
Grade 10	Grade 7	Grade 9
<b>Duration on HAART</b>	<b>Duration on HAART</b>	<b>Duration on HAART</b>
Since 2006	Since 2005	Since 2008

#### Interviewer: When did you start taking HAART?

FGAPC: Mmmhh, he-e, I do not know when I started, I just remember drinking them, I was still very small. But the treatment card will show, *'takes out treatment card'*;

FGAPB: I also don't remember exactly the date but I know I was still small and before I even started school.

FGAPA: I started taking the treatment in 2006.

#### Interviewer: The treatment you are taking, what is it for?

FGAPA: I know I am taking the treatment for HIV because I am HIV positive. It is not easy for me to talk about this HIV status, I respect and I know I am HIV positive and since 2006 I started taking this treatment. I do not want to go there, I do not like taking about it *'he started crying-then we had a moment of quietness.'*

#### Interviewer: Is it too painful for you to talk about this?

FGAPA: Ya, *'head bowed down, looking down'*, maybe you can ask the others.

FGAPC: Me, I know that I am HIV positive and I must take this treatment. You see, my Mom also has this HIV and she took me to the hospital one day. When we were at the hospital she said I must wait for her by the corner she is coming back she is going to buy me some sweets. She never came back. I was small and now I am sixteen and a half years old and she has not come back from the sweets. I have been staying in a Children's Home, and I have since learnt that my mom has three other children and she does not stay with any

of her children. I have visited her before and she keeps saying she will come and fetch me, but now I don't think she will come. You see, she is also sick, I think it is the HIV and she does not work.

**Interviewer: And you B, (referring to the 14 year boy) do you know what the treatment you are taking is for?**

FGAPB: I know I have this illness, HIV and if I don't take treatment I will fall sick. My mom passed away and I stay with my aunt. I know that I am taking treatment for HIV, my aunt told me about it.

**Interviewer: How has your experience been on HAART?**

FGAPA: The treatment is okay, it's just that the tablets are hard to swallow, they are bitter when you have to swallow and it is not nice. I used to drink many tablets, maybe 10 tablets two times a day. I had to swallow all of them like that. I used to just put all of them in my mouth at the same time and drink water but some of them would be stuck on the throat '*indicating the throat with her hand*', and it was hard to drink but I must drink because I want to be alive and grow up and be a chef.

FGAPB: Me too, '*nam futhi, aya baba lamapilisi*', so it was difficult but now I don't take as many tablets as before, now I take two tablets at 7 o'clock in the morning and 7 o'clock at night. Now it is easier to take the tablets.

FGAPC: Now I only have to take one tablet per day and it does not get stuck on my throat and it is easier to take the tablets. My weight has increased and the tablet that you take once a day, you must weigh a certain weight before they can give you that tablet, so because I was drinking the many tablets before and I am gaining weight so the Doctors at the clinic decided I can start taking the one tablet per day.

**Interviewer: What about you, you are quiet, how is this treatment for you? (referring to the 17 year old boy)**

FGAPA: This treatment, I don't like it and I don't like talking about it. My grandmother told me about I am HIV positive. I was always sick, attending hospital in and out frequently. Grandmother was told by the doctors about my HIV status and they tried to withhold information from me and I asked them to be honest with me because it is my life after all. I even asked the doctors though they were reluctant to tell me but finally I persuaded them to tell me and they told me. My mom died of this illness and she left me when I very small. Many people are dying of this illness that is why I don't like talking about it. You see I take the medication, three tablets at 7 o'clock at night.

**Interviewer: What does taking such medication mean to you?**

FGAPB: The treatment is important because it keeps us healthy. So taking the treatment means we can stay alive.

FGAPA: For me, it reminds me I am sick and '*keeps quiet and changes topic*', can I leave?

**Interviewer: I have two more questions, and I would appreciate your opinion, but yes you can leave if it gets too much for you, I see this is not comfortable for you.**

FGAPA: Ok, you see this disease, my Mom died because of this disease and so I must take medication so I can stay alive.

**Interviewer: What are the challenges you face being on HAART?**

FGAPB: The problem was the swallowing of the bitter tablets but now that problem is gone.

FGAPA: For me, you see I have friends and I stay out late hanging with my friends on the streets chilling and sometimes time flies by and I come home and the time for medicine is gone. My grandmother will tell me I am late and what what and this is making stress for me and I smoke dagga to make the stress go away.

I also have a girlfriend and we must use the condom and I must use the condom because I don't talk about the HIV with her and I don't know if she has the HIV or not (*looks at his watch and asks to be excused*).

**Interviewer: Thank you for your time, I appreciate the information you shared.**

FGAPA: Sure sure guys, see you next time neah (*looking at the two participants*).

FGAPC and FGAPB: sharp '*waving their hands in unison*'

**Interviewer: What are the benefits you experience as a result of being on HAART?**

FGAPB: I know I am healthy because of the medication, so it helps me a lot.

FGAPC: I am also ok, I know if I was not taking the medication I would not be like this, maybe I would be sick.

**Interviewer: What are the coping mechanisms and strategies you use as a result of being on HAART?**

FGAPC: At school, I have some friends and some of them are taking treatment and we are like ok, we don't have problems. But at the Children's Home, we do Bible reading and we each read a verse before we go to sleep and we go to church on Sundays so the praying helps a lot. The other children in the home are also taking medication so we all come together at 7 o'clock to take medication and we remind each other when it is time for medication. The house Mother also encourages us and support us, she makes sure there is food to eat before we take the medication.

FGAPB: My friend has some dogs next door, so I spend a lot of time with him looking after the dogs and I don't always remember that I am HIV positive and my friends are nice about my HIV positive status. You know many people take medication so it is like it is a normal thing around our street.

**Interviewer: Would you like to add any other comment that was not addressed by the questionnaire?**

FGAPC: No,

FGAPB: Nuh,

**THANK YOU**

## ADOLESCENT PARTICIPANT F

### EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE

**Objective:** To explore the experiences of the adolescents of the Masakhane Clinic regarding the experiences of the adolescents who are on HAART.

**Method:** The questions are open ended in nature. Verbal, face-to-face interviews conducted.

**Gender:** Female                      **Age:** 18 years                      **School Grade:** 09  
**Period on HAART:** **Since** October 2007                      **Place:** Tembisa Hospital

**Interviewer:** **When did you start taking HAART?**

**Participant:** I started taking treatment in October 2007. Initially, I was very sickly and at some point I had to be taken to the hospital you see. When I was in hospital, they drew my blood to have it tested and I was given treatment at the hospital. When I was discharged, I had to continue taking treatment.

**Interviewer:** **The treatment you are taking, what is it for?**

**Participant:** *(avoiding eye contact—looking at the ceiling and walls)*, I was still very young, my grandmother just told me I must drink medication in the morning and in the evening. You see, she would always remind me to take my medication and I always took my medication on time and every day when I was small. I did not know what the medication was for, I just drank it because my grandmother told me to.

But when I was in Grade 6, I gradually pieced together the story of me drinking tablets so many times. I started reading my hospital file when we went to fetch my treatment and that is how I learnt that I am drinking medication for HIV and AIDS and I discovered I am HIV positive but I just left it there, I did not talk to anyone or ask anyone about it.

Then when I started having my periods, I did not understand all this blood business and I was careless looking after my blood stained panties. One day, my grandmother was very angry with me because of my carelessness with my panties during my periods and she just shouted '*you will make us all sick with your sickness because of this blood of yours*', so I was very confused and I asked her what she was talking about. She just shouted at me in front of all my cousins and I was so shocked. I think I must have been about 15 or 16 years old when this happened, I was angry and wondered why she did not tell me this before.

**Interviewer:** **What does taking such medication mean to you?**

**Participant:** Drinking my medication helps me because I am not so sick anymore like before and my body *(you see—pointing at her body from head to toe, with a faded smile)*, my body looks healthy and I am ok. My health has improved.

**Interviewer:** **What are the challenges you face being on HAART?**

**Participant:** My problem with drinking this medication is that sometimes I forget, especially in the mornings. I take my medication at 07:00 in the morning and at 19:00 in the evening. The morning dose is a bit of a problem because sometimes I am bathing at that time and so I end up taking medication a bit later. Sometimes, because I am in a rush in the morning, I am not able to

drink. So I asked the Clinic Dr to please put me on the treatment which I take only once, if I take that one in the evening only, I think it will be better and easier for me because I don't have forgetting problems in the evening like I do in the morning (Fixed-dose combination).

Because of my sickness when I was younger, one time I stayed in hospital for two months and I missed out so much from school and I had to repeat Grade 3. I also repeated Grade 5 and I am only doing Grade 09 now, and most people my age are finishing Matric. So I sometimes feel that this sickness makes me slow at school.

**Interviewer:** I notice your file says you are 3 months pregnant, how do you feel about that?

**Participant:** *(some sniffles, pauses before responding, teary eyed)*. It is true, you see, I now stay with my Aunt, my mother's older sister. My mother passed away when I was small, and I then I had to stay with my grandmother and in 2012 I asked to come stay with my Aunt in Tembisa. My grandmother stays in Mpumalanga. I am scared of my Aunt and so I don't talk much with her about life issues and problems. Sometimes I wish my mother was alive, at least I would know certain things unlike now.

**Interviewer:** Things like what?

**Participant:** Things like getting pregnant. I did not think I would get pregnant when I had sex with my boyfriend.

**Interviewer:** In Life Orientation at school, don't they teach you about sex?

**Participants:** They teach us about sex and HIV and AIDS, but if you have an adult that you talk to at home, it is better. My aunt is not approachable and when I have problems I rather speak to my friends than my aunt. She likes shouting a lot.

**Interviewer:** How much can your friends tell you about life problems?

**Participant:** My friends are helpful sometimes because, you see, like now, I talked to them about pregnancy and they talk to their moms about it and they come back to me to tell me to go to the hospital.

**Interviewer:** Pregnancy means there was no condom use, not so.

**Participant:** Yes, the thing is my boyfriend, but he is not my boyfriend anymore. We broke up before I found out I was pregnant, but I told him I am pregnant and he says it is not his baby and I am so hurt and feeling bad. My ex-boyfriend did not want to use a condom. I would tell him to use a condom but he refused, so I just ended up just agreeing because I did not want to lose him. The problem is that he has so many girlfriends and he is always having so many girlfriend and I sometimes suspect he is HIV positive so we are all the same and it does not matter you see. Sometimes I give up on my life and I feel it does not matter. I feel so hopeless and I thing dying would be better, like in the beginning of the year, I decided I wanted to die and I took an overdose of my ARVs only to wake up the next day and I am still alive. So my friend told me the ARVs don't kill, they are to help me with my life and not for dying.

**Interviewee:** Have you had another thought of killing yourself since your attempt?

**Participant:** Not anymore, I feel bad for trying to kill myself, so I have not tried again. So, I also talk to my brother, he is older than me but he does not always help. He stays in a shack in Ivory Park and he uses Nyaope. He is not very helpful and not reliable. My aunt does not like him and she does not let him visit us a lot. He does piece jobs sometimes and makes money to buy nyaope.

**Interviewer: Do you know your brother's HIV status?**

**Participant:** He is older than me. He is 27 years old and he is HIV negative. He is actually my half-brother from my mother's side. We share a mother but I don't know his father and I don't know my own father. They tell me my father died whilst my mother was pregnant with me and I think this is how I got my HIV from my mother.

**Interviewer: How do you feel about your life, considering your HIV status and pregnancy, how will this impact on your schooling?**

**Participant:** It is a tough life. I feel so hopeless and I just want to give up on my own life. I doubt I will even pass Grade 9. I am 18 years old and in Grade 9. I will fail Grade 9 because I don't really have a very easy life. I stay with my aunt and her four children and her husband and life is not so nice for me. She looks after me but it is not the same. Sometimes I feel I want to go back to my grandmother in Mpumalanga and I have not seen my Mpumalanga relatives since I came to stay with my aunt. My aunt does not like our relatives in Mpumalanga so when I am here, I don't talk to her about anything that relates to Mpumalanga.

Next year when the baby comes, who will look after the baby when I go to school? This school issue, I doubt I will finish school. My life is a bit mixed up

**Interviewer: What are the coping mechanisms and strategies you use as a result of being on HAART?**

**Participant:** I just talk to my friends.

**Interviewer: You will need to talk to the Antenatal people about the HIV and pregnancy so that they will help you with treatment so you can prevent mother-to-child transmission and the sooner the better before pregnancy grows further. Also, I would also like to speak with your aunt, so I can get a perspective from her side how she sees the ARV treatment and you. Would you be ok with that?**

**Participant:** Will you tell her what I just told you?

**Interviewer: No. I won't tell her what we discussed, it would be better for you to tell her yourself or if you want me to tell her, you will have to give me permission and we agree to a meeting for you and her to talk together in my presence, otherwise, I would not tell her. I would like to know what she thinks and your social support, things like that.**

I will come back next week to start with the once a day tablet, they said I must bring my aunt, so when we come we will also come and see you, maybe next week or that other week if my aunt agrees.

**Interviewer: Would you like to add any other comment that was not addressed by the questionnaire?**

**Participant:** Nothing else.

**END**

## ADOLESCENT PARTICIPANT G

### Biographical Information

Gender : Male  
Age : 19 years  
Race : African  
Level of education : Technikon  
Accompanied by : Maternal Aunt  
Place of interview : Tembisa Hospital  
Period on HAART : since 2007 (6 years)

**Interviewer : Please take me through your experience of taking HAART.**

Participant : I was constantly sick and weak and had to be in hospital many times until they tested my blood and told me I had HIV. I believe I got my illness from my mom because I was sick long time before I started having a girlfriend. In 2003 my mother died because she was sick of HIV. My dad also died of HIV illness in 2001. Now I live with my grandmother.

**Interviewer : How has HAART treatment been for you?**

Participant : I take my tablets two times a day. I take three tablets in the morning and one tablet in the evening. My aunt reminds me to take my tablets most of the times. Before, I was not happy about the treatment. I was scared I would die like my parents. I was reluctant to play with other kids before, I was scared of their reactions. But now I am ok with it. I have two friends, one takes ARVs like me and the other does not take ARVs but is also HIV positive. And we share our stories and so it becomes easier to drink treatment.

**Interviewer : What kind of challenges did you go through since you started HAART?**

Participant : Having a girlfriend sometimes, it is hard to tell the girlfriend. The Doctor told me various ways of getting HIV infection; accident, unprotected sex and from your mother. Sometimes, the condom can work and sometimes it is not so easy you see. I know I must be protected, but sometimes, it does not happen. I had a girlfriend before and I told her about my HIV status, so she know and we would use condoms most of the times but the relationship ended and now I don't have a girlfriend.

**Interviewer : How does it feel to be constantly taking HAART?**

Participant : For me, I am fine with the treatment. I used to get Care Dependency grant, R1 200.00, but now the grant has stopped because my viral load is high. Now my aunt and grandmother receive grant so we are ok at home. I study at TUT, student loan is helping me.

**Interviewer : What does taking such medication mean to you?**

Participant : Sometimes, when I take the medication, it reminds me I am sick but I just have to take the medication. Before, I used to have big breast like I am a girl and I did not like that. But I told the Doctor and they changed my medication, so now my breast is going back to normal. Sometimes, I hear my ears are not working like before, I hear people when they shout and that is because of the medication.

**END**

## APPENDIX J: UNISA ETHICAL CLEARANCE LETTER

Ref. No: PERC-16013



### Ethical Clearance for M/D students: Research on human participants

*The Ethics Committee of the Department of Psychology at Unisa has evaluated this research proposal for a Higher Degree in Psychology in light of appropriate ethical requirements, with special reference to the requirements of the Code of Conduct for Psychologists of the HPCSA and the Unisa Policy on Research Ethics.*

**Student Name:** Musa MaseTshaba

**Student no.:** 30872588

**Supervisor/promoter:** Dr Sibusiso Mhlongo

**Affiliation:** External supervisor

**Title of project:**

Experiences of Long-Term Highly Active Anti-Retroviral Treatment by Adolescents in Tembisa, Gauteng Province.

The proposal was evaluated for adherence to appropriate ethical standards as required by the Psychology Department of Unisa and the Unisa Policy on Research Ethics. The application was approved by the Ethics Review Committee of the Department of Psychology without further conditions.

Signed:

A handwritten signature in black ink, appearing to read "P Kruger".

*Prof P Kruger*  
[For the Ethics Committee ]  
[ Department of Psychology, Unisa ]

Date: 8 April 2016

## APPENDIX K: LANGUAGE EDITOR'S REPORT

### DECLARATION BY LANGUAGE EDITOR



18 April 2016

TO WHOM IT MAY CONCERN

#### DECLARATION: LANGUAGE EDITING of PhD Thesis

I hereby declare that I have edited the Doctor of Literature and Philosophy in Psychology thesis of MUSA MASETSHABA entitled "**EXPERIENCES OF LONG-TERM HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT BY ADOLESCENTS IN TEMBISA, GAUTENG PROVINCE**" and found the written work to be free of ambiguity and obvious errors. Only the appendices section was not included during the editing process. It is the responsibility of the student to address any comments from the editor or supervisor. Additionally, it is the final responsibility of the student to make sure of the correctness of the thesis.

**Khomotso Bopape**

*Full Member of the Professional Editors' Guild*

Professional  
EDITORS  
Guild

*Let's Edit is a Level 1 EME B-BBEE Contributor (Procurement Recognition Level = 135%)*

Address: **P.O. Box 40208, Arcadia, Pretoria, 0007**  
Tel No.: **012 753 3670**, Fax No.: **086 267 2164** and Email Address: **khomotso@letsedit.co.za**