

UNIVERSITY OF KWAZULU-NATAL

**DEVELOPING, TESTING AND REFINING OF A MODEL FOR
IMPLEMENTATION OF HIV/AIDS SELF-MANAGEMENT
EDUCATION IN A SEMI-RURAL AREA IN KWAZULU-NATAL,
SOUTH AFRICA**

By

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DECLARATION

In accordance with the regulations of the University of KwaZulu-Natal, I, Folorunso Dipo Omisakin, declare that this PhD thesis entitled “**Developing, Testing and Refining of a Model for Implementation of HIV/AIDS Self-Management Education**”, except where otherwise indicated, is my original and independent research and that:

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Prof. Busisiwe Purity Ncama’s Signature_____Date_____

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ABSTRACT

The purpose of this study was to develop, test and refine a model for implementation of self-management education for people living with HIV/AIDS (PLWHA) in semi-rural KwaZulu-Natal, South Africa. The study consists of a purposive sample of 88 men and women over 18 years of age living with HIV/AIDS. A Quasi-experimental design, incorporating pre-test and post-test interventions and comparison groups, was used. These groups, equal in number and matched in other respects at baseline in terms of the recruitment criteria used, were designated Group A and Group B. Group A received seven weeks of intensive self-management education; Group B received only traditional health education. Group B, however, received (and its members were informed that they would do so) self-management education immediately after my intervention had concluded. Arrangements were made to prevent the two groups from interacting, or even meeting.

A conceptual model derived from the relevant literature on self management, and in particular on the teaching of self management to PLWHA, was tested using data from participants' health-related quality of life, CD4 counts, and viral loads before and after the self-management education intervention. Testing comprised an investigation into whether or not the outcomes included in the model adequately reflected those reported in the literature on effective self-management education, and also whether or not the predicted relationships between intervention and those outcomes existed in practice.

A priori assessment produced data for preparation and development of the new intervention devised by the researcher. The assessment process involved the collection of data on participants' perceptions of health, their difficulties of living with HIV/AIDS, self-management education needs; preferred methods of learning and perceived barriers to participation in this self-management education programme. Participants' health-related quality of life was measured at baseline and at the twenty-fourth week, using an SF-36 questionnaire. Data on participants' CD4 cell counts and viral loads were obtained from the clinic records at baseline and in the twenty-fourth week; comparisons were made for sample means using the data available on all participants in both groups. In-depth group interviews were conducted for systematic sampling of the intervention group after intervention to substantiate the effectiveness of the intervention.

Results indicated a significant trend toward improvement in health-related quality of life. The in-depth group interview results demonstrated that participants showed improvement in their health status through the acquisition of self-management skills, health practices, and communication with healthcare providers. Post-intervention results showed that the two groups were statistically significantly different in terms of their mean scores on physical functioning ($t=3.900$; $df=79$; $p<0.0001 < 0.05$), vitality ($t=3.285$; $df=79$; $p=0.002 < 0.05$) and general health ($t=2.107$; $df=79$; $p=0.039 < 0.05$), physical health ($p=0.001 < 0.05$) and role limitation due to emotional problems ($p=0.007 < 0.05$). No statistically significant difference appeared in terms of their mean scores on mental health ($t=1.422$; $df=79$; $p=.158 > 0.05$), bodily pain ($t=-.138$; $df=79$; $p=0.891 > 0.05$) and social functioning ($p=0.249 > 0.05$). Post-intervention, the two groups are statistically different in terms of their CD4 count mean scores ($t=3.741$; $df=80$; $p<.0001 <0.05$). The mean CD4 cell counts increased over the period of investigation; paired t-tests for difference between intervention and comparison groups were statistically significant ($p < 0.05$) for these variables. However, the differences between the two groups in terms of their viral load were not statistically significant. This may be the result of the fact that as researcher, I had no influence over the process by which viral load data were obtained: both at baseline and after the intervention, they were retrieved from patients' records, in which viral load was expressed, for example, as 'below 25 copies per mil'. This was of course an approximation; after the intervention, they were expressed similarly as 'below detectable limits', or 'below 80 copies per mil.'

My conceptual model provides a consistent, reproducible approach to assessment, monitoring, and evaluation of the key components of self-management education and allows for measurement over time and the tracking of changes; it has in addition a predictive ability. Overall, the programme seemed to have a positive impact on the health-related quality of life of PLWHA. The study confirms the effectiveness of self-management education in improving the health and well-being of PLWHA, even in a resource-limited semi-rural setting.

TABLE OF CONTENTS

| CONTENTS | PAGES |
|------------------------------|--------------|
| Title page | i |
| Declaration | ii |
| Acknowledgement | iii |
| Abstract | vi |
| Table of Contents | vii |
| List of Abbreviations | xv |
| List of Tables | xvii |
| List of figures | xix |
| Appendix | xx |

CHAPTER ONE: CONCEPTUALISATION AND INTRODUCTION

| | | |
|-----|---|----|
| 1.0 | Introduction | 1 |
| 1.1 | Background to the study | 1 |
| 1.2 | Problem statement | 7 |
| 1.3 | Purpose of the study | 9 |
| 1.4 | Objectives of the study | 9 |
| 1.5 | Research questions | 10 |
| 1.6 | Research hypothesis to be tested within the study | 11 |
| 1.7 | Significance of the study | 11 |
| 1.8 | Operational definition of terms | 14 |
| 1.9 | Outline of the thesis | 16 |

CHAPTER TWO: LITERATURE REVIEW

| | | |
|-------|--|----|
| 2.0 | Introduction | 19 |
| 2.1 | The current HIV/AIDS problem situation in the world | 22 |
| 2.2 | The challenge of living with HIV/AIDS | 23 |
| 2.3 | Differences between HIV/AIDS and other chronic illnesses | 25 |
| 2.4 | What is self-management? | 26 |
| 2.5 | Self-management education needs of PLWHA | 28 |
| 2.6 | Models of self-management programmes | 29 |
| 2.7 | Self-management education approaches | 31 |
| 2.7.1 | Internet self-management programmes | 34 |
| 2.8 | Barriers to self-management education programmes | 35 |
| 2.9 | Evaluation of self-management programmes | 40 |

| | | |
|-------|--|----|
| 2.10 | Self-management education programmes for PLWHA in developing countries | 42 |
| 2.11 | The meaning of urban and rural setting in the South African context | 43 |
| 2.12. | Standard HIV/AIDS care and management in the South African context | 46 |
| 2.13 | Conclusion | 53 |

CHAPTER THREE: CONCEPTUAL FRAMEWORK GUIDING THE STUDY

| | | |
|-------|---|----|
| 3.0 | Introduction | 54 |
| 3.1 | The concept of self-management | 54 |
| 3.2 | Emergence of self-management in health care | 57 |
| 3.3 | Philosophical underpinning of self-management education | 58 |
| 3.3.1 | Patient centeredness | 58 |
| 3.3.2 | Transformation through empowerment | 64 |
| 3.3.3 | Facilitation | 66 |
| 3.4 | Empowerment theories | 68 |
| 3.5 | Other theories reviewed related to the study | 71 |
| 3.5.1 | Social cognitive theory | 71 |
| 3.5.2 | Overlap in health belief models | 73 |
| 3.6 | Self-management education process | 73 |
| 3.7 | The models | 79 |
| 3.7.1 | The chronic care model | 79 |
| 3.7.2 | Precede-proceed model | 82 |
| 3.8 | The self-management education conceptual framework | 85 |
| 3.8.1 | The conceptual framework development process | 87 |

| | |
|--|----|
| 3.8.1.1 Selecting and defining concepts | 88 |
| 3.8.1.2 Developing relational statements | 93 |
| 3.8.1.3 Developing hierarchical propositional statements | 96 |
| 3.8.1.4 Constructing a conceptual map | 97 |
| 3.8.1.5 Conclusion | 99 |

CHAPTER FOUR: RESEARCH METHODOLOGY

| | |
|---|-----|
| 4.0. Introduction | 101 |
| 4.1. Philosophical underpinning of the research design | 101 |
| 4.2. Research design | 102 |
| 4.3 Intervention mapping (IM) | 105 |
| 4.4 Research setting entry negotiation process | 107 |
| 4.5 Research activities | 111 |
| 4.5.1 Assessment phase | 111 |
| 4.5.2 HIV/AIDS self-management education programme | 111 |
| 4.5.2.1 Intervention procedure | 115 |
| 4.5.2.2 A summary of HIV/AIDS self-management education programme | 117 |
| 4.5.3 Measuring the dose of programme intervention | 123 |
| 4.5.4 Evaluation (Phase Three) | 125 |
| 4.6 Research setting description | 125 |
| 4.7 Target population | 129 |
| 4.8 Sampling Technique and Sample Size | 129 |
| 4.8.1 Recruitment and retention of participants | 130 |
| 4.9 Power calculation | 132 |

| | | |
|----------|--|-----|
| 4.10 | Instrumentation for data collection | 132 |
| 4.10.1 | Research instruments and variables measured | 132 |
| 4.10.2 | Breakdown of the instruments | 138 |
| 4.10.3 | Measures to improve validity and reliability of data | 140 |
| 4.11 | Data collection process | 143 |
| 4.11.1 | Quantitative data collection | 143 |
| 4.11.2 | Biological markers | 144 |
| 4.11.3 | Qualitative data collection | 145 |
| 4.12 | Academic rigour | 145 |
| 4.13 | Data analysis | 147 |
| 4.13.1 | Quantitative data analysis | 149 |
| 4.13.2 | Qualitative data analysis | 149 |
| 4.13.2.1 | Qualitative data on self-management needs | 149 |
| 4.13.2.2 | Qualitative data analysis on experiences of the participants | 151 |
| 4.14 | Ethical considerations | 153 |
| 4.15 | Data management and storage | 156 |
| 4.16 | Conclusion | 157 |

CHAPTER FIVE: RESULTS OF THE ASSESSMENT PHASE

| | | |
|-------|--|-----|
| 5.0 | Introduction | 158 |
| 5.1 | Needs, assets and problems assessment | 159 |
| 5.2 | Presentation of assessment phase results | 159 |
| 5.2.1 | Describing data through statistics | 159 |

| | | |
|---------|--|-----|
| 5. 2. 2 | Assessments of personal and environmental factors | 160 |
| 5.2.2.1 | Biographical characteristics of PLWHA | 160 |
| 5.2.2.2 | Health characteristics of PLWHA | 166 |
| 5.3 | Self-Management education needs of PLWHA | 173 |
| 5.3.1 | Barriers to participating in self-management education | 176 |
| 5.3.2 | Preferred methods of learning | 178 |
| 5.3.3 | Categories of self-management needs of PLWHA | 178 |
| 5.4 | Health-related quality of life (H-RQOL) of PLWHA | 183 |
| 5.4.1 | Distribution of data | 183 |
| 5.4.2 | Groups A and B compared before the intervention | 184 |
| 5.4.2.1 | Gender of members of the A and B Groups | 185 |
| 5.4.2.2 | SF-36 Mean scores and SD for Groups A and B before the intervention | 186 |
| 5.4.2.3 | Groups A and Bs' CD4 cell counts and viral loads before the intervention | 188 |
| 5.5 | Conclusion | 189 |

CHAPTER SIX: RESULTS OF THE IMPLEMENTATION AND EVALUATION PHASES

| | | |
|-------|--|-----|
| 6.0 | Introduction | 192 |
| 6.1 | Input evaluation | 193 |
| 6.2 | Process evaluation | 200 |
| 6.2.1 | Self-management education programme implementation | 200 |
| 6.3 | Product evaluation | 205 |
| 6.3.1 | Outcome analysis | 205 |

| | | |
|-------|-----------------|-----|
| 6.3.2 | Impact analysis | 209 |
| 6.4 | Conclusion | 216 |

CHAPTER SEVEN: DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS

| | | |
|---------|---|-----|
| 7.0 | Introduction | 218 |
| 7.1 | Discussion of the conceptual model development phase | 218 |
| 7.1.1 | Discussion of the assessment phase | 221 |
| 7.1.1.1 | Self-management education needs and perception of health | 221 |
| 7.1.1.2 | Preferred methods of learning and barriers to participation in HASMEP | 225 |
| 7.1.1.3 | H-RQOL of participants before division into Groups A and B | 226 |
| 7.2 | Discussion of the Implementation and Evaluation phase | 228 |
| 7.2.1 | Product evaluation | 228 |
| 7.2.2 | Guidelines for Implementation of HIV/AIDS Self-Management Education | 234 |
| 7.3 | Presentation of the emerging model | 237 |
| 7.3.1 | Description of the model | 237 |
| 7.3.2 | Overview of the emerging model | 239 |
| 7.3.3 | The goal of the self-management education programme | 242 |
| 7.4 | Elements of the model | 242 |
| 7.4.1 | The context | 242 |
| 7.4.2 | The target | 243 |
| 7.4.3 | The objectives of self-management education | 243 |
| 7.4.4 | The provisions of the self-management education model | 243 |
| 7.4.5 | Structure of the model | 244 |

| | | |
|----------|--|-----|
| 7.4.6 | Propositions of the model | 247 |
| 7.4.7 | Expected outcomes | 248 |
| 7.4.8 | Purposes and uses of the model | 249 |
| 7.4.9 | Essentials of the model | 250 |
| 7.4.10 | The concepts of the model | 251 |
| 7.4.10.1 | Assessment of personal and environmental factors | 251 |
| 7.4.10.2 | Vectors of explanatory variables | 252 |
| 7.4.10.3 | Facilitation process | 252 |
| 7.4.10.4 | Self-concepts | 253 |
| 7.4.10.5 | Consciousness-raising | 254 |
| 7.4.11 | Relationships of the concepts in the model | 257 |
| 7.4.12 | Boundaries of the model | 259 |
| 7.4.13 | Basic assumptions of the model | 259 |
| 7.4.14 | General contributions of this study | 260 |
| 7.4.15. | Unique contributions of this study | 261 |
| 7.5 | Limitations of the Study | 262 |
| 7.5.1 | Using a quasi-experimental design | 262 |
| 7.5.2 | Using a single site imposed by gate-keeping in selected sites | 263 |
| 7.5.3 | Participants who dropped out of the project | 263 |
| 7.5.4 | Using self-reported behaviour as a measure of programme impact | 264 |
| 7.6 | Recommendations | 264 |
| 7.6.1 | Recommendations for health care providers | 264 |
| 7.6.2 | Capacity building for PLWHA | 265 |

| | | |
|-------|---|-----|
| 7.6.3 | Recommendations for further research | 266 |
| 7.6.4 | Recommendations for the South African health system policy makers | 266 |
| 7.6.5 | Recommendations for self-management education facilitators | 268 |
| 7.7 | Conclusions | 268 |

LIST OF ABBREVIATIONS USED

| <u>ABBREVIATION</u> | <u>MEANING</u> |
|----------------------------|--|
| AFB | Acid-fast bacilli |
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Antiretroviral therapy |
| ARVs | Antiretroviral (drugs) |
| BMI | Body Mass Index |
| BP | Bodily pain |
| CCMT | Comprehensive care management and treatment |
| CD4 | Cluster designation 4 |
| CDC | United States Centres for Disease Control and Prevention |
| CDSMP | Chronic Disease Self-Management Programme |
| DSMEP | Diabetes Self-management Education Programme |
| ELISA | Enzyme-linked immunosorbent assay |
| GH | General Health |
| HAART | Highly Active Antiretroviral therapy |
| HIV | Human Immunodeficiency Virus |
| HASME | HIV/AIDS Self-Management Education |
| HASMEP | HIV/AIDS Self-Management Education Programme |
| HRSA | Human Resources and Services Administration |
| MH | Mental health |
| NGOs | Non-governmental organisations |

| | |
|-------------|---|
| PCR | Polymerase chain reaction |
| PF | Physical functioning |
| PLWHA | People living with HIV/AIDS |
| RE | Role limitation due to emotional problem |
| RP | Role limitation due to physical problem |
| SD | Standard Deviation |
| SF | social functioning |
| SF-36 | Short form-36 |
| SMEPs | self-management education programmes |
| Stats SA | Statistics South Africa |
| STI | Sexually transmitted infections |
| STIs and TB | sexually transmitted infections and tuberculosis |
| UNAID | Joint United Nations Programme on HIV/AIDS |
| UNGASS | United Nations General Assembly Special Session (on HIV/AIDS) |
| UNICEF | United Nations Children's Fund |
| VCT | Voluntary counselling and testing |
| VT | Vitality |
| WHO | World Health Organization |

LIST OF TABLES

| | |
|---|-----|
| 1 Traditional Patient Education versus Self-Management Education | 5 |
| 2.1 Anticipated and Unanticipated Barriers Faced in Establishing DSMEP in Under-served Areas, Arkansas, 2003–2004 | 38 |
| 2.2 Key Barriers to and Enablers for Integration of Self-management Programmes in Australia | 39 |
| 2.3: On-site Treatment Monitoring | 52 |
| 4.3.1: The Intervention Mapping Process | 107 |
| 4.5.2.2: Objectives, activities and outcomes | 118 |
| 4.10.2 HIV/AIDS Self-management Education Needs Survey | 138 |
| 4.10.3 SF-36 Questionnaire | 139 |
| 5.1: Biographic Characteristics | 161 |
| 5.2: Health Characteristics | 166 |
| 5.3: Health, Well-being and Nutrition of PLWHA | 174 |
| 5.4: Management of HIV/AIDS | 175 |
| 5.5: Barriers to participating in self-management education | 176 |
| 5.6: Preferred Methods of Learning | 177 |
| 5.7. Overview of Categories of Needs | 182 |
| 5.4.0 One-Sample Kolmogorov-Smirnov Test | 183 |
| 5.4.1: Ages of Members of the A and B Groups | 184 |
| 5.4.2 Independent Samples Test Results for age | 185 |
| 5.4.3: The A and B Groups' Gender compared | 185 |
| 5.4.4 Group Statistics for Normally Distributed Data before the Intervention | 186 |
| 5.4.5 Independent Samples Test Result for Normal Data before the Intervention | 186 |
| 5.4.6 Ranks for Skewed Data (Non-normally Distributed Data) | 187 |

| | |
|--|-----|
| 5.4.7 Mann-Whitney Test Results for Skewed Data | 187 |
| 5.4.8 A and B Groups' CD4 Cell Counts before the Intervention | 188 |
| 5.4.9 Independent Samples Test Results for CD4 counts before the Intervention | 188 |
| 5.4.10 A and B Groups' Viral Loads before the Intervention | 188 |
| 5.4.11 Independent Samples Test Results for Viral Loads before the Intervention | 189 |
| 6.1 Group Statistics for Normally Distributed data after the Intervention | 210 |
| 6.2 Independent Samples Test Results for Normal Data after the Intervention | 211 |
| 6.3 Ranks for Skewed Data (Non-normally Distributed Data) after the Intervention | 212 |
| 6.4 Mann-Whitney Test Results Skewed Data after the Intervention | 212 |
| 6.5 Groups A and Bs' CD4 Cell Counts after the Intervention | 213 |
| 6.6 Independent Samples Test Results for CD4 Cell Counts after the Intervention | 214 |
| 6.7 Groups A and Bs' Viral Loads after the Intervention | 214 |
| 6.8 Independent Samples Test Results after the Intervention | 215 |
| 6.9 1 Transformed Variable: Average | 215 |
| 6.9 2 Group A Paired Samples Statistics | 215 |
| 6.9 3 Group B Paired Samples Statistics | 216 |

LIST OF FIGURES

| | |
|--|-----|
| 3.5 Self-management education process | 78 |
| 3.7.1 The Chronic Care Model | 79 |
| 3.7.2 Precede-Proceed Model | 83 |
| 3.8 Conceptual model Developed from Literature | 98 |
| 4.1 Schematic diagram of study design | 104 |
| 5.1: Description of PLWHA according to Their Gender | 162 |
| 5.2. Description of PLWHA according to Age | 163 |
| 5.3: Description PLWHA according to level of education | 164 |
| 5.4: Description of PLWHA according to Diagnosis with HIV and AIDS | 165 |
| 5.5: Describing PLWHA according to Their Perception of Health Status | 168 |
| 5.6: Perception of Difficulty Living with HIV/AIDS | 169 |
| 5.7: Perception of Difficulty Taking Prescribed Medications | 170 |
| 5.8: Description of PLWHA in terms of Prescribed HAART Regimen | 171 |
| 5.9: Describing PLWHA according to Use of Alternative or Complementary Therapies | 172 |
| 7.1 The Emerging Model | 241 |

APPENDIX

- APPENDIX 1: Ethics approvals
- APPENDIX 2: National Department of Health Endorsement Certificate
- APPENDIX 3: Permission letters for instruments and tools.
- APPENDIX 4: Informed Consent Form
- APPENDIX 5: Instruments
- APPENDIX 6: Letters of Introduction and Permission to Conduct Research
- APPENDIX 7: Research Settings
- APPENDIX 8: HIV/AIDS Self-Management Education Programme Peer Group Leader's Manual
- APPENDIX 9: Self-Management Education Handbook for People Living with HIV/AIDS
- APPENDIX 10: Application for amendment of protocol

CHAPTER ONE

CONCEPTUALISATION AND INTRODUCTION OF THE STUDY

1.0 INTRODUCTION

This chapter deals with the conceptualisation of the study. It highlights the background to the study, the problem statement, the purpose and objectives of the research and the significance of the findings of this thesis. It also presents the definitions of key terms as they are used in the thesis, and closes with a brief account of each chapter in the thesis.

1.1 BACKGROUND TO THE STUDY

HIV/AIDS remains a threat to the health of all communities in South Africa, as in many sub-Saharan African countries, being a deadly and infectious disease that spreads rapidly among general population, causes many deaths, and puts enormous pressure on public resources. The health care system, already markedly under resourced, has been severely stressed as increasing numbers of people require care and treatment for HIV (Dohrn, Nzama and Murrman, 2009). South Africa's health care system is struggling to respond to the devastating impact of HIV/AIDS while at the same time respecting its post apartheid mandate to provide equitable health services to all. These unprecedented challenges are forcing a rethinking and reorganization of health resources and systems (Dohrn et al., 2009).

The emergence of HIV/AIDS as a chronic illness, manageable in the long term, brings with it a need for self-management education programmes (SMEPs) which can teach people living with HIV/AIDS (PLWHA) to be effective self-managers, in respect of life style changes, management

of symptoms, awareness of appropriate occasions for resorting to healthcare services and the administration of prescribed medication. The growing interest in supporting self-management as a way of helping PLWHA has brought about international pressure to locate more resources to treatment programmes for people living with HIV/AIDS (Shiffman, 2006). The reasons for international interest in self-management are three fold: political, clinical and economic. The political driver is the changing dynamics between healthcare professionals and their clients in response to consumer pressure for greater participation by the patient in decision-making (Coulter and Elins, 2007). The clinical driver is the growing body of knowledge demonstrating the health benefits of programmes that promote self-management (Barlow, Turner and Gilbchrist, 2006; Lorig and Holman, 2003; Wright, Barlow, Turner, and Bancroft, 2003). The anticipated cost-savings, that can be made if more people adopt self-management behaviours, is the economic driver.

Present-day healthcare policy and practice are increasingly informed by the reported benefits of self-management programmes. Little is known about how PLWHA accommodate the lifestyle change and problems precipitated by their HIV/AIDS. Evidence of the impact of self-management and how it can best be supported by healthcare professionals is needed (Hubbard, Kidd, Donaghy, McDonald and Kearney, 2006), and evidence of people's desire to take on risks and responsibilities of exercising personal control (Bandura, 2001) through self-management programmes is also required. Little information is available to those interested in implementing such programmes to help them decide how to design and structure their programmes. Similarly, evaluating programme success is complex, and there is little guidance on the processes of self-

management which might allow health care professionals to choose a set of measures that can reasonably assess whether the programme is accomplishing what it was designed to do.

Living with the illness and dying with dignity at home are possible only if people are willing to take responsibilities for themselves (Kellhear, 2001). Self-care management maybe termed either self-care or self-management (Thorne and Paterson, 2001). According to Orem (1995) self-care is behaviour initiated and performed by individuals on their own behalf to save their lives and promote health. Self-care suggests that individuals use their resources, including personal attributes such as knowledge, skills, positive attitudes, determination, courage, and optimism, to resolve poor health (Akinsola, 2001). Self-care or self-management can be said to comprise decisions and actions taken by someone, who is facing a health problem, in order to cope with it and improve his or her health.

Patient self-management is “the ability of patients with chronic illness, in a complementary partnership with their health care providers, to manage the symptoms, treatment, lifestyle behaviour changes, and the many physical and psycho-social challenges that they face each day”(Coleman and Newton, 2005: 1503). Lorig and Holman (2003) identified five core self-management skills which include: problem solving, decision making, resource utilization, the formation of patient/health care provider partnerships and implementation of prescribed measures.

The economic and social burdens of chronic disease have led to a shift in health policy involving a focus on self-management (Jordan and Osborne, 2007). Chronic disease self-management

programmes seek to empower patients both by providing information and by teaching skills to improve self-care and provider-patient interactions. Self-management education also enables PLWHA “to take preventive measures to protect individuals against HIV infection, thus curbing the spread of HIV/AIDS within the community as well as facilitating treatment and care of the infected individuals” (Ncama, 2007: 392). The societal and economic burden imposed by HIV/AIDS signals the need for a shift towards a health policy that focuses on a healthy lifestyle, HIV/AIDS prevention, and self-management. Self-management has become a common term in health education and is the name attached to many health promotion and patient education programmes. It is an essential part of chronic disease care, and it includes both patient and provider responsibilities. The intentions behind self-management interventions are the empowerment of PLWHA, to be active participants in their own care, and to enhance their ability to make sound health decisions. This new paradigm of self-management has sparked debates regarding the expected level of individual responsibility and the expectations that individuals demonstrate the capacity to manage their health and wellbeing (Peerson and Saunders, 2009).

It is important that our thinking should not be limited to the self-management structured patient-education component. This self-management should include interventions that combine different forms of patient education; collaborative goal-setting, for example, involving both patient and healthcare professional, is more likely to be successful (Rukeyser, Stenbock and Agins, 2003). Self-management education differs from traditional patient education in what is taught, how problems are formulated, the relation of what is taught to the disease, and the theory underlying the goal of persuading and empowering the patient to adopt a behaviour pattern which will lead

to improved health. The theory underlying patient education is that increasing a patient's knowledge about a disease leads to behavioural change that improves clinical outcomes. An underlying theory of self-management education is that the patient's belief in his or her own ability to adopt a specific behaviour pattern or achieve a reduction in symptoms will lead to improved clinical outcomes.

Self-management support expands the role of health care professionals from delivering information to helping patients gain confidence to make choices that lead to improved self-management and better outcomes (Coleman and Newton, 2005). Patient education typically is given by a health care professional but self-management can be taught and supported by other professionals such as office support staff, peer group leaders, and other patients. Table 1 compares self-management education with traditional patient education.

Table 1: Traditional Patient Education versus Self-Management Education

| | Traditional Education | Self-Management Education |
|--|---|--|
| Content | Disease-specific information and technical skills. | Problem-solving skills that can be applied to chronic conditions in general. |
| Definition of the problem | Inadequate control of disease is the problem. | Patient formulates the problem, which may or may not be directly related to disease. |
| Theoretical construct underlying the education. | Disease-specific knowledge produces behaviour change and leads to improved clinical outcomes. | Patient's self-efficacy (learned through setting short-term action plans) leads to improved clinical outcomes. |
| Goal | Patient compliance with prescribed behaviour changes will improve clinical outcomes. | Increased self-efficacy will improve clinical outcomes. |
| Educator | Health professional | Health professional or peer group leader and other patients in the group. |
| (Bodenheimer, Wagner, and Grumbach, 2002a) | | |

As HIV/AIDS is a chronic illness, conducting interventions for increasing the self-management abilities of PLWHA for long-term care is essential. PLWHA may show different symptoms; therefore, an effective plan, including education, support, counselling, behaviour and skill training, and self-medication is required to promote self-management amongst PLWHA by increasing their self-care knowledge and encouraging positive living and health-promoting behaviour.

HIV/AIDS Self-Management Education Programme (HASMEP) is the process of facilitating the knowledge, skill, and confidence necessary for HIV/AIDS self-care. This process incorporates the needs, goals and life experiences of PLWHA and be guided by evidence-based standards. HASMEP can be described as a critical element of care for PLWHA and is necessary to improve patient care outcomes. HASMEP will not conflict with existing programmes or occasional interventions by professionals to enhance regular self-treatment and HIV/AIDS specific education. It enables PLWHA to develop skills to coordinate all the activities needed to manage their health, as well as to help them in their lives. According to HRSA HIV/AIDS Bureau (2006), for PLWHA to be effective self-managers they must:

- Learn about their HIV/AIDS disease.
- Develop effective communication skills
- Actively become partners with providers in decision-making
- Practice action-planning and problem solving
- Self-monitor symptoms and follow treatment directions
- Seek expert medical care and advice where and when necessary
- Use family, peer, and community support resources

- Maintain emotional and psychological balance
- Practice health-enhancing behaviour.

This study is an attempt to develop, test and refine a comprehensive model for the implementation of self-management education, focusing on the totality of PLWHAs' life experience with the purpose of (a) explicitly involving PLWHA, as active participants in their healthcare; (b) facilitating the acquisition of skills and knowledge necessary to collaborate with their healthcare providers and implement treatments effectively; and (c) enabling PLWHA to develop confidence for putting their skills and knowledge into practice.

1.2 PROBLEM STATEMENT

The increase in AIDS, HIV-related illnesses and deaths has put an additional burden on already constrained services in developing countries. HIV/AIDS is expected to affect various institutions and individuals in several ways: such as increased sick leave and absenteeism, high medical expenses, low productivity, higher worker turnover, loss of skilled labour, increased training costs and increased expenditure on health and death benefits (Boon, James, Ruiter, Borne, Williams and Reddy, 2010; Orner, 2006). HIV/AIDS has its particular biological and social characteristics that dictate the shape of an effective response: its impact is greatest among young adults; it is mainly sexually transmitted; infection may remain invisible for many years. Overcoming the stigmatisation of PLWHA is a precondition for explicit action against the disease (Piot, Bartos, Ghys, Walker and Schwartlander, 2001).

Biomedical intervention in the form of antiretroviral therapy has substantially reduced morbidity and mortality associated with HIV/AIDS for those populations able to afford access to the

necessary medication, it has had a significant impact on preventing mother-to-child transmission. The fact that PLWHA now live longer and suffer complications from the side effects of medication, and the likelihood of opportunistic infections, leads to increased strain on health workers, especially nurses. The successes of antiretroviral therapy have been relevant only to a small proportion of the world's population affected by HIV/AIDS. Other potential biomedical interventions in the form of effective topical microbicides seem to be having breakthroughs but vaccines have to date proved elusive.

Not all PLWHA can be admitted to hospitals because of limited facilities. For PLWHA in African countries to be given an opportunity to experience a healthy and fulfilling life, better health care must be provided; existing services must be expanded and/or transformed. Hence there is a need for HIV/AIDS Self-Management Education that would be appropriate in poorly resourced settings. While there is a substantial amount of research occurring in the field of HIV/AIDS care, "true progression in the field has been hindered by a failure to integrate findings including model accuracy, variable influence, or behavioural applicability, into the substantive cumulative knowledge of the field" (Noar and Zimmerman, 2005: 283) Inappropriately selecting theories in research and interventions can have ramifications to study outcomes including lack of translatability, lack of innovation, and misappropriation of statistical variance (Traude, Holloway and Smith, 2011). It is difficult to determine which of the many health behaviour theories is most precise in explaining health-related behaviour change necessary for self-management amongst PLWHA. Validating models for accuracy, variable influence, and behavioural applicability facilitates HIV/AIDS care researchers to effectively applying empirical results from clinical practice to theoretical models that inform health outcomes. Theoretically informed interventions

are crucial to the field of HIV/AIDS care. Theories must be developed, tested and refined to facilitate the implementation of self-management education programmes in practice. This study will provide an overview of a process of developing, testing and refining a comprehensive model for the implementation of HIV/AIDS self-management education.

1.3 THE PURPOSE OF THE STUDY

The purpose of this study is to develop, test, and refine a conceptual model for the implementation of HIV/AIDS self-management education for PLWHA within a semi-rural area on the south coast of KwaZulu-Natal, including Umgaba, Danganya, and Ilfracombe. By the term ‘semi-rural’ I mean an area which lies at the interface between the core urban and the rural settings, which to an extent shares the attributes of both urban and rural areas. The area which is described in this study is extensive, but has only one clinic. There is only one tarred main access road, as well as a railway line which intersects the area; there are railway stations at Umgababa and Ilfracombe.

1.4 OBJECTIVES OF THE STUDY

The objectives of the study are to:

1. Identify the self-management educational needs of PLWHA within a semi-rural South African context;
2. Develop and test HIV/AIDS Self-Management Education Conceptual Model;
3. Establish if there is a difference in the health-related quality of life of PLWHA who have been exposed to HIV/AIDS Self-Management Education (HASME) versus a group which has had no such exposure.

4. Refine the HASME conceptual model to facilitate the ability of PLWHA in partnership with their health care providers to manage the physical and psychosocial challenges that they face.

1.5 RESEARCH QUESTIONS

To achieve the purpose of this study, the following research questions will be addressed:

1. What are the educational needs for the understanding of health, and the undertaking of self-management, for PLWHA?
2. What are the, barriers to participation in self-management education and the preferred learning methods of PLWHA in a semi-rural African setting?
3. What is the health-related quality of life of PLWHA before division into intervention (Group A and comparison groups (Group B)?
4. Is there a significant difference between Groups A and B in terms of age, gender and health-related quality of life of PLWHA before intervention?
5. Is there a significant difference in the CD4 counts and viral loads of Groups A and B before the intervention?
6. How effective is the HIV/AIDS Self-Management Education Programme (HASMEP) in facilitating the ability of PLWHA, in partnership with their healthcare providers, to manage the physical and psychosocial challenges that they face?
7. Is there a significant difference between the health-related quality of life of the Group A and Group B after the intervention?
8. Is there a significant difference in the CD4 counts and viral loads of the Group A and Group B after the intervention?

1.6 RESEARCH HYPOTHESIS TO BE TESTED WITHIN THE STUDY

1. There is no significant difference between Group A and Group B in terms of terms of age, gender and health-related quality of life of PLWHA before the intervention.
2. There is a significant difference between Group A and Group B in terms of health-related quality of life after the intervention.
3. There is a significant difference between the CD4 cell counts and viral loads of Group A and Group B before the intervention.
4. There is a significant difference between the CD4 cell counts and viral loads of Group A and Group B after the intervention.

1.7 SIGNIFICANCE OF THE STUDY

In South Africa as elsewhere in Africa, there is a serious paucity of empirical data on HIV/AIDS self-management programmes for PLWHA. There remains a need for studies that will explore the development of HIV/AIDS self-management education and develop a conceptual model for its implementation among PLWHA in a South African context. This study aims at helping PLWHA develop positive self-care behaviour which will include: lifestyle (diet and exercise); persistence in management therapy; using services effectively, understanding of their symptoms and problems, and appropriate responses to them. The study will impact positively on nursing practice, research, education, health policy/administration, and the empowerment of PLWHA.

Practice and service provision Educational programmes for the self-management of PLWHA will improve their functional ability and feelings of control, thus reducing absenteeism from

work, days of reduced activity, visits to an emergency department, and disturbed nights (Inouye et al., 2001). HIV/AIDS self-management programmes have the potential to serve as the foundation for a more effective and satisfying PLWHA-provider partnership, to enhance the psychosocial and physical well-being of PLWHA, and reduce the resources needed for case management (HRSA HIV AIDS Bureau, 2006). Nurses' contributions to HIV/AIDS care will be enhanced if nursing explores develop and tests self-management related interventions and therapies so that their contributions are evidence-based. Because HIV/AIDS remains without a final cure to date, conducting interactions for alleviating associated symptoms and side effects of medication, and increasing the self-care abilities of PLWHA is essential.

Empowerment The incorporation of self-management education into care activities could empower PLWHA to take a more proactive role in managing their illness and improving their quality of life. The need for self-management studies among PLWHA cannot be over emphasized. Self-management education will address most of the problems facing PLWHA, by motivating them to participate actively in their own care, and by giving them knowledge, skills and confidence to set and achieve health goals. My study will not only lead to a sustainable change of behaviour, but also to raised awareness amongst PLWHA as to what abilities and resources to mobilize for action. An effective education, support, counselling, behaviour and skills training, including self-medication, will ease symptoms and increase self-care knowledge and health promotion behaviour among PLWHA (Haffejee, Groeneveld, Fine, Patel and Bowman, 2010; Hegazia, Bailey, Ahadzieb, Alabib and Petersonb, 2010; Kaye and Moreno-Leguizamon, 2011; Igumbora, Scheepersb, Ebrahimc, Jasond and Grimwoodd, 2011; Mutchlera, Wagner, Cowgilld, Mckayb, Risleyf and Bogartg, 2011). Even though PLWHA must face the fact that there is at present no permanent cure for their disease, the aim of this

study is pertinent. Also, sustained enhancement of skills to enable PLWHA to take an active role in the national response to the epidemic through HIV/AIDS self-management education programme (HASMEP) is essential.

Research/education The study will provide baseline information on the development of an HIV/AIDS self-management conceptual framework for PLWHA in rural communities in South Africa. Such information will be useful for the communities involved in the study when they seek funding for their HIV/AIDS project. Also, this study will fulfil the nursing need to develop a model that will define the nursing approach to HIV/AIDS management and take control over the way its intellect, energy and labour are utilized within the health care system. There exists a need to develop more detailed empirical knowledge of specific nursing activities, related to clinical outcomes, so that these activities are connected to the needs of patients.

Health policy All the stakeholders in the research project, such as the communities, the Department of Health, the community care programme, and other care programmes elsewhere in South Africa will find the results of the study valuable since it will provide a clear explanation of issues that need to be considered in developing HIV/AIDS Self-Management programmes. This study will help the KwaZulu-Natal province to understand the needs of PLWHA and, most importantly, to develop their own strategic plans in relation to the care of PLWHA.

Economy the self-management education programme, which aims at enabling and promoting good health among PLWHA, and preventing further spread of HIV/AIDS, can be made cost-effective.

1.8 OPERATIONAL DEFINITION OF TERMS

1.8.1 Self-management

Self-management consists of a patient's ability to deal with chronic illness; including symptoms, treatment, physical and social consequences, and lifestyle changes.

1.8.2 Self-management support

Self-management support is the process of making changes in health care systems and the community to facilitate patient self-management.

1.8.3 Patient education

Patient education refers to knowledge-based instructions for the treatment and management of a specific disease.

1.8.4 Self-care

Self-care comprises tasks performed by PLWHA at home to control or reduce the impact of disease on health status.

1.8.5 Patient self-management

Patient self-management is the ability of a patient with chronic illness, in a complementary partnership with healthcare providers, to manage the symptoms, treatment, lifestyle changes, and physical and psychosocial challenges faced.

1.8.6 HIV/AIDS Self-management education

HIV/AIDS self-management education is the process of facilitating knowledge, skills, behaviour and attitudes necessary for HIV/AIDS self-management.

1.8.7 Empowerment

Empowerment means the restoration to individuals of a sense of their own value and strength and their capacity to handle life's problems.

1.8.8 Positive living

Positive living refers to the acceptance of diagnosis by PLWHA, the beginnings of hope, respect, love for oneself and others, and the adoption of certain patterns of behaviour that promote health.

1.8.9 Effectiveness

Effectiveness refers to the ability to produce a desired result.

1.8.10 HIV/AIDS

The terms 'HIV/AIDS' is generally accepted as the term for a particular disease in its different phases. HIV is the accepted acronym for the Human Immunodeficiency Virus and AIDS is used for the Acquired Immune Deficiency Syndrome.

1.8.11 ARVS

This acronym is used for anti-retroviral medications used in the treatment of infection by retroviruses, primarily HIV.

1.8.12 HAART

This is a form of treatment in which several drugs, three or four anti-retroviral medications (ARVs) are taken in combination, typically two nucleoside or nucleotide reverse transcriptase inhibitors (NRTI) plus a non-nucleoside reverse transcriptase inhibitor or a protease inhibitor or another NRTI.

1.8.13 Conceptual framework

This is an overview of ideas and practices that shape the way self-management education is implemented for PLWHA in semi-rural KwaZulu-Natal (KZN).

1.8.14 Semi-rural

Semi-rural areas consist of townships and informal settlements located between core urban and rural settings.

1.9 OUTLINE OF THE THESIS

This section, (1.10) is an attempt to put the whole thesis into perspective. Being a conceptual model development, the thesis outline will not follow the traditional practice of presenting literature review, methodology and results. The layout of the thesis is as follows:

Chapter One: Introduction

This chapter starts with the background to the problem and the problem statement, both aiming at providing an overview of the scope of the HIV/AIDS self-management programmes around the globe and in particular, in South Africa. Then, significance, purpose, objectives, research questions and hypothesis of this research are presented. I also present the operational definitions of key terms used in the thesis and close with a list of the chapters in the thesis.

Chapter Two: Literature Review

This chapter presents a review of the relevant literature. It starts with the impact of HIV/AIDS globally and in South Africa, followed by an account of the challenges of living with HIV/AIDS, then examines the definitions of self-management by different authorities, self-management education needs of PLWHA, models of self-management programmes, self-management education approaches, problems of self-management programmes, evaluation of self-management programmes. I go on to describe urban and rural settings in the South African

context and conclude with a review of the present standard HIV/AIDS care and management in South Africa.

Chapter Three: Conceptual framework guiding the study

This chapter presents the theoretical framework that forms the basis of the study. The concept of self-management, self-management education, emergence of self-management education in health care, philosophical underpinning of self-management education, and empowerment theories as well as related models are all considered in this chapter. The chapter also discusses the development of a conceptual framework based on literature.

Chapter Four: Methodology

The methodology and methods used in this study are discussed in this chapter, which starts with the research design and goes on to discuss the process of selecting sites, obtaining of permission, assessment of the numbers of PLWHA who were attending clinics and consultation with health professionals in the area to determine whether they believed a need existed for a self-management programme. I also discuss the selection of participants and administration of questionnaires. The methods used in data collection and analyses are also discussed.

Chapter Five: Development phase results

This chapter presents the development phase results and the manner in which a conceptual framework for the self-management education was developed. All data collected and analyzed during the development phase are reported.

Chapter Six: Implementation and Testing phase results

This chapter presents the implementation and the testing phase's results. The chapter describes the empirical implementation and testing of the conceptual model for the self-management education with attention to the issues of reliability, validity, and sensitivity to change of PLWHA.

Chapter Seven: Emerging Model

This chapter starts with discussions of the development, implementation and evaluation phases. The emerging model is presented, together with the recommendations, limitations of the study and conclusions.

CHAPTER TWO

LITERATURE REVIEW

2.0 INTRODUCTION

This chapter review the relevant theoretical and empirical literature. The review serves several important functions. It helps to identify the theoretical and philosophical basis on which the development of the self-management education model rests. Empirical literature helped to illuminate the significance and relevance of the study, since it presented different models and approaches used for the implementation of self-management programmes. The literature review highlights studies conducted in the area of self-management and their advantages or shortcomings. I conducted an extensive literature review to identify self-management programme approaches used internationally. This helped me to identify problems experienced in other countries and to identify models in their implementation. Standard HIV/AIDS care and management in South African context was also examined.

I launched an extensive search for relevant information applicable to the development of a self-management education model. A limited search of the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medline, and Pubmed was undertaken initially by means of keywords in the title. The keywords used were: self-management, self-management support, self-care, symptom management, symptom control, self-management education, people living with HIV/AIDS, and health setting. The following databases were searched: CINAHL, Medline, Pubmed, Psychinfo, ERIC, Cochrane, as well as Google Scholar. Specific literature related to the development of self-management education models for PLWHA and other self-management programmes for chronic conditions were also located. A record sheet was developed to ensure

consistent documentation of all pertinent information for each article, including aims and objectives, condition, country, sample description, study design, outcome measures, assessment and self-management approach, key results, study limitations and quality of the study. Study designs were classified as randomized, control trials (RCTs) or non-randomized, controlled trials (non-RCTs).

The review provided the starting point for the definition of my intended, intervention, its likely problems and the outcome indicators. I intended to put the identification of the needs and self-knowledge of PLWHA first, and to follow up with interaction between PLWHA and professionals, in order that my intervention should be directed by needs. The literature review culminated in the development of my own self-management education model, described in chapter three.

Most of the reviewed literature focuses on a particular component or subset of self-management education rather than a comprehensive programme of care. In most studies (Coleman and Newton, 2005; Kielhofner, Braveman, Fogg and Levin, 2008; Thorpe, 2008; Bhargava and Booyesen, 2010; Majumdar and Mazaleni, 2010; Bashook, Linsk, Jacob, Aguado, Edison, Rivero, Schechtman and Prabhughate, 2010) participants significantly improve in mood and have decreased anger, confusion, tension, depression and fatigue. The mean number of symptoms for the intervention and control groups did not differ significantly: no significant effect was found on CD4 counts (Inouye, Flannelly and Flannelly, 2001). In several studies (Ironson, Weiss and Lydson, 2005, Inouye et al., 2001; Bodenheimer et al., 2002a; Bodenheimer, Wagner and Grumbach, 2002b; Lorig, Ritter and Gonzalez, 2003) it was reported that the number of severe

symptoms decreased in the intervention group and increased in the control group, but no significant differences were found in pain, fatigue, depression, stress, anger, or CD4 cell count measures between groups. Also, it was reported that, an increase in AIDS self-efficacy was significantly correlated with increases in CD4 count and decreases in viral load over time but not associated with changes in either depression or anxiety. Increases in self-efficacy to medication adherence were related to decreases in viral load. Increases in cognitive-behavioural self-efficacy also were associated with decreases in viral loads, depression and anxiety but it was not with changes in CD4 counts (Ironson, Weiss and Lydson, 2005). Improved adherence to dosing schedules for antiretroviral medication and increased self-management skills (Smith, Rublein, Marcus, Brock and Chesney, 2003) were noted. The medication adherence and self-management support component, in particular, received a significant amount of attention, perhaps reflecting that patients with chronic conditions need medication want to manage as many aspects of their disease as possible.

The earlier studies were not without limitations or weaknesses. The small sample used in most of the studies diminished the authority of some analyses. The time allotted to most of the studies was seven to twelve weeks, which is too short for any noticeable change and also makes it difficult to determine whether changes have been sustained over time.

In all the studies examined, it was observed that self-management education intervention improved at least one process or outcome. There is consensus concerning the usefulness of self-management programmes in promoting greater efficiency in the management of health and social well-being and consequently improved quality of life for PLWHA. The literature review is

presented under the following subheadings: current HIV/AIDS problem situation in the world and South Africa in particular; meaning of self-management; self-management education needs and strategies used by PLWHA; self-management education approaches; evaluation of self-management programmes and barriers to self-management programmes.

2.1 THE CURRENT HIV/AIDS PROBLEM SITUATION IN THE WORLD

Over the past 27 years, an estimated 36 million people worldwide have been living with HIV; nearly 25 million people have died from AIDS (UNAIDS and WHO, 2007), giving a cumulative total number of HIV/AIDS infections of 61million. More than 90 percent of PLWHA live in the developing world (UNICEF, 2007). Sub-Saharan Africa remains the epicentres of the HIV infection, with two-thirds of adults and children infected (UNAIDS and WHO, 2007). Presently, South Africa has most of the HIV infection in terms of numbers (UNAIDS and WHO, 2007) and is currently experiencing one of the most severe AIDS epidemics in the world. The dimensions (Dorrington, Bourne, Bradshaw, Laubscher and Tmaeus, 2001) of the HIV/AIDS epidemic in South Africa include adult HIV prevalence 18.1% (UNAIDS/WHO, 2009), and a fall in life expectancy from 63 years in 1990 to 54 years in 2007. With 5.7 million of the 48.3 million citizens infected with HIV (11.8%), South Africa has the highest number of infected adults and children in the world, 17% of the global HIV epidemic. The estimated number of children 0-17 years of age orphaned due to AIDS in South Africa ranges from 1.4 million (UNAIDS/WHO, 2009) to 1.91 million. There is a growing recognition that HIV does not discriminate by age, race, gender, ethnicity, sexual orientation, or socioeconomic status: everyone is susceptible.

Based on the sample of 33,488 women attending 1,415 antenatal clinics across all nine provinces, the South African Department of Health's study estimated that 28% of pregnant women were living with HIV in 2007. The provinces that recorded the highest HIV rates were KwaZulu-Natal, Mpumalanga and the Free State. Because infection rates vary between different groups of people, the findings from antenatal clinics cannot be applied directly to men, newborn babies and children. This is why South Africa has sought also to survey the general population. Based on this survey, the researchers estimated that 10.8% of all South Africans over 2 years old were living with HIV in 2005. Among those between 15 and 49 years old, the estimated HIV prevalence was 16.2% in 2005 (SANAC, 2007). This study suggests that KZN has the highest HIV prevalence of 2,729 new infections per year.

2.2 THE CHALLENGE OF LIVING WITH HIV/AIDS

HIV/AIDS causes debilitating illness and premature death in people during their prime years and has devastated families and communities. Being diagnosed as HIV positive constitutes a serious life crisis that requires considerable coping resources. When receiving an HIV diagnosis, a person has to deal not only with issues such as HIV-related symptoms and the threat of death, but also with a change in life expectancy, change in body image, decisions about disclosure, mistrust in relationships, social stigma and possible social isolation or rejection (Hudson, LEE, Miramontes and Portillo, 2001; Skinner and Mfecane, 2004). Living with HIV/AIDS poses difficult challenges for infected persons, often including living in poverty, lack of medications, stigma and discrimination, and loss of quality of life due in part to the progressive development of HIV-related symptoms. Considering these challenges, it is daunting, particularly in resource-poor environments; to cope with and manage the numerous symptoms that occur in all stages of

the illness (Sukati, Mndebele, Makoa, Ramukumba, Makoe, Seboni, Human and Holzemer, 2005).

“PLWHA must deal not only with disease symptoms but also with the associated stigma”(Sukati et al., 2005: 390). PLWHA also experience “verbal and physical abuse ... frequently accompanied by neglect and refusal of basic services by the family, community, and health institutions. The abuse manifested by some health workers was in form of refusing treatment to PLWHA or at least limiting their access to certain treatments.” (Dlamini, Kobi, Uys, Phetlhu, Chirwa, Naidoo, Holzemer, Greeff and Makoe, 2007: 397).

Further, HIV/AIDS has complicated efforts to fight poverty, improve health, and promote development by:

- Diminishing a person’s ability to support, work and provide for his or her family. At the same time, treatment and healthcare costs related to HIV/AIDS consume household incomes. The combined effect of reduced income and increased costs impoverishes individuals and households.
- Deepening socioeconomic and gender disparities. Women are at risk of infection and have few options for providing for their families. Children affected by HIV/AIDS, due to their own infection or parental illness or death, are less likely to receive education, as they leave school to care for ailing parents and younger siblings.
- Straining the resources of communities, hospitals, social services, schools and businesses. Health care workers, teachers, business and government leaders have been lost to

HIV/AIDS. The impact of diminished productivity is felt on a national scale (Kaiser Family Foundation, 2007).

The increase in AIDS-related illnesses and deaths also puts an additional burden on social services, affecting various institutions in several ways: increased sick leave and absenteeism, high medical expenses, low productivity, higher worker turnover, loss of skilled labour force, increased training costs, and increased expenditure on health and death benefits (UNAIDS and WHO, 2007). Highly active antiretroviral therapy (HAART) continues to have a favourable impact on disease progression and mortality in settings where it is available to PLWHA, but this also puts increased strain on health workers. As access to treatment is slowly expanded throughout the continent, millions of lives are being extended and hope is being given to people who previously had none. The survival period for many PLWHA who have access to HAART has lengthened significantly over the past 12 years but is associated with drug side effects and complications, thereby increasing the burden of care on nurses.

2.3 DIFFERENCES BETWEEN HIV/AIDS AND OTHER CHRONIC ILLNESSES

HIV/AIDS is now widely accepted as a chronic illness and, as such, requires ongoing primary care management (Siegel and Lekas, 2002; Herek, Capitanio and Widaman, 2002). Several features make management of HIV/AIDS different from other chronic illnesses:

- Adherence to antiretroviral regimens is complex and requires extraordinarily rigid adherence, dietary guidelines; side effects may occur.

- Daily self-monitoring of HIV/AIDS is difficult due to the nature of the disease itself. No self-administered HIV laboratory tests exist that can give patients immediate feedback on the effectiveness of self-management.
- HIV/AIDS stigma persists, the discrimination and social ostracism that many infected people experience is severe. The disclosure of their HIV positive status has exposed people to violence, loss of jobs and housing, and even death (Herek et al., 2002).
- In addition, chronic illnesses bear some stigma. The degree of stigma largely depends on factors such as whether the person is perceived as being responsible for acquiring the disease and whether the disease is communicable (Herek et al., 2002).

2.4 WHAT IS SELF-MANAGEMENT?

A consistent definition is indispensable: self-care management is variously referred to as self-care or self-management (Thorne and Paterson, 2001). The UK Centre for Advancement of Health (2002) proposes that: self-management involves [the person with the chronic disease] engaging in activities that protect and promote health, monitoring and managing symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to a treatment regimen. Self-management refers to the individual's ability also to manage the physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. It also includes the ability to monitor one's condition and affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life (Barlow et al., 2002).

Self-management is also about enabling “participants to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise, to practice new health behaviours, and to maintain or regain emotional stability” (Lorig, 1993).

Self-care suggests that individuals use their resources, including personal attributes such as knowledge, skills, positive attitudes, determination, courage, and optimism, to improve poor health (Akinsola, 2001). Patient self-management is “the ability of patients with chronic illness, in a complementary partnership with their health care providers, to manage the symptoms, treatment, lifestyle behaviour changes and many physical and psychosocial challenges that they face each day” (HRSA HIV AIDS Bureau, 2006). Self-management is an essential part of chronic disease care, and it includes the responsibilities of both patient and provider. It implies engaging in activities that promote health, build physiological reserves, and prevent adverse sequelae. It also entails interaction with healthcare providers and adherence to recommended treatment protocols; monitoring physical and emotional status and making appropriate management decisions on the bases of self-monitoring; and managing the effects of illness. Whilst there is no clear consensus across the literature on what self-management is (the terms self-management, self-care and self-help are used interchangeably), the UK Department of Health (2006) has adopted the following definition: self-care includes the actions individuals and carers take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions, and maintain health and well-being after an acute illness or discharge from hospital.

According to Richard and Shea (2011), self-care involves both the ability to care for oneself and the performance of activities necessary to achieve, maintain, or promote optimal health. It may be viewed as a continuum ranging from complete independence in managing health to complete reliance on medical care (Wilkinson and Whitehead, 2009). It should be noted that: self-care is situation and culturally influenced; involves the ability to make decisions and perform actions directly under the control of the individual; and is influenced by a variety of individual characteristics Gantz, 1990). It is also good to note that the concept of self-care underpins many nursing interventions, particularly those supportive and educative activities intended to promote the ability of individuals or families to assume responsibility for an individual's healthcare needs (Cebeci and Senol, 2008; Sidani, 2011).

Self-management is the ability of the individual , in conjunction with family, community and healthcare professionals to manage symptoms, treatments, lifestyle changes and psychosocial, cultural, and spiritual consequences of chronic diseases (Wilkinson and Whitehead, 2009). It is an ability and process that individuals use in conscious attempts to gain control of his or her disease, rather than being controlled by it (Thorne et al., 2003). There is consensus among scholars that, the term self-management can apply to health promotion activities as well as to those related to acute or chronic illness (Wagner, Davis, Shaefer, Von Korff and Austin, 2002; Lorig and Holman, 2003; Jerant, von Friederichs-Fitzwater and Moore, 2005; Wilde and Garvin, 2007). It is different from disease-management which is not under the individual patient's control but refers healthcare systems that are put in place to facilitate healthcare provider's ability to manage a patient's chronic illness (Wagner, 2000). The process of self-management

includes monitoring perceived health and implementing strategies to manage treatments and medications, safety, symptoms, and other implications of chronic disease (Thorne et al., 2003).

2.5 SELF-MANAGEMENT EDUCATION NEEDS OF PLWHA

Although current literature often presents PLWHA as partners in their health care, less is known about the process of identifying PLWHAs' preferred self-management educational needs. Self-management educational needs of PLWHA may include general health needs, applicable to all persons with chronic illness, or specific needs such as prevention of disease transmission, living with HIV/AIDS; and managing HIV/AIDS-related health risks, symptoms, or side effects. Because self-management is focused on patient concerns and problems, a detailed needs assessment must be done for each new topic and group of patients. Patient self-management programmes which tailor educational content and methodology to individual patients and which are integrated into medical care may prove to be more effective than structured self-management education courses, for which only specific patient subgroups might be ready (Warsi, Wang, and LaValley, 2004).

2.6 MODELS OF SELF-MANAGEMENT PROGRAMMES

The health care system of the USA, for example, is neither effective nor efficient (Lorig and Holman, 2004): the traditional healthcare delivery systems have not fully evolved to meet the needs of patients and populations with chronic diseases; care is fragmented, duplicated and directed at acute disease. Recognition of this shortcoming has now led to new strategies for care delivery, including the concept of self-management. In South Africa healthcare services are not

evenly distributed throughout the country, and are everywhere under severe strain. In these circumstances self-management becomes a necessity.

My literature search revealed that most self-management approaches have multiple components and the contents are not always described in sufficient detail to allow a thorough understanding of the process, or a valid evaluation of the programme. Over the past 20 years, overlapping approaches have emerged. The most influential work on self-management has been conducted by Lorig in the USA (Lorig and Holman, 2003). This work has focused on the delivery of educational programmes for people with rheumatoid arthritis, led either by healthcare professionals or service users. The Stanford Model was developed by Kate Lorig (1993) and her associates. These programmes provide information, skill and training to empower people to manage their conditions. The Chronic Disease Self-Management Programme (CDSMP) is a structured group-based self-management programme for people with chronic conditions, addressing general management problems for various chronic conditions. The CDSMP is based on the self-efficacy theory developed by Bandura (1997) and incorporates skills mastery; reinterpretation of symptoms, modelling, and social persuasion to enhance self-efficacy expectancies (Lorig, Sobel, Ritter, Laurent and Hobbs, 2001); Lorig and Holman, 2003). It enables people to work in a group setting, to understand the components of self-management and to learn skills and strategies to improve their ability to manage their lives.

Another model is the Flinders Model, developed by Malcolm Battersby (2007) and associates at the Flinders Human Behaviour and Health Research Unit, South Australia. The model, underpinned by cognitive behavioural therapy principles, offers a generic approach to chronic

condition self-management that can be applied to a wide range of health conditions. It provides a structured, patient centred framework for collaborative problem definition, goal setting, care planning and review between an individual and the health professional. The Stanford and Flinders models are complementary approaches to chronic condition self-management. There is also San Francisco Model of care, developed by Bill Holzemer (2004) and associates at the School of Nursing, University of California, San Francisco. The model is about coping and managing the numerous symptoms in all the stages of HIV/AIDS and provides strategies for controlling symptoms for PLWHA.

In Africa, there is a paucity of empirical data on HIV/AIDS self-management; there has been a partial and adapted use of the San Francisco Model in some southern African countries; through studies conducted by Sukati et al., (2005).

There remains a need for studies that will explore the development of HIV/AIDS self-management education models in the African context. Self-management appears to be a broad concept. However, this has been used in very different ways by different schools of thought. It is this heterogeneity that makes it hard to determine possible effects on the quality of life and on the effectiveness of a chronic condition's self-care management. Heterogeneity not only hinders our understanding of what self-management actually is, but also prevents uniform evaluation of self-management programmes and, consequently, also the comparison of study results. This study focuses on PLWHA in self-management education initiatives within the specific context of southern KZN, asking the question of how a model for HIV/AIDS self-management education

allows for needs assessment, and implementation of self-management education programmes. How does it enable evaluation of programmes and the outcomes of self-management education?

2.7 SELF-MANAGEMENT EDUCATION APPROACHES

Self-management approaches to chronic disease care explicitly recognize and promote the central role of the patient in evaluating symptoms and planning and coordinating health services (Gifford and Sengupta, 1999). The majority of self-management approaches target adults; few have focused on children or carers (Barlow, Wright, Sheasby, Turner and Hainsworth, 2002). Self-management interventions are delivered in a variety of settings, with the most popular being clinical locations (hospitals) or the home environment. Other locations such as adult education centres, community facilities (church halls), primary care centres, rehabilitation centres, research centres, residential camps, schools, tertiary care centres and work sites were also reported in the literature. A range of tutors, by no means always doctors or nurses delivered self-management interventions, although the majority were health professionals. Dietitians/nutritionists, doctors, educators, nurses, occupational therapists, pharmacists, physiotherapists/physical therapists, psychologists, researchers/social scientists, social workers, speech/language therapists and lay people with chronic conditions were also trained to deliver the intervention.

Self-management approaches were either group-based, individualized, or a combination of both. Group approaches typically comprise between six and twelve participants and are often supplemented with written materials and audiotapes. Individual approaches range from manuals that participants work through at home, to sessions with a health professional on a one-to-one basis in the clinical setting. They may include books and audiotapes given to individuals by

healthcare professionals/workers, computer-generated, written advice mailed to individuals, flip cards, internet, manuals, and TV/radio programmes, as well as videos of group sessions plus written materials and videotape.

The format of self-management approaches varies and includes booklets, lectures, role play and contracting (goal setting). Most approaches combine at least two formats of delivery (lectures and manuals). A list of formats used comprises audiotapes, videotapes, behavioural ratings, booklets, the buddy system (involving people being paired and encouraged to compare their progress), computer generated materials, individualized written advice, contracting, counselling, exercise sessions, flip cards, goal setting, group discussion, individual plans (diet, exercise), instruction from health professionals (in the use of medication), lectures/talks by health professionals, manuals, problem solving sessions, reward systems, role play, sharing experiences (Barlow et al., 2002).

A diverse range of self-management components was identified. These were broadly classified as the provision of information, drug management, symptom management, dealing with psychosocial consequences, life style changes (including exercise), social support, communication and other self-management strategies, such as career planning, goal setting and accessing of support services (Barlow et al., 2002). Most self-management approaches are multi-faceted. One limitation of the published literature is that the content is not always described in sufficient detail to allow a thorough understanding of the intervention. It is difficult to tease out the precise mechanisms leading to change among participants in a multi-component approach. However, this difficulty must be balanced against the fact that multi-component programmes are

usually designed to increase the repertoire of participants' self-management skills within the realities of living with a chronic condition. Effective self-managers will feel confident in selecting the technique(s) that they believe will meet their specific needs at a given point of time, and in a given environment or situation.

Overall, there is a growing body of evidence to show that, when compared to no intervention (standard care), self-management approaches can benefit participants, particularly in terms of knowledge, performance of self-management behaviour, self-efficacy and aspects of health status (Barlow et al., 2002). Individualized approaches appear to be as effective as group approaches, although many group approaches include individualized aspects (access to counselling). There is, however, one major problem with individualized approaches involving one-to-one contact with health professionals, and this relates to cost. Finally, self-management approaches appear to be as effective as other cognitive-behavioural interventions.

2.7.1 Internet self-management programmes

Information technology, especially Internet access, is likely to provide numerous opportunities for informing PLWHA about their condition, treatment options, and health promotion strategies. "Widespread access to the Internet has the potential to improve the health care and quality of life of people with chronic illnesses, including PLWHA, however, the Internet is not equally accessible to all persons" (Kalichman, Weinhardt, Benotsch, DiFonzo, Luke and Austin, 2002: 109). In a survey of PLWHA regarding their experiences using the Internet, identified a broad range of health-related Internet services, including searching for health, AIDS-specific information, and use of the Internet to communicate with providers. They also noted that among

current internet users, individuals who had internet connections in their homes reported significantly more experiences used Internet, including internet use for interpersonal communication and search functions. They then concluded that a digital divide exists among PLWHA and benefits of internet appear to be better achieved with home access.

The Stanford Patient Education Research Centre entered the online world in 1998, attempting to learn if the sharing and support could be transferred to the online community. Stanford's first patient education programme on the internet was the Back Pain Internet Education Programme, which was developed to determine the effectiveness of a moderated internet discussion group in improving health status and health care utilization. Participants with recurring back pain were randomized to form part of an email list where all members received the posts of all other members, or a control group that received a popular magazine subscription. The study concluded in 2000 and at one year, 69% of the email group demonstrated less disability, fewer worries about their health, and less interference in their daily activities. They also had increased confidence in the management of their symptoms, and increased orientation toward self-care. There was also a trend towards check up visits to physicians. Since then, other internet self-management programmes such as Healthier Living with Ongoing Health Problems, Healthier Living with Arthritis, Healthier Living with Diabetes and Positive Self-Management Programme for HIV have come into being. The Positive Self-Management Programme was a workshop for people with HIV, which was given for two and a half hours, once a week, for seven weeks, in community settings such as centres for seniors, churches, libraries and hospitals. Workshops were facilitated by two trained leaders, one or both of whom were non-health professionals, themselves being HIV positive.

The programmes are effective and give people with chronic conditions the skills to coordinate all the things needed to manage their health, as well as to help them keep active. Although internet self-management programmes are available, they are unlikely to be accessible to semi-rural communities where internet facilities are not readily available.

2.8. BARRIERS TO SELF-MANAGEMENT EDUCATION PROGRAMMES

Chronic disease self-management education programmes aim to empower patients through providing information, and teaching skills and techniques to improve self-care and provider-patient interaction, with the ultimate goal of improving the quality of life of patients (Jordan and Osborne, 2007). Barriers to engagement include uncertainty concerning the benefits of self-management programmes and limited local evidence on the impact of such programmes on patients' self-care abilities. (Kennedy, Gately and Rogers, 2004). This evidence appears to be necessary to convince both patients and professionals of the worth of self-management education programmes. Another factor that has limited the effectiveness of self-help programmes is the poor understanding of self-management within the broader community. Reliance on social marketing alone to raise awareness and encourage patient self-referral to programmes is labour-intensive and time-consuming and does not sufficiently engage marginalized sectors of the community (Kennedy et al., 2004). This has led to concerns that self-management activities promote increasingly social inequities, as illiterate people with low incomes are not being reached (Foster et al., 2003).

Barriers to implementation

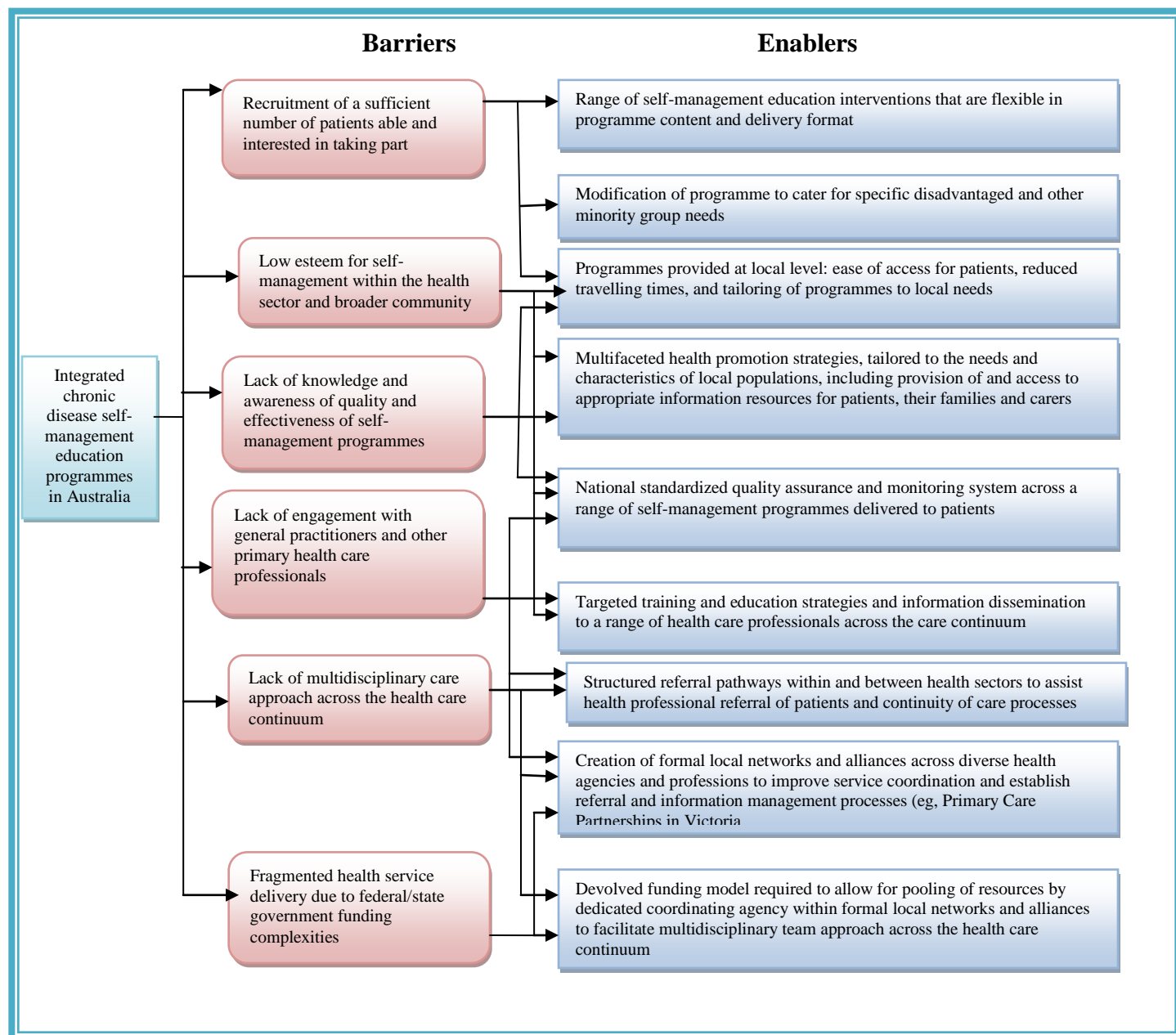
In a community case study conducted in Arkansas, USA, by Balamurugan, Rivera, Jack, Allen and Moris (2006), it was found that there were anticipated and unanticipated barriers to implementation at both the patient and programme levels. These barriers were categorised as: at patient level, inadequate transportation, low literacy levels, difficulties of reimbursement to Medicaid recipients and retention of participants. At programme level the problems included: selection of programme sites, financial constraints such as the difficulties of carrying out the programme without medical insurance reimbursement, shortage of registered dieticians who can teach patients about appropriate nutrition, and difficulties of collecting and classifying data at programme level. Balamurugan et al (2006) provide a summary of anticipated and unanticipated barriers and strategies used to minimize or eliminate the barriers (see Table 2.1, on p 38 below).

In another study conducted in Australia by Jordan and Osborne (2007) key barriers identified were: difficulty in recruitment of a sufficient number of patients able and interested in taking part, poor understanding of self-management among health sector professionals and the broader community, The community as a whole lacked awareness of the quality and effectiveness of self-management programmes. Instructors tended fail to engage with general practitioners and other primary health care professionals, they tended to have difficulty in adopting a multidisciplinary approach across the health care continuum; finally, health service delivery tended to be damagingly fragmented due to federal/state government funding complexities (See Table 2.2 below).

Table 2.1: Anticipated and Unanticipated Barriers Faced in Establishing Diabetes Self-management Education (DSME) Programmes in Underserved Areas, Arkansas, USA, 2003–2004.

| Barriers | Anticipated or unanticipated | How barrier was overcome | Lessons learned |
|--|------------------------------|---|--|
| Programme level | | | |
| Recruitment of programme sites | Anticipated | Coalition members provided hands-on training and technical assistance | Cost-effectiveness data are needed to increase buy-in among those interested and as a marketing tool to promote significance of DSME |
| Financial constraint | Anticipated | Coalition assisted with resources | Arkansas Diabetes Programme should look for funds to sustain existing programmes and to establish new programmes |
| Insurance reimbursement to health centres | Anticipated | Funds were met through grants | Coalition is exploring opportunities for bridging gaps in funding |
| Shortage of registered dietitians | Anticipated | Programmes shared their dietitian | Shortage of registered dietitians must be addressed |
| Data collection | Unanticipated | Barrier could not be overcome | Evaluation plan and involvement of all stakeholders are essential during planning phase of the programme |
| Patient level | | | |
| Transportation | Anticipated | Transportation was provided from hospital or church | Relationship with local community organizations should be established |
| Literacy levels | Anticipated | Staff members assisted with reading and interpreting materials | Culturally and linguistically appropriate materials should be used |
| Reimbursement to Medicaid recipients | Anticipated | Barrier could not be overcome | Reimbursement issues negatively affected programme retention |
| Retention | Unanticipated | Participants received postcard and telephone reminders from some DSME staff members | No unified effort to retain participants was made, possibly because of lack of evaluation plan |

Table 2.2: Key barriers to and enablers for integration of self-management programmes in Australia



2.9 Evaluation of Self-Management Programmes

Five common threads in programme evaluation; according to Shadish, Cook and Campbell (2001), are woven throughout the literature on programme evaluation. First is a concern with *how to construct valid knowledge*. This concern has both a philosophical component and a methodological component; the philosophical component relates to the kinds of things healthcare providers needed to know about programmes. The methodological component comprises the designs, measures, and analyses that are used to create and organize data. A second concern is with *how researchers calculate the relative values of results*. Data do not speak for themselves, in the sense of declaring their own value or relevance. The third concern is with *how programmes must change and adapt*. Programme evaluation is intended to be a practical area of study, which aims to make a difference in people's lives. Researchers must be able to distinguish the points at which particular programmes are required to be changed.. The fourth concern is *how to use evaluation results* productively to form policy. This concern is about how to get our results to the stakeholders and help them to make use of the data. Finally is the concern with *how to organize evaluation practice*, given the implications of all the preceding issues for the role of the evaluator in any given evaluation. This fifth concern is always a matter of tradeoffs, for one can never do everything perfectly in a single evaluation.

Demand for Accountability and Results:

Decision and accountability, client centred and responsive case studies, and outcomes monitoring are a few of the evaluation approaches that have met the high standards of usability, feasibility, propriety, and accuracy (Stufflebeam and Shinkfield, 2007). Because of the need for multidisciplinary and multidimensional approaches to address factors that influence chronic

diseases, the use of one or more evaluation approach to ascertain programme effectiveness is necessary. Sometimes a combination of methods is used to capture the merits of a particular study.

Framework for programme evaluation:

Martin and Heath (2006) used the Framework for Programme Evaluation in Public Health (CDC, 1999) to discuss a hypothetical case study of a physical activity programme to prevent diabetes. They discuss each of the six steps: (1) engage stakeholders, (2) describe the programme, (3) focus on the evaluation design, (4) gather credible evidence, (5) justify conclusions, and (6) ensure use and sharing of lessons learned. The authors also present a logic model with possible short-term, intermediate, and long-term objectives, and briefly discuss quantitative and qualitative data gathering and analysis. They conclude with a brief discussion of the ways to share programme evaluation findings with the community.

Measurements in the process evaluation:

In order to determine the feasibility of the programme, four process outcomes should be assessed by means of structured evaluation forms: (1) the extent to which the programme was performed according to protocols and the time spent on the sessions, (2) patients' attendance, (3) overall patient adherence and specific adherence to regulations concerning homework assignments; and (4) the opinions of the patients and leaders of the programme (Smeulders, Haastregt, Van Hoef, Van Eijk and Kempen, 2006).

Measurements in the evaluation of effects:

The primary outcomes of the evaluation are psychosocial attributes, conceptualized as self-efficacy expectancies, perceived control, and cognitive symptom management (Smeulders et al., 2006). These are assumed to be directly influenced by the self-management programme. The secondary outcomes considered to be indirectly influenced by the programme are health related behaviour, quality of life, and use of health care facilities. Health behaviour can be divided into three measurements: (1) lifestyle and body mass index (BMI), (2) physical activity level, and (3) self-care behaviour. Physical activity can be measured with appropriate scales. Quality of life can be conceptualised as health-related, perceived self-care ability and management of symptoms. It can be measured using generic and disease-specific instruments. Finally, health care utilization can be measured by patients' self-reports on the number of contacts with a general practitioner or specialist, the number of hospitalization days, the reason for hospitalization, and the number of visits to accident and emergency departments. Key indicators of quality of self-management education programmes include: (1) active engagement in life; (2) health-directed behaviour; (3) acquisition of care-related skills and technique; (4) constructive attitudes and approaches; (5) self-monitoring and insight; (6) ability to contact appropriate health services; (7) social integration and support; and (8) emotional wellbeing (Nolte, Elsworth, Sinclair and Osborne, 2007).

2.10 SELF-MANAGEMENT EDUCATION PROGRAMMES FOR PLWHA IN DEVELOPING COUNTRIES

The self-management education programmes for PLWHA in developed countries have generally been in existence for at least two decades longer than those in African countries and have been

accumulating experience. Studies on self-management education are not extensive in developing countries, where more than 90% of PLWHA reside. The most extensive of these studies focuses on symptom management: Sukati, Mndebele, Makoa, Ramukumba, Makoe, Seboni, Human and Holzemer (2005) describe self-reported strategies used by PLWHA in Botswana, Lesotho, South Africa, and Swaziland to manage common HIV-related symptoms. The self-management strategies were coded into eight categories: medications, complementary treatments, self-comforting, changing diet, seeking help, exercise, spiritual care, and daily thoughts/activities. Overall, participants reported medication adherence as the most frequently occurring symptom management strategy and the most effective. A small inventory of behavioural strategies was available to participants to help them manage their HIV-related symptoms. The researchers concluded that PLWHA should receive information that enables them to use strategies and resources other than conventional medicines to ameliorate their symptoms and maintain function. The researchers also suggest that more qualitative research may help capture new self-care behaviours in the population groups with which they worked, and that trials are needed to test the effectiveness of self-management strategies used to manage HIV/AIDS symptoms

2.11 THE MEANING OF URBAN AND RURAL SETTINGS IN THE SOUTH AFRICAN CONTEXT

The terms ‘urban’ and ‘rural’ settings have a complicated history in South Africa, and there is still no precise agreement about what constitutes urban or rural settings. Urban settings are cities and towns, in which until the political change of 1994, only whites were, in general, allowed to reside. One distressing legacy of these past policies is that the rural settings where black people live in the countryside tend to be poor and decaying, and lack educational facilities, especially

universities and colleges, which could teach individuals the skills of modern living. They have become places which are traps for the old and the young. The poorest and least-developed rural community settings are those that were located in the former homelands. Although KZN was never declared a homeland, the province exhibits some attributes of these former homelands. The legacy of poverty and neglect persists, partly because of the emphasis in South Africa on urban development. The realities faced by people, most especially PLWHA in rural settings cannot always be addressed by policies made elsewhere. PLWHA in rural communities need methods of managing their affairs and ways of developing social networks and cultural practices that will improve their quality of life. The preliminary aspect of this study, therefore, includes an assessment of the self-management education needs of PLWHA in semi-rural KZN.

Semi-rural settings can be said to be an inter-phase between core urban and rural settings. This study is located in one of such settings. Despite post-apartheid policies that have increased health spending in poor districts, rural and African residents bear the largest burden of illness (Coovadia, Jewkes, Barron and Sanders, 2009; Chopra, Lawn, Sanders, Barron, Abdool Karim, Bradshaw, Jewkes, Abdool Karim, Fisher, Mayosi, Churchyard and Coovadia, 2009). Migrant labour and underdeveloped health services for African people, have resulted in an environment that allows for the efficient transmission of HIV (Abdool Karim et al., 2009, Coovadia et al., 2009). Although post-apartheid policies have aimed at redistributing funds to primary health care, and equalizing the distribution of funding between rural and urban clinics, this section of the health system remains inadequately funded and resourced (Chopra et al., 2009; Coovadia et al., 2009; Abdool Karim et al., 2009; Sewankambo and Katamba, 2009). Consequently, much of the burden of caring for those infected with HIV/AIDS falls onto households and communities

(Tshililo and Davhana-Maselesele, 2009, Russell and Schneider, 2000, Ndaba-Mbata and Seloibe, 2000).

Recently, efforts in health care have been directed towards eliminating health disparities. Emphasis has been placed on reaching the goal of health for individuals in all areas of South Africa where such disparities exist, especially for PLWHA. The burden of HIV and AIDS for PLWHA differs between urban and rural areas, and this is due solely to individual behaviours and social contexts which contribute to the spread of HIV (Adimora and Schoenbach, 2005; Herbst, Beeker, Mathew, McNally Passin and Kay, 2007). This difference may be particularly important in rural South African communities, which tend to be unplanned and characterized by higher rates of poverty and unemployment. These social and economic disparities act synergistically to increase the likelihood of high risk behaviour and may affect individuals in low and higher risk sexual networks (Adimora, Schoenbach, Martinson, Coyne-Beasley, Doherty and Stancil, 2006) including PLWHA. Isaacs and Schroeder (2004) argue that PLWHA tend to use a disproportionate amount of health care resources, and to experience greater morbidity and mortality than others; they therefore need to learn health-promoting behaviour.. However, there is limited empirical evidence to support this. It is helpful for clinicians who work with PLWHA to understand their readiness and willingness to adopt healthy lifestyle practices.

Community health nursing aims at improving the health of the individuals and therefore incorporates interventions that assist individuals to adopt health-promoting practices (Williams, 2005). Theoretically, embracing health-promoting behaviour implies orientation on a future, and belief that making change in the present will impact on future health. Personal behaviour along

with interactions with the physical and social environment is deeply involved in the causation and management of chronic conditions, including HIV/AIDS (Katz, 2003).

2.12 STANDARD HIV/AIDS CARE AND MANAGEMENT IN THE SOUTH AFRICAN CONTEXT

My source here is Standard HIV/AIDS care and management in South African context (National Department of Health, 2008). The purpose of guidelines is to set standards as the basis for the use of ARVs in South Africa on which training and support programmes should be based. All health care workers in the public and private sector are urged to familiarize themselves with the content of these guidelines so that they can provide the best possible care for those with HIV and AIDS in South Africa. The field of antiretroviral therapy is dynamic and changes rapidly; thus these guidelines are reviewed periodically to ensure that South Africa continues to provide quality care to PLWHA.

These guidelines serve to assist the medical team in the management of patients on antiretroviral drugs as outlined in the Comprehensive Plan for HIV and AIDS Care, Management and Treatment. The approach adopted is that of the continuum of care, with a holistic patient focus in an integrated health system from primary (primary health care is given in homes and communities; secondary care takes place in clinics and general hospitals; tertiary care is provided by specialist hospitals to tertiary levels), as well as from the clinic to the community and from pre-diagnosis to palliative treatment, whichever is appropriate. In the case of self-management programmes, the focus is at the primary health care level within the context of the district health system being implemented throughout the country. These guidelines are revised as necessary to

reflect the changing treatment of HIV and the efforts to ensure the highest possible standard of care for all South Africans.

Description

HIV enters lymphocytes and replicates, leading to the progressive destruction of the immune system, until the infected person becomes unable to fight infection and develops the syndrome of Acquired Immune Deficiency Syndrome (AIDS). During the course of the initial HIV infection antibodies are developed to the virus and the person changes from HIV negative to HIV positive. This is known as seroconversion or primary infection and is characterized by: glandular fever type illness; maculopapular rash; and small orogenital ulcers.

South Africa has adapted the WHO staging system for HIV infection and disease in adults and adolescents. TB has been moved to stage 3 in the South African adapted WHO staging.

Methods of Diagnosis

- Adequate pre-and post-test counselling must be provided.
- Patient confidentiality must be ensured.
- HIV in adults must be confirmed by a second test. This can either be two rapid tests, using kits from different manufacturers or a single laboratory test, usually ELISA.
- There is a window period of up to three months in which antibodies cannot be detected by blood tests. There is a short period between becoming infected and the appearance of antibodies which are detectable by blood tests.

General Measures

- Patients and their families must be supported and encouraged to join support or peer groups.
- Patients must be counselled on preventive methods of reducing the spread of the disease.
- Multivitamins must be given orally, once daily (do not exceed the dose and do not give vitamin B complex).

Antiretroviral Therapy (adults)

Only facilities accredited as CCMT service points may initiate long term ARV therapy.

All HIV-infected patients must have a CD4 count requested and WHO clinical staging done. The CD4 count should be repeated every six months. All eligible patients must be referred to the nearest CCMT service point for antiretroviral therapy. The patient should be counselled about antiretroviral therapy prior to referral.

For the management of uncomplicated HIV and AIDS in adults:

Regimen 1

- Stavudine, oral, 30 mg 12 hourly or for overweight patients with a BMI greater than 28 Zidovudine, oral, 300 mg 12 hourly and Lamivudine, oral, 150 mg 12 hourly, plus Efavirenz, oral, 600mg at night, or for women of child-bearing potential, Nevirapin, oral, 200 mg daily for the first 2 weeks increasing to 200 mg 12 hourly thereafter.

Regimen 2

- Zidovudine, oral, 300 mg 12hourly and Didanosine, oral, 400 mg once daily on an empty stomach or if less than 60 kg: 250 mg once daily plus Lopinavir/ritonavir 400/100 mg, oral, 12 hourly.

Patients on long term ARV treatment, who become pregnant, should be referred back to their CCMT site.

For patients with a positive hepatitis B surface antigen:

The combination of tenofovir 300 mg daily and lamivudine 300 mg daily will be replaced:

- Stavudine and Lamivudine in regimen 1
- Zidovudine and Didanosine in regimen 2

Note:

In patients with hepatitis B, do not stop tenofovir and lamivudine as this can cause a severe flare up of hepatitis B. Even if patients fail regimen 1 and commence regimen 2, continue with tenofovir and lamivudine, replacing zidovudine and didanosine. Tenofovir may be substituted for stavudine if lipo-atrophy occurs. Tenofovir and lamivudine are recommended to substitute for stavudine and lamivudine or zidovudine and didanosine if patients develop symptomatic hyperlactataemia.

Primary prophylaxis with cotrimoxazole, oral, 160/800 daily prevents many infections.

Indications for primary prophylaxis:

- WHO clinical staging II, III or IV for HIV infection and disease in adults and adolescents.
- CD4 count less than 200 cells/ microL

Prophylaxis may be discontinued if the CD4 count increases on antiretroviral therapy to more than 200 cells/microL for at least 6 months.

Specific treatments are also provided for opportunistic infections as appropriate.

Diagnosis in Children

Infant HIV testing (0-18 months)

- Early HIV testing in infants exposed to HIV during pregnancy and/or breastfeeding is essential to optimize child survival because children can then access care, treatment and support as early as possible. HIV tests can never be 100% accurate. Therefore if HIV test results are discrepant with the clinical picture, repeat the HIV test.
- Testing children younger than 18-months:
 - Virological testing using PCR is the test of choice.
 - After counselling has been done and consent has been obtained, test ALL HIV-exposed infants at six weeks of age, using PCR.
 - If an infant is symptomatic for HIV infection, do not wait until 6 weeks to perform PCR test; perform the test and retrieve the result as a matter of urgency. If PCR test result is negative, consider other causes for symptoms.
 - If the PCR test was performed earlier than 4 weeks of age in an HIV-exposed child and the result is negative, repeat the PCR at 6 weeks of age to exclude HIV infection.
 - Up to 18 months, an antibody test could be falsely positive, because of the presence of the circulation antibodies from the mother, an antibody test cannot definitively diagnose HIV in this age group.
 - However, a negative antibody test in children under the age of 18 months can be helpful in excluding HIV infection in symptomatic children.
 - In an HIV exposed, HIV PCR negative breastfed infant, repeat PCR 6 weeks after cessation of breastfeeding; if the cessation of breastfeeding happens after the child turns 18 months then an antibody test is done.
 - If an HIV-exposed, HIV PCR negative breastfed child becomes symptomatic of HIV infection, perform a repeat PCR.

Testing children older than 18 months:

- At 18 months on *all* HIV-exposed children (PCR negative and positive) antibody tests should be done to confirm their HIV status and to rule out false positive results as well as to exclude new infections.
- HIV antibody testing can be used to confirm HIV status in children older than 18 months as stated in the VCT policy.
- Testing should be done with counselling of parent/legal guardian/primary caregiver and, where appropriate, the child.

Management of HIV infected children

All HIV positive children should receive standard preventive care: immunization, deworming, and Vitamin A.

Children under one year of age:

Refer as soon as possible to an accredited CCMT service point for assessment.

Children over one year of age:

At PHC facility, do:

- Routine clinical staging every three months
- Six monthly CD4 percentage and absolute count.

Once the child fulfils the medical and social criteria for ART, refer to a CCMT service point for initiation of ART.

Stabilized children on ART at PHC

Ongoing care for children on ART includes:

- Monitoring treatment adherence

- Ensuring the child receives the necessary ARVs on a monthly basis
- Referral for laboratory investigations and re-assessment as required
- Assessment for drug side effects or other complications
- Routine care for immunization and weight monitoring as per the EPI schedule and the Road-to-Health card.
- Management of undercurrent infections, including TB
- Counselling and support of the parents/caregivers
- Arranging for palliative care where appropriate, with the support of non-governmental organisations (NGOs)

Table 2.3: On-site Treatment Monitoring

| Regimen | Drugs | Monitoring tests | Frequency |
|---------|--|---|---|
| 1A | Tenofovir,Lamivudine/Emtricitabine and Efavirenz. | -CD4, HEP B, -VL, -ALT | -Staging, 6 monthly - Baseline, 6-monthly -Symptomatic |
| 1B | Tenofovir,Lamivudine/Emtricitabine and Nevirapine. | CD4, HEP B, VL, ALT, LFT, AST | -Staging, 6 monthly - Baseline, 6-monthly Baseline, week 2, 4 and 8, thereafter 6 monthly |
| 1C | Zidovudine, Lamivudine and Efavirenz. | CD4, HEP B, VL, ALT, LFT, AST | -Staging, 6 monthly - Baseline, 6-monthly Baseline, week 2, 4 and 8, thereafter 6 monthly |
| 2A | Tenofovir,Lamivudine/Emtricitabine and Lopinavir. | CD4. FBC, HEP B, Fasting cholesterol and triglyceride. Fasting glucose | -Staging, 6 monthly Baseline, then monthly for 3 months, then 6 monthly (with CD4) Baseline, 6 months and thereafter every 12 months |
| 2B | Zidovudine, Lamivudine and Lopinavir. | CD4. FBC, HEP B, Fasting cholesterol and triglyceride. Fasting glucose blood level | -Staging, 6 monthly Baseline, then monthly for 3 months, then 6 monthly (with CD4) Baseline, 6 months and thereafter every 12 months |

2.13 CONCLUSION

This chapter presented a review of the relevant theoretical and empirical literature and rounded off with the standard HIV/AIDS care and management in the South African context.

CHAPTER THREE

CONCEPTUAL FRAMEWORK GUIDING THE STUDY

3.0 INTRODUCTION

This chapter starts by discussing the concept of self-management, the emergence of self-management education in health care, and goes on to discuss the philosophical underpinnings of self-management related theories. It concludes with the development of a conceptual framework.

3.1 THE CONCEPT OF SELF-MANAGEMENT

Self-management means different things in different fields, in business, education, and psychology, self-management refers to methods, skills, and strategies by which individuals can effectively direct their own activities toward the achievement of objectives, and includes goal setting, decision making, focusing, planning, scheduling, task tracking, self-evaluation, self-intervention, self-development. In the field of computer science, self-management refers to the process by which pre-programmed computer systems will (one day) manage their own operation without human intervention. Self-management may also refer to a form of workplace decision-making in which the employees themselves agree on choices (for issues like customer care, general production methods, scheduling, division of labour) instead of the supervisor telling workers what to do, how to do it and where to do it, in the traditional way.

The concept of self-management is understood both as an educative process and an outcome. As an educative process, self-management programmes include: participation in education designed to bring about specific outcomes; preparation of individuals to manage their health conditions on

a day-to-day basis; the practice of specific behaviour; and the development of skills and abilities needed to reduce the physical and emotional impact of illness, with or without the collaboration of the healthcare team (McGowan, 2005). Self-management programmes range from simple, self-help approaches to intensive case-management programmes designed to promote continuity, communication, and collaboration between patients and providers. As an outcome, self-management programmes for the chronically ill aim to have participants achieve the knowledge, skills, and confidence to manage their health and engage in particular behaviours that control or reduce the impact of the disease (McGowan, 2005). This requires patients to become active partners with healthcare providers to the extent that they can take effective control over their chronic condition(s) in their lives (Lorig, 1993). In health care, self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and the lifestyle changes inherent in living with a chronic condition (Barlow et al., 2002). Efficacious self-management encompasses the ability to monitor one's condition and to achieve the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life.

Self-management education aims at helping patients to maintain, mainly by their own efforts, the best possible health. This is done by concentrating on three sets of tasks, as delineated by Corbin and Strauss (1988). According to these authors, the first task involves the medical management and includes taking medication, adhering to a special diet, or using an inhaler. The second set of tasks involves maintaining, changing, and creating new meaningful behaviour of lifestyles. The final task requires one to deal with the emotional sequelae of having a chronic condition, which alters one's view of the future. Emotions such as anger, fear, frustration, and depressions are

commonly experienced by someone with a chronic disease; learning to manage these conditions therefore becomes part of the work required to manage the condition. Self-management education, according to Corbin and Strauss (1988), must include content that addresses all three tasks: medical and behavioural management, lifestyle management and emotional management. Although most health promotion and health education programmes deal with the medical and behavioural management, most do not systematically deal with all three tasks.

For self-management education to focus on patient concerns and problems, a detailed needs assessment must be done for each new topic and group of patients. Lorig and Holman (2003) have identified five core self-management skills: problem solving, decision making, resource utilization, formation of a patient/health care provider partnership, and taking action. People living with chronic conditions must be taught basic problem solving skills. These include problem definition, generation of possible solutions, including the solicitation of suggestions from friends and health care professionals, solution implementation and evaluation of results. A second self-management skill is decision making.

Persons with chronic illness must make day-to-day decisions in response to changes in disease conditions. To do this they must have the knowledge necessary to respond to common changes. Decision-making is based on having sufficient appropriate information. The understanding of the self, which will allow for appropriate decision making, is central to self-management education. A third self-management core skill is the finding and utilization of resources. Self-management education includes teaching people how to use resources and helping them to seek these from different sources. For the best results, it is important to contact several potential resources at the

same time as if casting a net widely for information. This skill is basic but often overlooked in traditional health promotion and patient education programmes. The fourth self-management skill is helping people to form partnerships with health care providers. The patient must be able to report accurately the trends and tempo of the disease, make informed choices about treatment, and discuss these with the health care provider. Self-management training prepares people with chronic illness to undertake these tasks. Finally, self-management should be within the capabilities of each person.

3.2 EMERGENCE OF SELF-MANAGEMENT IN HEALTH CARE

The use of self-management in health care started in the 1960s, and the term self-management indicated that the patient was an active participant in treatment. Since that time the term has been used widely, mainly in referring to chronic disease patient education programmes, but has not always been well conceptualized or defined (Lorig and Holman, 2003). A major transformation in the public health profiles and health care systems of many societies, associated with demographic and epidemiological transitions has been experienced in the recent past (Newbould, Taylor and Bury, 2006). In England, longer life expectancy and increasing numbers of people living with chronic conditions has meant that the responsibility for daily disease management has gradually shifted from health care professionals to the individual. A parallel development is the shift away from paternalistic models of health care that sited the patient in the role of passive recipient. This was in part due to the fact that people, at least in the developed world, live longer and are prone to chronic ailments of old age (Lorig and Holman, 2003). As a means of bridging the gap between patients' needs and the capacity of health and social services to meet these needs, the Expert Patient Programme (EPP) in England was announced in 2001. The

establishment of the EPP was based on the notion of patients as ‘experts,’ able to access information relevant to their health care needs and carry out the self-management tasks needed for their condition (Barlow et al, 2002).

Self-management is well known in the field of health and social care, the term is linked with models of coping with adversity through self-help, self-reliance, and family and community reliance (Newbould et al., 2006). The emergence and development of self-management programmes can be attributed to: (1) the growth of policy-makers’ interest in self-care and lay-led self-management approaches to living with chronic illness; (2) the increasing numbers of people seeking to control their own approaches to living with illness with or without the help of medical practitioners and other professionals; (3) an increase in awareness of the need to address chronic illnesses, and employ self-management and other approaches to minimize the distress and other cost that they impose; (4) the belief that promoting self-management and helping individuals to manage potentially disabling conditions better may well have the potential to help them enhance their quality of life; and (5) the process of demographic and epidemiological transition, along with the emergence of new attitudes towards health care delivery, which have been the main drivers of self-management in health care.

3.3 PHILOSOPHICAL UNDERPINNING OF SELF-MANAGEMENT EDUCATION

3.3.1 Patient centeredness

Self-management education utilizes a patient-centred approach and operates through empowerment. The patient-centred approach focuses on the inherent growth principle and the major attitudinal conditions. It calls for self-awareness, reflective listening, empathy and

development of communication skills by clinicians (Mead and Bower, 2000, Epstein et al., 2005). It includes exploring the social and psychological aspects of the patient's health status; understanding the personal meaning of illness for patients by eliciting their concerns, ideas, expectations, needs, feelings and functioning; promoting the understanding of patients within their unique psychosocial context; sharing power and responsibility, and developing common therapeutic goals that are concordant with patients' values (Drach-Zahavy, 2009). The central hypothesis of this approach is that the individual has within him or her vast resources for self understanding, for altering his or her self-concept, attitudes, and self-directed behaviour. These resources can be tapped if a definable climate of facilitative psychological attitudes can be provided (Barbara, 1986).

According to Smith (2004), we cannot teach another person directly; we can only facilitate his learning. The educational situation which most effectively promotes significant learning is one in which (1) threat to the self of the learner is reduced to a minimum and (2) differentiated perceptions of the field of experience are facilitated. The facilitation of significant learning rests upon certain attitudinal qualities that exist in the personal relationship between the facilitator and the learner (Rogers and Freiberg, 1993). Carl Rogers emphasized the attitude of the facilitator, stating that there are 'ways of being' with others that foster exploration and encounter-and these are more significant than the methods employed. Three conditions apply in any situation in which the development of the person is a goal:

1. *Realness in the facilitator of learning.* When the facilitator is sincerely trying to enter into a relationship with the learner without presenting a front or a façade, she is much more likely to be effective. This means that she is in touch with her own emotions and able to

communicate them if appropriate. She can achieve a direct personal encounter with the learner, meeting her on a person-to-person basis. It means that she is being herself, not denying herself.

2. *Prizing, acceptance, trust.* The facilitator's acceptance of the learner is an operational expression of her essential confidence and trust in the capacity of the human organism. The learner is described as an imperfect human being with many feelings, many potential abilities. The facilitator must care for the learner, but non-possessively. She must accept this other individual as a separate person, being worthy in her own right.
3. *Empathic understanding.* A further element that establishes a climate for self-initiated experiential learning is empathic understanding. When the teacher has the ability to understand the student's reactions, has a sensitive awareness of the way the process of education and learning affects the student, the likelihood of significant learning is increased. Students feel deeply appreciative when they are simply understood, not evaluated, not judged, simply understood from their own point of view, not the teacher's (Rogers, 1965).

In a clinical situation, the empathic understanding response process involves the clinician's maintaining consistently and constantly, the therapeutic attitudes, and expressing him/herself to the client through empathic responses. These are responses intended to express the therapist's empathic understanding experience of the client. The client is viewed as the expert about himself and the therapist views himself as expert only in maintaining the attitudinal conditions in the relationship with the client, not as an expert on the client.

The therapeutic relationship is inherently an unequal relation in which the client is self-defined as vulnerable and in need of help and the therapist is self-defined as one who can help. An element in the person-centered approach is the belief that unequal relationships are to some extent hurtful or harmful to the persons involved in them. The professional is particularly mindful of the harmful potential side-effect of the unequal therapeutic relationship and tries to share his authority as much as possible. This awareness and effort influences all his actions in relation to the client. Basically, the professional must understand that the patient is the final authority on his condition and the way the client uses the relationship is always left to the client.

The non-directive attitude has a significant influence on the way therapy is conducted, influencing what is done and what is not done. The non-directive attitude serves not only to protect the client's autonomy and to enhance self-direction; it contributes to the distinctive therapeutic quality of the relationship between therapist and client. This quality involves the fostering in the client of a combination of feelings – of freedom, of a positive sense of self, and of empowerment. The therapist provides the basic therapeutic attitudes of congruence, acceptance and empathy. He combines these with non-directiveness, that is, the absence of directive attitudes and behaviours that would determine the content of the client's expression or determine the processes that take place in him. This whole way of being produces a unique experience, of an authority (the therapist) consistently behaving in a non-authoritative manner. This abdication of the usual forms of authority carries meaning for most clients. It conveys that they are not being evaluated, supervised or controlled. They are not being treated in these usual ways by an authority, which means that they are being treated with respect, are being trusted, and are free, to a great extent, in the relationship. As a consequence the relationship takes on the

qualities referred to above, of freedom, of enhancement of the client's sense of self and sense of personal power.

To bring about the deep change required and to resolve conflict, facilitators must be willing to challenge deeply-held assumptions. There are three conditions which constitute this growth-promoting climate, when we are speaking of the relationship between therapists and client. The first element has to do with sincerity or congruence. The more the therapist is him or herself in the relationship, putting up no professional front or personal façade, the greater is the likelihood that the client will change and grow in a constructive manner. The second attitude of importance in creating a climate for change is acceptance, caring or prizing, that is, unconditional positive regard. It means that when the therapist is experiencing a positive, nonjudgmental, accepting attitude towards whatever the client is at that moment, therapeutic movement or change is more likely. The third facilitative aspect of the relationship is empathic understanding. This means that the therapist senses accurately the feelings and personal meanings that are being experienced by the client and communicates this acceptance to the client (Rogers and Freiberg, 1993). The educational effort must also go beyond traditional education in its content and methods, to support learners in dealing with the emotional upheaval they are likely to experience.

PLWHA, like any other patients with chronic conditions, are compelled to make decisions and engage in behaviour that affects their health. Glasgow, Davis, Funnell and Beck (2003) emphasise that: notwithstanding helpful recommendations, advice and counselling from healthcare professionals, patients themselves must decide which self-care actions to put into practice (Bodenheimer, Lorig and Holman, 2002). Still the question remains, what mechanism will make patient intervention work?

Social cognitive theory specifies a core set of determinants of effective self-management: health habits which include knowledge of health risks and benefits of different health practices, confidence that one can exercise control over one's health habits, health goals people set for themselves and perceived facilitators, as well as social and structural impediments to the change they seek (Bandura, 2004). This theory offers both predictors and principles on how to inform, enable, guide, and motivate people to adapt habits that promote health and reduce those that impair it (Bandura, 1997). Patients who are empowered are effective in self-management and better prepared to positively influence disease control and health outcomes (MacStravis, 1999; Ormel, Linderberg and Steverink, 1997).

In the case of PLWHA, the regulation of behaviour is not solely a personal matter: some of the impediments to healthful living reside in society and its health systems. These impediments are rooted in societal values and in the ways in which health services are structured. PLWHA may be oppressed; suffer rejection, disapproval and neglect from family members and even lovers, are often stigmatized and discriminated against, and may be verbally and “physically abused, even in healthcare settings” (Sukati et al., 2005).

Transformation theory focuses on how we learn to negotiate and act on our own purposes, values, feelings and meanings rather than on those we have uncritically assimilated from others (Mezirow, 2000). Bush and Folger (1994) explicitly outline a framework for the practice of transformative mediation and propose that mediation can effect deeper changes in people and their interpersonal relationships, beyond remedying a short-term problem. They state that

mediation's greatest value lies in its potential not only to find solutions to people's problems but to change people themselves for the better, in the midst of conflict. This can be achieved by employing a specific perspective on mediation practice as well as techniques to change people's behaviour, not only toward their adversaries in particular conflicts, but also in their day-to-day lives thereafter.

3.3.2 Transformation through Empowerment

The transformative approach to mediation seeks the empowerment and mutual recognition of the parties involved. The primary goal of transformative mediation is to foster the parties' empowerment, enabling them to approach their current problem, as well as later problems, with a stronger, more open view. Professionals should listen carefully to statements made by PLWHA, looking for transformative opportunities, and should prioritise encouragement and support. They should support PLWHA in deliberation about the range of choices available to them. Professionals should consciously try to avoid shaping issues, proposals, or terms for settlement, or even pushing for settlement but should rather encourage PLWHA to define problems and find solutions for themselves.

The transformative mediation approach to learning actively involves participants and focusses on behaviour change; for these reasons it seems most suitable for both professionals and PLWHA. There should be a complementary partnership between PLWHA and healthcare providers. The transformative mediation approach to learning explains this. The PLWHA-professional partnership paradigm implies that while professionals are experts about diseases, PLWHA are experts about their own lives (Bodenheimer et al., 2002). Learning is essential for being an

expert; it gives professionals more knowledge and expertise, and it allows PLWHA to identify their problems and cope with their conditions (Lemmens, Nieboer, Schayck, Asin and Huijsman, 2008).

Empowerment, according to Bush and Folger, means enabling parties to define their own issues and to seek solutions on their own. Recognition means enabling the parties to see and understand the other person's point of view, to understand how they define the problem and why they seek the solution that they do. Empowerment means the restoration to individuals of a sense of their own value, strength and capacity to handle life's problems. Through empowerment, disputants gain "greater clarity about their goals, resources, options and preferences" and use this information to make their own "clear and deliberate decisions" (Bush and Folger, 1996). Clarity means that the parties will gain a better understanding of what they want and why, and that their goals will be legitimate and should be considered seriously. They will better understand what resources are available to them and what resources they need to make an informed choice; and become aware of the range of options available to them. They will understand the relative costs and benefits of each option, and understand that the choice of options is theirs alone. They will reflect and deliberate on their own, making a conscious decision about what they want to do, based on the strengths and weaknesses of both sides' arguments and the advantages and disadvantages of each option.

Developing clarity in these areas will strengthen parties' own abilities to resolve the conflicts in which they are involved. This type of empowerment may be called skill-based empowerment, meaning that parties are empowered by improving their own conflict-resolution skills. PLWHA are empowered when they learn how to listen, communicate, analyze issues, evaluate

alternatives, and make decisions more effectively than they could before. Empowerment-oriented interventions enhance wellness, while they also aim to ameliorate problems, provide opportunities for participants to develop knowledge and skills, and engage professionals as facilitators instead of authoritative experts.

PLWHA are expected to make decisions and engage in behaviour that positively affects their health; involving them in their own care process would therefore seem crucial. Patients who are empowered are effective in self-management and are better prepared to positively influence disease control and health outcomes (MacStravis, 1999; Ormel, 1997). Therefore, self-management education that is intended to improve the quality of life of PLWHA should not be only interactive and dialogical, but also nurturing. HIV/AIDS self-management education should go beyond traditional education in its content and methods, to support PLWHA in dealing with the emotional upheaval they are likely to experience. The professionals thus perform the role of facilitators.

3.3.3 Facilitation

Facilitation is a technique by which one person makes things easier for others (Heron, 1989). It describes the support required to help people change their attitudes, habits, skills, ways of thinking, and working. It has received particular attention within nursing quality improvement and clinical practice development initiatives (Morrison, 1992; Burrows, 1996). Nurses as facilitators help PLWHA understand what they have to change and how to change it to achieve the desired outcome. By engaging staff and PLWHA in implementing change in discussing their positions it may be possible to devise action plans that will lead to successful implementation.

It should be noted that openness, supportiveness, approachability, reliability, self confidence, and the ability to think laterally and non-judgementally are central to successful facilitation. Thus facilitators should bring with them a personal repertoire of skills, as well as an ability to work within and across role and structural boundaries in the organization.

For PLWHA, knowledge should lead to enhanced self-efficacy, which in turn influences health behaviour and eventually health status. For professionals, access to decision support should affect professional behavioural intentions, which influence professional behaviour and eventually leads to improved health outcomes. The more active involvement of PLWHA is in keeping with the realities of chronic disease, whereby responsibility for day-to-day disease management gradually shifts from health care professionals to the individual. The PLWHA and the health professional collaboratively identify problems within a motivation process for the PLWHA, leading to sustained behaviour change. Using a transformative mediation approach, PLWHA are allowed to take responsibility for their own learning, by increasing their understanding of the environment in which they live, and by understanding how they are affected by current and potential policies and structures. Equipped with this greater understanding and with new confidence in themselves, PLWHA can develop policies and structures that better meet their needs and strategies for bringing those policies into being.

3.4 EMPOWERMENT THEORIES

Theories of empowerment include both processes and outcomes, suggesting that actions, activities, or structures may be empowering, and that the outcomes of such processes result in higher levels of empowerment (Swift and Levin, 1987). Empowerment theories link individual well-being with the larger social and political environment. The concept connects mental health to mutual help within a responsive community. Empowerment links individual strengths and competencies, natural helping systems, and proactive behaviour to social policy and social change. It recognizes that individual behaviour is governed by societal and cultural norms and that individual knowledge, attitudes and beliefs cannot affect behaviour directly as they are mediated by the relationship among partners and associates (Morris, 1997). As a consequence, a focus on empowerment should recognize the political, social and cultural constraints on health and address the underlying barriers, both at the individual and the societal level, that place an individual in a position of heightened vulnerability. Individual empowerment works to change the extent to which members of a group can overcome their socially structured lack of choice; it strengthens communities' works to change the social structure of their situation.

The strategies for empowering PLWHA can be grouped into three general approaches: education, organization, and networking. The prime theorist on education for empowerment is Paulo Freire in his *Pedagogy of the Oppressed*. According to Freire (1972), consciousness-raising involves a critical and liberating dialogue in which individuals discover the power imbalances within a society that contributes to their oppression, as well as the hidden distortions within themselves that help to maintain an oppressive society. Freire locates this dialogue between oppressed peasants, who contribute the empirical, experiential knowledge of their lives, and revolutionary leaders, who contribute the theoretical analysis of that experience. Freire

emphasizes the elimination of class differences in literacy campaigns using radical teaching methods. At the point of encounter, ‘there are neither ignoramuses nor perfect sages’ there are only men who are attempting together to learn more than they now know (Freire, 1972: 63). His underlying tenet is that the disempowered already know a great deal about the sources of their oppression and what must be done to overcome it.

Empowerment involves access to information, comprehension of the information, the ability to make a decision regarding behaviour change and the ability to carry out that decision (De Guzman, 2001). Empowerment compels us to think in terms of wellness versus illness, competence versus deficiencies, and strengths versus weaknesses. Similarly, empowerment research focuses on identifying capabilities instead of cataloguing risk factors, and exploring environmental influences of social problems instead of blaming victims. Empowerment-oriented interventions enhance wellness while also aiming to solve problems, provide opportunities for participants to develop knowledge and skills, and engage professionals as collaborators instead of authoritative experts. Empowerment, according to Bush and Folger, means enabling parties to define their own issues and seek solutions on their own. Recognition means enabling the parties to see and understand the other person’s point of view – understand how they define the problem why they seek the solution that they do. Empowerment means restoration to individuals of a sense of their own value, strength and capacity to handle life’s problems. Through empowerment, disputants gain “greater clarity about their goals, resources, options and preferences” and they use this information to make their own “clear and deliberate decisions” (Bush and Folger, 1996).

These clarities mean that the parties will gain a better understanding of what they want and why, and that their goals are legitimate and should be considered seriously. They will better understand what resources are available to them and between what resources they need to make an informed choice. They will become aware of the range of options available to them, and understand the relative costs and benefits of each option, understand that the choice of options is theirs alone to make. They will make a conscious decision about what they want to do, base on the strengths and weakness of both sides' arguments and the advantages and disadvantages of each option. Developing clarity in these areas will strengthen parties' own ability to resolve the conflict in which they are involved. This type of empowerment may be called skills-based empowerment, meaning that parties are empowered by improving their own conflict-resolution skills. PLWHA are empowered when they learn how to listen, communicate, analyze issues, evaluate alternatives, and make decisions more effectively than they could before. Interventions need to address both of these dimensions by affecting intermediary variables that determine the vulnerability of PLWHA.

Freire's approach is aligned with "transformative" learning theory. Transformation theory's focus is on how we learn to negotiate and act on our own purposes, values, feelings and meanings, rather than on those we have uncritically assimilated from others—to gain greater control over our lives as socially responsible, clear-thinking decision makers (Mezirow, 2000). Bush and Folger (1994) explicitly outline a framework for the practice of transformative mediation and propose that mediation can effect deeper changes in people and their interpersonal relationships, beyond remedying a short-term problem. They state that mediation's greatest value lies in its potential not only to find solutions to people's problems but to change people

themselves for the better. By employing a specific perspective on mediation practice as well as specific techniques, they believe mediation possesses the power to change people's behaviour, not only toward their adversary in a particular conflict, but also in their day-to-day lives thereafter.

Freire's perspective is an example of an innovative strategy that has been implemented successfully to stimulate social change in an oppressed group. His findings can be used within the realm of emancipatory nursing, which is emerging as an important body of theory and practice that challenges nurses to work as social activists to help people overcome social inequalities as a central strategy for enhancing health (Butterfield, 1990). Emancipatory nursing provides direction for nurses to work with the oppressed in such a way that social inequalities influencing health are identified, and confronted (Maxwell, 1997). In this study I shall place this emancipatory project within an African context to test and refine the self-management conceptual model for future use.

3.5 OTHER THEORIES REVIEWED RELATED TO THE STUDY

3.5.1 Social Cognitive Theory:

This theory posits a multifaceted causal structure in which self-efficacy beliefs operate together with goals, outcome expectations and perceived impediments and facilitators in the regulation of human motivation, behaviour, and well-being. It specifies a core set of determinants of effective self-management health habits which include knowledge of health risks and benefits of different health practices, perceived confidence that one can exercise control over one's health habits, the health goals people set for themselves and the concrete plans and strategies for realizing them, as

well as the perceived facilitators, social and structural impediments to the change they seek (Bandura, 2004).

Individual health care is also affected by the outcomes people expect their actions to produce, which take several forms. Firstly, the physical outcomes include the pleasurable and aversive effects of the behaviour and the accompanying material losses and benefits. The social approval or disapproval which behaviour produces in one's interpersonal relationships also affect health care, as does the positive and negative self-evaluative reactions to one's health care behaviour and health status. People adopt personal standards and regulate their behaviour by their self-evaluative reactions. They do things that give them self-satisfaction and self-worth and refrain from behaving in ways that breed self-dissatisfaction.

Motivation is enhanced by helping people to see how habit changes are in their own interests and serve their broader goals. Personal goals, rooted in a value system, provide incentives and guides for health habits. Long-term goals set the course of personal change. But there are too many competing influences at hand for distant goals to control current behaviour. Short-term attainable goals help people to succeed by enlisting effort and guiding action in the here and now (Bandura, 1997, 2000). According to Bandura, personal change would be easy if there were no impediments to surmount, and perceived facilitators and obstacles are part of the determinants of health habits. Some personal factors may deter performance of healthier behaviour. Self-efficacy beliefs must be measured against gradations of challenges to successful performance. This regulation of the behaviour of PLWHA is not solely a personal matter: some of the impediments

to healthful living reside in the society and health systems. These impediments are rooted in societal values and the ways in which health services are structured socially and economically.

3.5.2 Overlap in Health Belief Models:

Bandura posits that many psychosocial models of health behaviour are founded on the common metatheory that psychosocial factors are important contributors to human health. Most of the factors in the different models are mainly different types of outcome expectations. Perceived severity and susceptibility to disease in the Health-Belief Model are expected negative physical outcomes. The perceived benefits are the positive outcomes. In the theory of reasoned action and planned behaviour, attitudes toward behaviour and social norms produce intentions that determine behaviour. Attitude is measured by perceived outcomes and the value placed on those outcomes. Most of the models of health behaviour are concerned only with predicting health habits, and do not provide guidelines on how to change health behaviour. Social cognitive theory offers both predictors and principles on how to inform, enable, guide, and motivate people to adapt habits that promote health and reduce those that impair it (Bandura, 1997). But the fact that PLWHA suffer rejection, neglect and disapproval from family members and lovers, and may be stigmatized and discriminated against, even verbally and physically abused, must be considered in the design of an educational intervention for this group of people.

3.6 SELF-MANAGEMENT EDUCATION PROCESS

In the following section, I conceptualize the self-management education process to indicate the mechanisms responsible for producing favourable outcomes. The process outlined involves complementary partnership between PLWHA and healthcare providers, and includes assessment,

advisement, agreement, assistance, arrangement, personal action planning, evaluation and outcomes (See figure 3.5 below p. 74).

Assessment: During assessment, healthcare professionals employ various methods to learn about a PLWHA's perceived and actual needs, as well as the regulatory context in which the intervention will operate. The healthcare provider may use multiple data collection activities such as interviews with individuals, focus groups, and participant observation surveys to understand the PLWHA's needs. A self-management educator may include secondary data analysis or original data collection, and must prioritize the PLWHA's health needs and establish programme goals and objectives. He or she must identify factors, both internal and external to PLWHA, that affect the health problem, review the literature and apply theory to map out these factors. He or she must identify antecedent and reinforcing factors that must be in place to initiate and sustain change.

The educator can use individual, interpersonal, or community level change theories to classify determinants of behaviour into one of these categories and rank their importance. Because each type of factor requires different intervention strategies, classifying them helps the educator to consider how to address the PLWHA's needs. The three types of influencing factors include: (1) predisposing factors, which motivate or provide a reason for behaviour; they include knowledge, attitudes, cultural beliefs, and readiness to change; (2) enabling factors, which enable persons to act on their predispositions; these factors include available resources, supportive policies, assistance, and services; (3) reinforcing factors, which come into play after behaviour has been initiated; they encourage repetition or persistence of behaviour by providing continuing rewards

or incentives. Social support, praise, reassurance and symptom relief may all be considered reinforcing factors. Healthcare providers may also employ intervention strategies that reflect information gathered in previous steps; the availability of needed resources; and organizational policies and regulations that could affect programme implementation.

Advisement: The health care provider should use neutral non-judgmental language to correct any inaccurate knowledge and complete gaps in the client's understanding of his or her condition. He or she should provide specific information about HIV/AIDS and related health problems and emphasise the benefits of positive living; empower and prepare PLWHA to manage their health care by encouraging them to set goals, identify barriers and challenges, and monitor their own conditions. He or she should also provide PLWHA with visual reminders – for example posters or other written matter – to help them manage their health and emphasize their central role and the use of effective self-management support strategies such as self-monitoring, goal-setting, action planning, problem solving and follow-up.

Agreement: The healthcare provider should ensure efficient care and self-management support by taking care that PLWHA understand what is recommended for them, and ensuring that the programme is in accord with their cultural background. The provider defines roles and distributes tasks in collaboration with PLWHA; they collaboratively set goals based on the PLWHA's interest and confidence in their competence; and together they develop agreements that facilitate care coordination within and across organizations. The PLWHA and care providers define problems clearly and harmonise their perspectives. Providers define problems in terms of diagnosis, poor compliance with treatment, or continuation of unhealthy behaviour. PLWHA

define problems in terms of pain, symptoms, interference with functioning, emotional distress, difficulty carrying out treatment or lifestyle changes, or fears about unpredictable health consequences of illness. The health care provider should negotiate the selection from the different options and both should agree upon goals that reflect the patient's priorities. The provider should ensure that the negotiated goals are clear, measurable, realistic, under the patient's direct control and limited in number.

Assistance: The healthcare provider should use planned interaction to support evidence-based care and provide clinical case management services for complex patients; he or she should mobilize community resources to meet the needs of PLWHA and encourage them to participate in effective community programmes, form partnerships with community-based organizations to support and develop interventions that fill gaps in needed services and advocate for policies that improve the healthcare of PLWHA. The provider should also organize internal and community resources to provide ongoing self-management support to PLWHA.

Arrangement: The healthcare provider should arrange regular, proactive, planned visits, phone calls and mail reminders which incorporate PLWHA goals to help them maintain optimal health, and allow health systems to better manage their resources. Regular follow-up for the specific action plan by the care team is thus ensured. By contacting PLWHA at specified intervals, care providers can obtain information on medical and functional status, identify potential complications early, check progress in implementing the care plan, make necessary modifications, and reinforce their efforts.

Personal Action Plan: PLWHA should list specific goals in behavioural terms, list barriers and strategies to address them, share the action plan with the healthcare team and social support groups. Providers and PLWHA should focus on a specific problem, establish realistic objectives, and develop an action plan for attaining those objectives. They may initiate many changes at once to prevent poor health and discouragement.

Evaluation: The process of evaluation should determine to what extent a programme is being carried out according to plan. The healthcare provider should then perform impact evaluation looking for changes in behaviour and health status that influence the likelihood that behavioural and environmental change will continue, and finally the provider should conduct outcome evaluation, looking at the indicators to determine whether the intervention has affected the health and quality of life of the PLWHA.

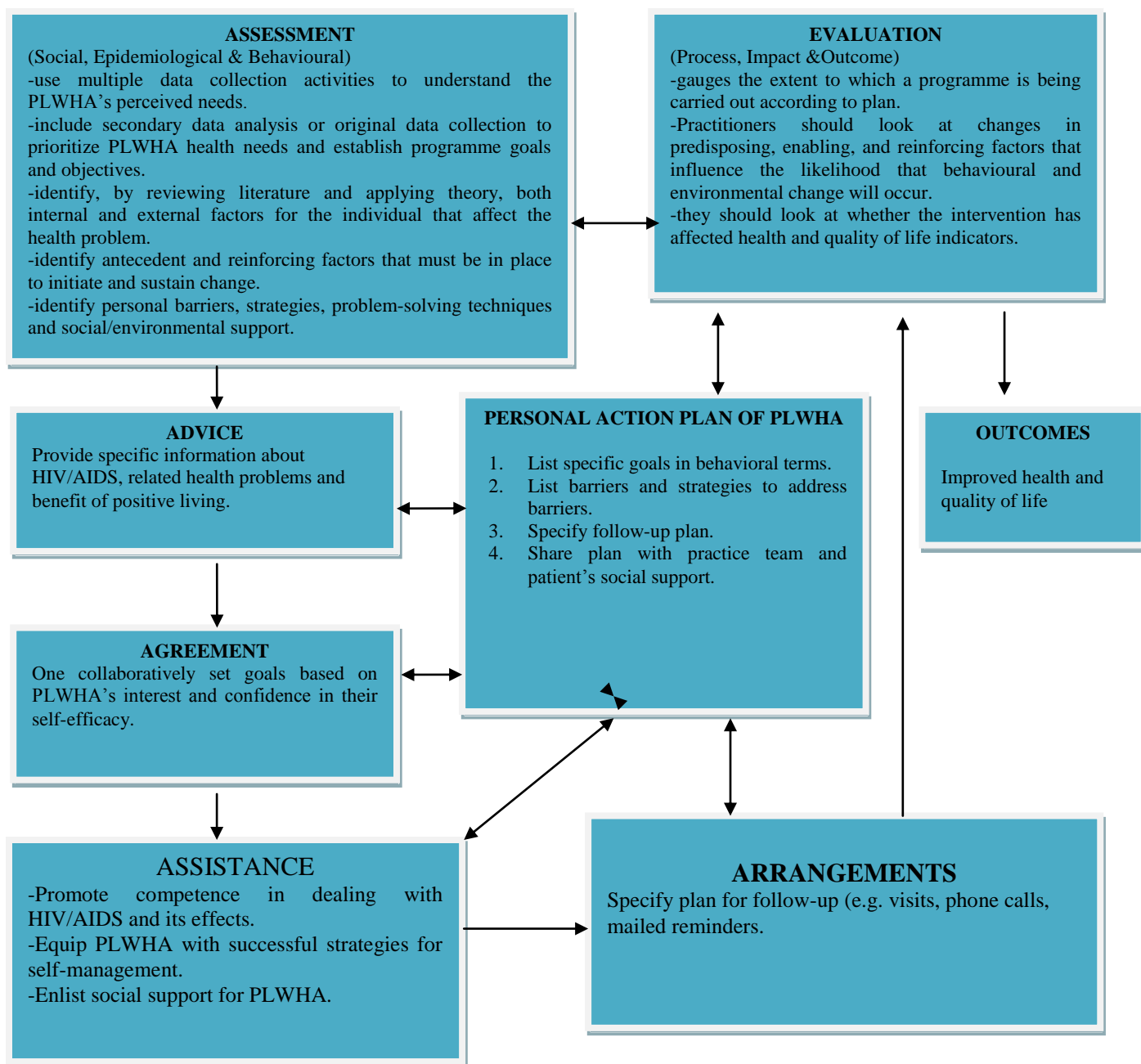


Figure 3.5: Self-Management Education Process

3.7 THE MODELS

The models from which the conceptual framework was developed are briefly discussed below.

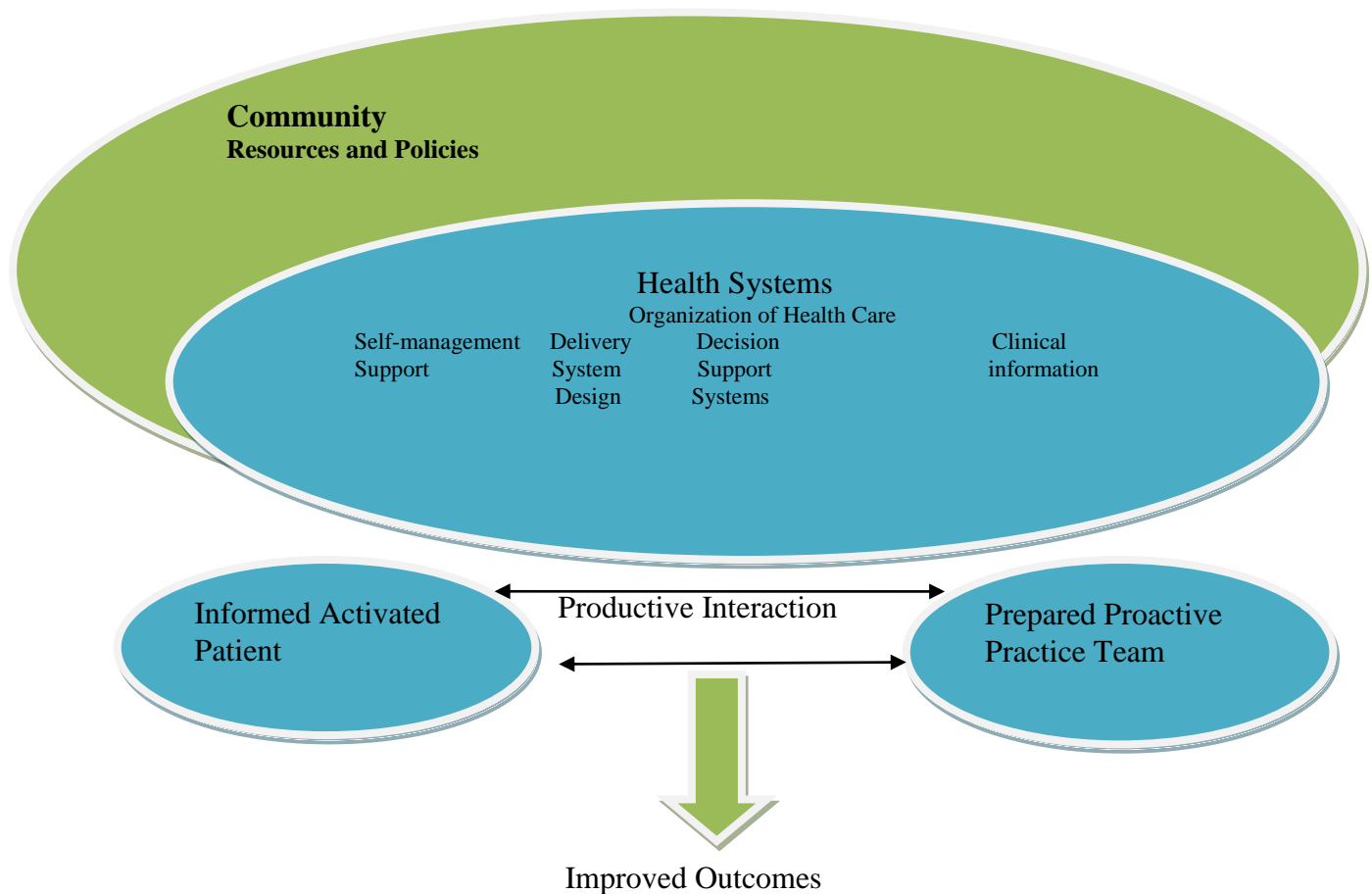


Figure 3.7.1: The Chronic Care Model (Wagner et al., 2001)

The Community

The community should mobilize community resources to meet the needs of the patients. Community resources, from school to government, non-profit and faith-based organizations, should be used to bolster health systems' efforts to keep chronically ill patients supported, involved and active.

It should also:

- Encourage patients to participate in effective community programmes.
- Form partnerships with community-based organizations to support and develop interventions that fill gaps in needed services.
- Advocate for policies that improve patient care.

Health systems

Health systems should create an organization that provides safe, high-quality care. A health system's business plan reflects its commitment to apply the Chronic Care Model across the organization; clinician leaders are the visible, dedicated members of the team.

Health care systems should:

- Visibly support improvement at all levels of the organization, beginning with the senior leaders.
- Promote effective improvement strategies aimed at comprehensive system change.
- Encourage open and systematic handling of errors and quality problems to improve care.
- Provide incentives based on quality of care.
- Develop agreements that facilitate care coordination within and across organizations

Self-Management Support

Self-management support should empower and prepare patients to manage their health care. Patients should be encouraged to set goals, identify barriers and challenges, and monitor their own conditions. A variety of tools and resources will provide patients with visual reminders to manage their health. They should:

- Emphasize the patient's central role in managing his or her health.
- Use effective self-management support strategies that include assessment (physician or self?), goal-setting, action planning, problem solving, and follow-up.
- Organize internal and community resources to provide ongoing self-management support to patients.

Delivery System Design

Delivery System Design should assure effective, efficient care and self-management support.

Regular, proactive planned visits should be made, which incorporate patient goals and help individuals maintain optimal health, as well as allowing health systems to better manage their resources. Visits often employ the skills of several team members, who should:

- Define roles and distribute tasks among team members.
- Use planned interactions to support evidence-based care.
- Provide clinical case management services for patients with complex health problems.
- Ensure regular follow-up by the care team.
- Give care that patients understand and that is in accord with their cultural background.

Decision Support

Healthcare providers and patients must cooperate to promote care consistent with scientific data and patient preferences.

Clinicians have access to the latest evidence-based guidelines for the care of each chronic condition. Continual educational outreach to clinicians reinforces utilization of these standards. They should be encouraged to:

- Embed evidence-based guidelines into their daily clinical practice.
- Share evidence-based guidelines with patients to encourage their participation.
- Use proven provider education methods.
- Integrate specialist expertise and primary care.

Clinical Information Systems

These should organize data to facilitate efficient and effective care. Health systems harness technology to provide clinicians with an inclusive list of patients with a given chronic disease. A list provides the information necessary to monitor patient health status and reduce complications.

It can also:

- Provide timely reminders for providers and patients.
- Identify relevant subpopulations for proactive care.
- Facilitate individual patient care planning.
- Share information with patients and providers to coordinate care.

3.7.2 Precede-proceed model

This model developed by Green and Kreuter (1999), guides planners through a process that starts with desired outcomes and works backwards to identify a mix of strategies for achieving objectives. The PRECEDE acronym stands for Predisposing, Reinforcing, and Enabling Construct, Educational/Environmental Diagnosis and Evaluation. The PROCEED stands for Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development. The PRECEDE-PROCEED model has nine steps. The first five steps are diagnostic, addressing both educational and environmental issues. They include: (1) social assessment, (2) epidemiological assessment, (3) behavioural and environmental assessment, (4)

educational and ecological assessment, and (5) administrative and policy assessment. The last four comprise implementation and evaluation of health promotion intervention. They include: (6) implementation, (7) process evaluation, (8) impact evaluation, (9) outcome evaluation.

THE PRECEDE-PROCEED MODEL

PRECEDE

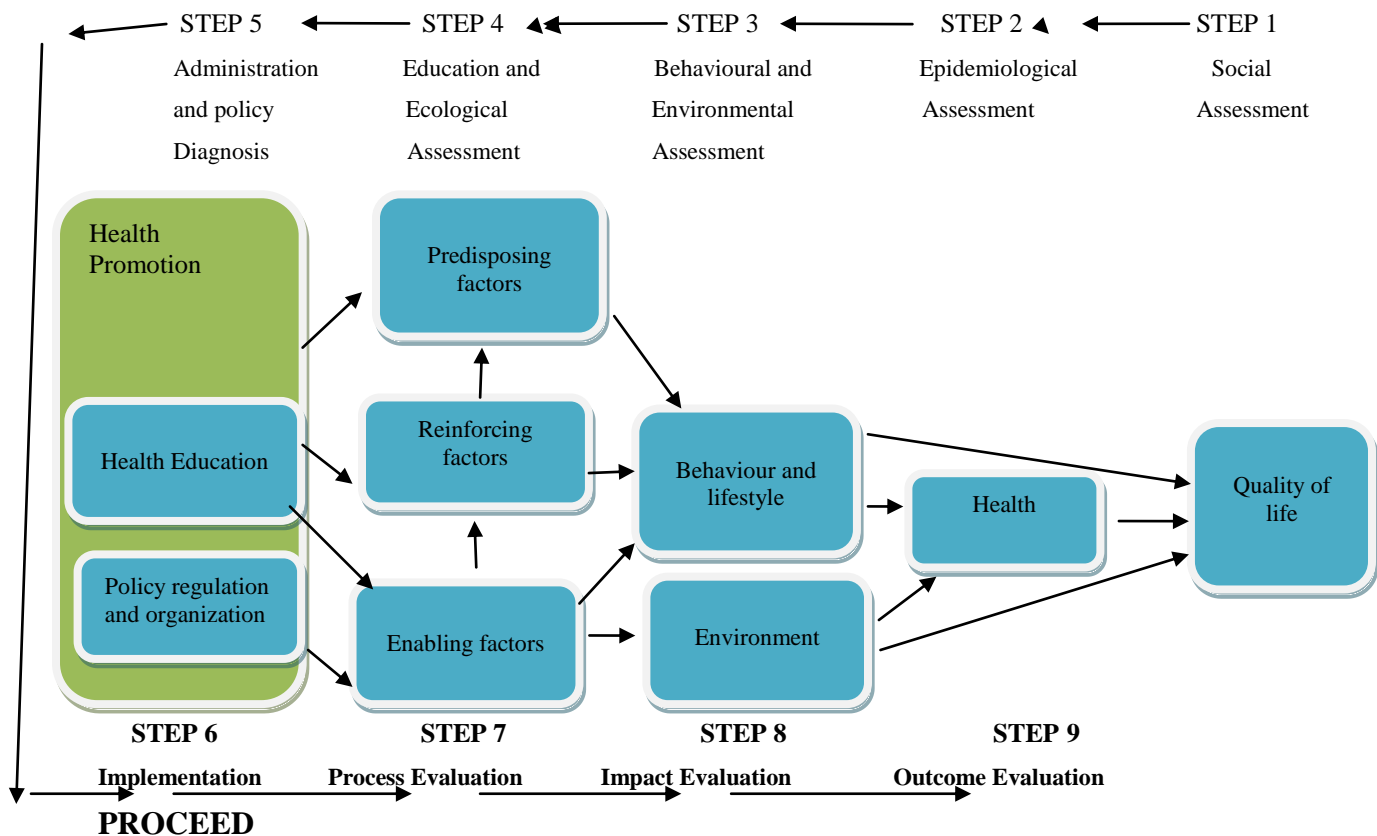


Figure 3.7.2: Precede-Proceed Model (Green and Kreuter, 1999)

The Precede-Proceed Model (P-PM) incorporates social cognitive, empowerment and related theories to reflect the theoretical concepts and implementation issues in self-management education. These theories are relevant for nursing research and practice. The CCM was built on the premise that redesigning practices has the potential to improve care (Cassalino, 2005). “The CCM incorporates self-management interventions, decision support, delivery system design and

clinical information systems, as well as the relationships of the healthcare delivery systems with larger healthcare organization and community. The interventions proposed should result in a well prepared, proactive practice team that interacts with an informed, activated patient leading to improved outcomes” (Lemmens et al., 2008). The CCM does not clarify the underlying mechanisms of the components of self-management but rather focuses on the definition of the components and their empirical evidence. The P-PM provides a comprehensive structure for assessing health and quality-of-life needs, and designing, implementing, and evaluating health promotion and other public health programmes to meet those needs. Developed by Green and Kreuter (1999)

Precede (Predisposing, Reinforcing, and Enabling Construct in Educational Diagnosis and Evaluation) outlines a diagnostic planning process to assist in the development of targeted and focused public health programmes. Proceed (Policy, Regulatory, and Organisational Constructs in Educational and Environmental Development) guides the implementation and evaluation of the programmes designed by the use of Precede. Precede consists of five steps or phases. Phase one involves determining the quality of life or social problems and needs of a given population. Phase two consists of identifying the health determinants of these problems and needs. Phase three involves analysing the behavioural and environmental determinants of the health problems. In phase four, the factors that predispose to, reinforce, and enable the behaviour and lifestyles are identified. Phase five involves ascertaining which health promotion, health education and/or policy-related interventions would best be suited to encouraging the desired changes in the behaviour or environment and in the factors that support that behaviour and environment. Proceed is composed of four additional phases. In phase six, the interventions identified in phase

five are implemented. Phase seven entails process evaluation of those interventions. Phase eight involves evaluating the impact of the interventions on the factors supporting behaviour, and on behaviour itself. The ninth and last phase comprises outcome evaluation-that is, determining the ultimate effects of the interventions on the health and quality of life of the population. The model helps practitioners to develop programmes step by step, integrating multiple theories to explain and address health problems. The Chronic Care Model (CCM) and Precede-Proceed Model (P-PM) are complementary approaches to HIV/AIDS self-management Education. Therefore, the integration of the two models is essential for the development of a comprehensive conceptual model for HIV/AIDS self-management education.

3.8 THE SELF-MANAGEMENT EDUCATION CONCEPTUAL FRAMEWORK

This section focuses on the process of developing a conceptual framework for the implementation of self-management education among PLWHA. It will be appropriate to define some of the terms for better understanding. A *concept* is a term that abstractly describes an object or a phenomenon, thus providing it with a separate identity or meaning (Burns and Grove, 2009). A *theory* presents a systematic way of understanding events or situations. It is a set of concepts, definitions, and propositions that explain or predict these events or situations by illustrating the relationships between variables. Classically, scientists have used the term *theory* to refer to an abstract generalization that offers a systematic explanation about how phenomena are interrelated. The term *model* is often used in connection with symbolic representation of a conceptualization. A model helps to structure the way any situation event or group of individuals could be viewed. *Conceptual models*, like theories, deal with abstractions (concepts) that are assembled because of their relevance to a common theme. Conceptual models provide a

perspective regarding interrelated phenomena, but are more loosely structured than the theories. A conceptual model broadly presents an understanding of the phenomenon under consideration, and reflects the assumptions and philosophic views of the model's designer. A framework is an abstract, logical structure of meaning that guides the development of the study and enables the researchers to link the findings to the body of knowledge used in nursing (Burns and Grove, 2009). The framework for a research study helps to organize the study and provides a context in which to examine a problem, and to gather and analyze data. A theoretical framework is based on propositional statements from an existing theory, while a conceptual framework is one that has been developed by the researcher through identifying and defining concepts. A conceptual framework presents the deductive system of propositions that assert and explain relationships among concepts. It is the conceptual underpinning of a study, including an overall rationale and conceptual definitions of key concepts (Polit and Beck, 2008). Developing a framework is one of the most important steps in a research process but perhaps also one of the most difficult (Burns and Grove, 2009). By developing a framework within which ideas are organized, the researcher is able to show that the proposed study is a logical extension of current knowledge (Brink, 2006).

Novice researchers may think of themselves as unqualified to develop a conceptual scheme of their own. But theory development depends much less on research experience than on powers of observation, grasp of a problem, and knowledge of prior research. There is nothing to prevent an imaginative and sensible person from formulating an original conceptual framework for a study. (Polit and Beck, 2008)

Despite growing acknowledgement within the research community that the implementation of self-management programmes results in improved outcomes, the process may appear complex and varies with different schools of thought; there should in each case be a specific conceptual framework describing the process and the interactions involved upon which evaluation can be based. There are limited data to guide the successful implementation and evaluation of self-management education programmes. A major policy implication is the need for a consistent definition and framework for self-management. In this era, plagued by ever-tightening healthcare resources, it is of the utmost importance to identify interventions that are of value to quality and efficiency of care. As the body of knowledge related to self-management education grows, it becomes imperative for researchers who are themselves nurses, to develop a model to express the body of knowledge which they possess in relation to provision of nursing care in the management of chronic conditions such as HIV/AIDS. An impressive presentation of a model may conceal the careful, thoughtful work required to arrive at that point. Therefore, as a novice researcher, I attempt to learn how to perform the thoughtful work required in developing a conceptual model.

3.8.1 Conceptual framework development process

According to Burns and Grove (2009), the reasoning used to develop a framework consists of four steps. The steps of the process are (1) selecting and defining concepts; (2) developing statements relating the concepts; (3) expressing the statements in organised fashion; and (4) developing a conceptual map that expresses the framework. There should be a flow of thought from one step to another, back and forth, as ideas are developed and refined (Burns and Grove, 2009). The conceptual framework is either developed to test statements in a substantive theory or

on the basis of a conceptual model. Developing a framework designed to test statements in substantive theory requires that all concepts in the framework be derived from the substantive theory (Burns and Grove, 2009).

When constructing a study framework on the basis of a conceptual model as in the case of this study, the framework must include both the conceptual model and the middle-range theory. Thus, the conceptual map for the study must illustrate relationships among the constructs of the model, the concepts of the middle-range theory, and the link between the concepts and relationships in the middle-range theory. (Burns and Grove, 2009: 152)

3.8.1.1 Selecting and defining concepts

Concepts are selected in terms of their relevance to the phenomenon under study. It will be appropriate to define some of the important concepts for understanding how people self-manage chronic conditions. ‘Self’ is the sole motivational construct in self-management education programmes. The self is described as: the organized, consistent, conceptual entity composed of perceptions of the characteristics of “I” or “me” and the perception of the relationships of the “I” or “me” to others and to various aspects of life, together with the value attached to these perceptions (Rogers, 1959: 200). The self develops through interactions with others and involves awareness of being and functioning. A distinctly psychological form of the actualizing tendency related to this “self” is the “self-actualizing tendency”. It involves the actualization of that portion of experience symbolized in the self (Rogers, 1959). Connected to the development of the self-concept and self-actualization are the “need for positive regard from others” and “the

need for positive self-regard” an internalized version of the previous (Maddi, 1996). *Self-interest* is seen as the motivation for action; people become involved when they see that it will benefit them to take action. In other words, people are willing to change and actually become involved in the process of change when they believe it is in their self-interest. Love of self is a crucial ingredient in the progress toward self-determination and emancipation (Henderson, 1997), while self-acceptance is a prerequisite to personality change.

Self-monitoring can be defined as awareness of symptoms or bodily sensations that is enhanced through periodic measurements, recordings and observations to provide information for improved self-management. The interplay between awareness, measurements and observations can enhance self-management by improving the ways in which individuals self-monitor or pay attention to their health. According to Wilde and Garvin (2007) self-monitoring is composed of two complementary components: (1) awareness of bodily symptoms, sensations, daily activities, and cognitive processes and (2) measurements, recordings and observations that inform cognition or provide information for independent action or consultation with care providers.

Self-tailoring is using self-management skills and knowledge and applying these to oneself as appropriate. It distinguishes self-management education from more traditional health promotion and patient education programmes. Self-tailoring is done by the individual, based on learning the principles for changing behaviour and self-management skills. Patients who self-tailor must have the principles for making specific behaviour changes as well as decision-making and problem-solving skills. All these are part of self-management programmes and lead to successful self-tailoring.

Another relevant concept is *self-regulation*. Piaget (1971) distinguishes two types of regulatory mechanisms: one regulates structure and the other regulates function. An analysis of these two mechanisms leads to the identification of principles of self-regulation and assists in the critical evaluation of the nature of the autonomy conceived as authority. “Structural regulating mechanisms, such as homeorhesis, promote a dynamic equilibrium, whereas functional self-regulatory mechanisms, such as homeostasis, sustain a static equilibrium. Functional self-regulatory mechanisms achieve stability by insulating the individual and promoting a static equilibrium in response to changes initiated in the environment. Structural self-regulating mechanisms achieve a dynamic equilibrium through evolution with the environment” (Piaget, 1971). In functional self-regulation, change is predicated as contingent upon the environment, whereas in structural self-regulation, change incorporates the environment as essential to the evolution of the structure.

These self-regulatory mechanisms, as implied in autonomous activity, must be structural in nature to assure authority connoting self-governance. Allport (1955) targets autonomy as a concept central to his personality theory. According to Allport, there are two levels of functional autonomy, namely; (1) preservative functional autonomy which illustrates infrahuman preservative activities or circular mechanisms that keep the organism going. (2) Propriate functional autonomy refers to acquired interests in attainment of progressively higher levels of authentic maturity. The parallel between Piaget’s notion of two types of self-regulating mechanisms and Allport’s notion of two levels of functional autonomy is the characterization of activity as a dynamic interchange between the organism and the environment. Allport’s

preservative functional autonomy and Piaget's functional self-regulatory mechanism point to a static, circulatory activity that is envisioned as dialogue, serves only to sustain inquiry. Activity so conceived cannot advance a dialogue that evolves as a discourse for inquiry assuring the generation of new knowledge.

For an effective implementation of self-management education, it is important to understand the nuances of individuals and the context within which they construct their lives. Although two clients may resemble each other, it is unlikely that both have identical motives, goals, strivings, adaptive strategies, or self-images. Indeed, people are more than the sum of their scored responses on inventories and tests. Therefore, an understanding of specific contextualized features of the self-concept is necessary for understanding the client's lifestyle and everyday behaviour. To effectively assist clients with clarifying their self-concepts during self-management education, healthcare providers need to understand the uniqueness of the individual and identify specific behaviour that stems from dispositional traits. By adding a contextualized approach to self-management education, a more complete picture of the client develops, thereby making the process more useful and producing a better outcome. Self-management education intervention requires recognition of persons involved. *Recognition* is the process in which a nurse, in interaction with a patient, gathers patient-based evidence, interprets patterns related to meaning of patient experience against pre-existing knowledge and experience, and consciously labels the phenomenon-based or patient-specific patterns (Steis et al., 2009).

Consciousness may be defined as the state of being aware, especially of something within oneself, but also of external objects, states or facts (Henderson, 1997). *Consciousness-raising*

refers to the process of increasing the state or quality of being aware, particularly as it applies to issues of personal and political freedom and it has generally been defined as an educational engagement in which people recognize and articulate the social, political, economic, and personal constraints on their freedom and become empowered to take action to remove those constraints. Consciousness-raising can contribute to psychological change for the individual and to social transformation for groups and communities. Fonow and Cook (1991) emphasize the importance of both personal and political outcomes of consciousness-raising as emotional catharsis, academic insight and intellectual product, and increasing politicization and activism. This process occurs in a tripartite, overlapping experience of enlightenment, empowerment, and emancipation. Each of these exists in a dynamic relation to the others. *Enlightenment* is the experience of coming to see oneself and one's place in society in a radically new way. This occurs when connections are made between others with similar experiences in a way that encourages self-reflection and analysis (Fay, 1987, Lather, 1991). *Empowerment* is the process by which a group of individuals become galvanized to act on their own behalf (Gibson, 1991, Lather, 1991). It is also a state of feeling more powerful than the previous one; of feeling one has the ability to affect others and to change social institutions. Empowerment is an interpersonal and intrapersonal experience, with each contributing to the other. Often, shared anger combined with an initial expression of self-regard is a key motivator in empowerment. *Emancipation* is both the process and the state of liberation (Fay, 1987; Lather, 1991).

There are personal and environmental factors that must be in place to initiate and sustain change. According to Glanz and Rimer (2002), three types of influencing factors include: (1) *Predisposing factors*, which motivate or provide a reason for behaviour; they include knowledge,

attitudes, cultural beliefs, and readiness to change. (2) *Enabling factors*, which enable persons to act on their predispositions; these factors include available resources, supportive policies, assistance, and services. (3) *Reinforcing factors*, which come into play after behaviour, has been initiated; they encourage repetition or persistence of behaviour by providing continuing rewards or incentives. *Facilitation* is a technique by which a person makes things easier for others (Heron, 1989). The term describes the support required to help people change their attitudes, habits, skills, ways of thinking, and working. It has received particular attention within nursing quality improvement and clinical practice development initiatives (Morrison, 1992, Burrows, 1996) *Education* in the largest sense is any act or experience that has a formative effect on the mind, character or physical ability of an individual. In its technical sense, education is the process by which society deliberately transmits its accumulated knowledge, skills and values from one generation to another.

3.8.1.2 Developing relational statements

A relational statement declares that a relationship of some kind exists between or among two or more concepts (Walker and Avant, 2004). Relational statements are the core of the framework; these statements are tested through research (Burns and Grove, 2009). Understanding relational statements is essential for appraising a framework. Judging whether the study was successful depends, in part, on identifying the statements in the framework and tracking their examination within the study. The next step in framework development is to link all the concepts through relational statements:

1. The healthcare provider relinquishes his pastoral power (his accepted authoritative expertise) and assumes the status of a facilitator, to provide an enabling environment for people to go

through a process of self-exploration, self-discovery and self-regulation being motivated by self-actualization tendency. Healthcare providers seek to expand peoples' sense of self-interest to a wider sphere. People grow through these facilitation processes, and develop the self-management skills needed to perform self-management tasks. Within the confines of the research process, people are encouraged to seek self-knowledge and share this with the facilitator. Consequently, people develop through a process of knowing the self to practice in taking care of oneself. Similarly, during self-management interventions, evolution of the self activated through self-reflection is prompted by the caring agent (the researcher) who helps participants to consider their actions and beliefs in comparison to acknowledged or newly-unveiled discourses and associated truths.

2. The need for positive regard from others and positive self-regard is closely related to the way in which an individual evaluates himself/herself, and there is likely to be congruence between self and experience, with full psychological adjustment as a result (Rogers, 1959). When 'significant others' (partners, parents, close friends or relations) in the person's world provide positive regard, the person introjects the desired values, making them his or her own, and acquires "conditions of worth" (Rogers, 1959).
3. The human capacity for awareness and the ability to use symbols gives us enormous power, but this is a double-edged phenomenon: undistorted awareness can lead to full functioning and a rich life, while distortion in awareness can lead to maladjustment and destructive behaviour (Rogers, 1965). The fully functioning person is open to experience, creative and able to live 'the good life'. The good life is a process, not a state of being; it is direction, not destination (Rogers, 1961). The individual's self-concept then becomes based on these standards of value rather than on evaluation. The need for positive self-regard leads to a

selective perception of experience in terms of the conditions of worth that now exist. Experiences are perceived and symbolized accurately in awareness, while those that are not relevant are distorted or denied into awareness.

4. Engagement in self-management programmes allows the participant to use self-reflexivity to discover, with the assistance of the facilitator, dominating discourses and power structures. By coming to know the self, and gaining an awareness of a set of rules of conduct, the participant can then redirect activities according to this newly-acquired knowledge. Evolution of self allows persons to adopt newly-discovered ways of being by acting on their own initiative in relation to the enabling environment.
- 5 Self-management intervention participants examine their own (and others) behaviour and beliefs against a set of pre-established norms. The participants undergo the process of evolution of self, and gain a new understanding of selves. They may then use this knowledge to move towards a new way of being and gain functional autonomy, becoming fully functioning persons. This movement towards full function is the change process which the facilitator should be attempting to capture. Therefore, change emerges organically from the research process and “effective emancipation is achieved through the process of stringent self-examination, exposure of dominating ideologies and the subsequent actions taken by participants themselves to move towards a new way of being (McCabe and Holmes, 2009).
6. In self-management education, people learn who they are and gain the collective power to determine the direction of their lives. Because human beings cannot be separated from their social and historical contexts, reality is not a static entity but a process of transformation. By engaging in acts of enlightenment and empowerment, human beings become liberated and therefore become more fully human. It should also be noted that people often experience

enlightenment, empowerment, and emancipation as overlapping circles of insight and action that create and are the result of raised consciousness. Empowerment and potential emancipation depend on the relations of power in a particular context, and result from techniques employed by both teachers and participants during the research process (McCabe and Holmes, 2009).

7. Emancipation involves the understanding of the environmental truths which influence people and requires individuals or groups to negotiate new modes of acting. The empowerment that results from awareness of the current set of truths and dominating power structures encourages people to undertake actions to improve their situation and move towards emancipation (Manias and Street, 2001).

3.8.1.3 Developing hierarchical propositional statements

A hierarchical statement is composed of a specific proposition and a hypothesis or research question (Burns and Grove, 2009). “If a conceptual model is included in the framework, the statement set may also contain a general proposition. The proposition is listed first, with the hypothesis or research question immediately following” (Burns and Grove, 2009). In the following section, the propositions are listed to indicate the mechanisms responsible for change; producing favourable, intended outcomes during self-management education intervention.

Propositional statements

1. People undergo the process of evolution of self, and gain a new understanding of themselves. They may then use this knowledge to move towards a new way of being, and gain functional autonomy, becoming a fully functioning person.
2. Emotions are critical element in the process of consciousness-raising.

3. Love of self is a crucial ingredient in the progress toward consciousness-raising.
4. Consciousness-raising involves a critical and liberating dialogue in which people discover the power imbalances within a society that contribute to their oppression, as well as the hidden distortions within themselves that help to maintain an oppressive society.
5. The knowledge produced in consciousness-raising is not disconnected from, but must be based on the experience of the knower, that is, consciousness is experience as well as awareness of experience.
6. Knowledge produced in consciousness-raising is experiential and contextual, that is, grounded in a particular life context, in bodies, in families, in communities, in culture, and in time.
7. Motivation is enhanced by helping people to see how habit changes are in their own interests and the broader goals they value.
8. Personal goals, rooted in value systems, provide further self-incentives and guides for health habits. Still, the question remains, what mechanism is responsible for change that will make patient intervention work?

3.8.1.4 Constructing a Conceptual Map

A conceptual map explains which concepts contribute to or cause an outcome, partially or completely. Conditions, both direct and indirect, that may produce the outcome are specified. A conceptual map illustrates the process in which factors must cumulatively interact in some sequence to have a causal effect. Conceptual maps vary in complexity and accuracy, depending on the available body of knowledge related to the phenomenon.

Conceptual maps may be useful beyond the study for which they were developed” (Burns and Grove, 2009). A framework provides a practical experience for understanding how interventions within the context of self-management affect outcomes of care. The conceptual framework provides a consistent, reproducible approach to assessing, monitoring, and evaluation of the key components of self-management education and allows for measurement and tracking of changes as well as having a predictive ability.

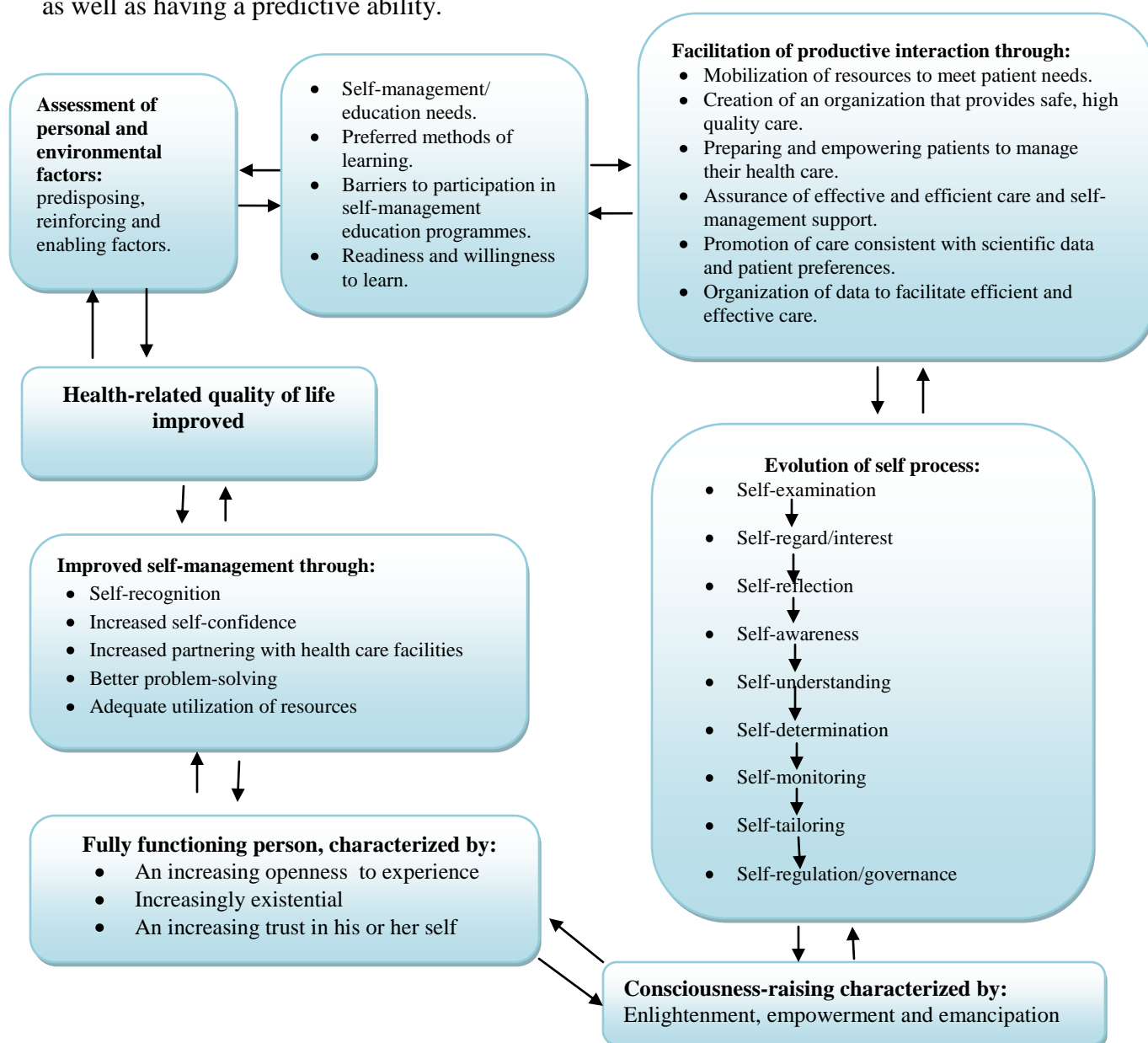


Figure 3.8: Conceptual framework developed from literature

3.8.1.5: CONCLUSION

This conceptual framework provides a good starting point for the definition of structure; process as well as outcome indicators (Donabedian, 1980). It clarifies some of the theoretical positions and serves as a basis for professional nurses to assess what they need to do to successfully implement self-management interventions. The framework provides steps for planning, implementation and evaluation of self-management programmes. It is designed to create an enabling environment to support and empower PLWHA in self-management with long-term partnership with health care systems. The needs-driven and outcomes-based process also provides the basis for prospective ongoing evaluation, improvement of health outcomes and delivery of health care services to this group of people. It puts the interaction between the PLWHA and the professional first, and thus the interventions are directed at these two key players.

The HIV/AIDS self-management education conceptual framework presents the interplay and interdependence of many factors influencing the implementation of self-management education in nursing care of PLWHA. Representations of the elements in the framework may be used to help clinicians to think about their implementation strategies. The framework might also be used to assist practitioner decisions on appropriate healthcare in specific clinical circumstances. The conceptual framework elucidates the underlying mechanisms of self-management education, providing mechanisms for patient's learning and behavioural change as well as professional support and professional behaviour change mechanisms. Identification of mechanisms which are nested in transformative learning facilitates the construction of the conceptual framework. Consistent use of this framework will enable valid comparisons of efficiency and outcomes of

self-management programmes. I hope that the conceptual framework will stimulate further debate from colleagues and other disciplines on how to improve outcomes for PLWHA and quality of care for this group of people.

CHAPTER FOUR

RESEARCH METHODOLOGY

4.0. INTRODUCTION

The methods used to conduct the study are discussed in this chapter. The chapter starts with the philosophical underpinning of the research design, intervention mapping, and my own negotiation of the research setting. I shall go on to discuss the process through which the study was developed. Ethical considerations will be considered, as well as data management, storage and measures taken to improve validity and reliability of data. The methods used in data collection and analysis are also discussed.

4.1. PHILOSOPHICAL UNDERPINNING OF THE RESEARCH DESIGN

A mixed methods approach was used as the inquiry strategy for this study. Campbell and Fiske (1959) introduced the “multimethod” approach and suggested that researchers collect multiple quantitative measures and assess them with separate methods to study one psychological construct. This encourages researchers to recognize the limitations of using a single method and to prefer multiple approaches to collecting data within a single study. Despite the fact that qualitative and quantitative researchers differ in the processes by which they gain knowledge and the research questions they address, they can both be applied to the same research problem (Cresswell and Plano Clark, 2007). Mixed method research is the collection, analysis and interpretation of both quantitative and qualitative data within one study (Cresswell, 2009, Cresswell and Plano Clark, 2007). Using a mixed methods approach in healthcare research is becoming increasingly common (Chow et al., 2010) since the strongest argument in this kind of research is that certain questions require such an approach. Pragmatism provides a basis for

asserting the “dictatorship of the research question” (Tashakkori and Teddlie, 2003: 21). A pragmatic researcher considers the research question as the driving force of the inquiry, and believes that the question is more important than the methods used. When a researcher wants to collect several types of data about a single phenomenon at the same time in order to compare and contrast different findings to produce valid conclusions, he or she will choose the mixed methods approach (Cresswell et al., 2003). Another strong pragmatic argument is that quantitative and qualitative methods are compatible. Thus, in a mixed methods study both numerical and text data are collected and analyzed to address different aspects of the same research problem and provide more complete level of understanding. A quantitative approach focuses on relationships between variables, while a qualitative approach seeks in-depth understanding of an individual’s experiences.

4.2. RESEARCH DESIGN

A longitudinal study, using triangulation, and a mixed methods approach, was conducted in order to develop an HIV/AIDS self-management education conceptual model for improving the self-management and quality of life of PLWHA in semi-rural KwaZulu-Natal. Longitudinal designs examine changes in the same subjects over an extended period of time. These designs are expensive and require a long period of researcher and subject commitment (Burns and Grove, 2009). In the case of my study, the participants to be studied, the variables and the scales on which they were to be measured were clearly identified before data collection could begin. Measurements were clearly planned since they were to be used repeatedly over a period of six months. I am aware that the variables being measured change – and in this case, changed – over time. For example, an individual’s CD4 count is checked every six months; if the CD4 count has

been checked before the research intervention begins, it is likely that a significant change in CD4 count might have occurred before the next check of the CD4 count. Before my intervention began, I administered SF-36 (a research questionnaire) in order to measure the health-related quality of life; twenty-four weeks later, when the participants could be expected to have internalized their experiences from the intervention and to have changed their behaviour, I re-administered SF-36 in order to estimate the effect of the intervention on their health-related quality of life.

Four situations call for a longitudinal design (Polit and Beck, 2008):

1. Studying time-related processes. Some research problems specifically concern phenomena that evolve over time (e.g., healing, learning, recidivism, and physical growth).
2. Determining time sequences. It is sometimes important to determine the sequence of phenomena.
3. Making comparisons over time. Some studies are undertaken to examine whether changes have occurred over time. For example, an experimental study might examine whether an intervention had both short-term and long-term benefits.
4. Enhancing research control. Quantitative researchers sometimes collect data at multiple points to enhance the interpretability of the results.

Quantitative and qualitative data were collected concurrently, compared and contrasted to produce valid conclusions for the subsequent phases of the study. The qualitative approach was used in order to explore participants' current self-management needs before intervention, and their experiences and perspectives on self-management issues after the intervention. Participants were divided into an 'intervention' group, which received self management education, and a

‘comparison’ group which received traditional health education. The quantitative approach was used to examine participants’ self-management education needs and health-related quality of life at baseline and after intervention. This was a quasi-experimental design, a non-equivalent (pre-test and post-test) intervention and comparison groups design.

In this design, a popular approach to quasi-experiments, the intervention (Group A) and the comparison (Group B) are selected randomly (Cresswell, 2009:140). Both groups submitted to a pre-test and post-test.

Group A O ————— X ————— O

Group B O ————— O

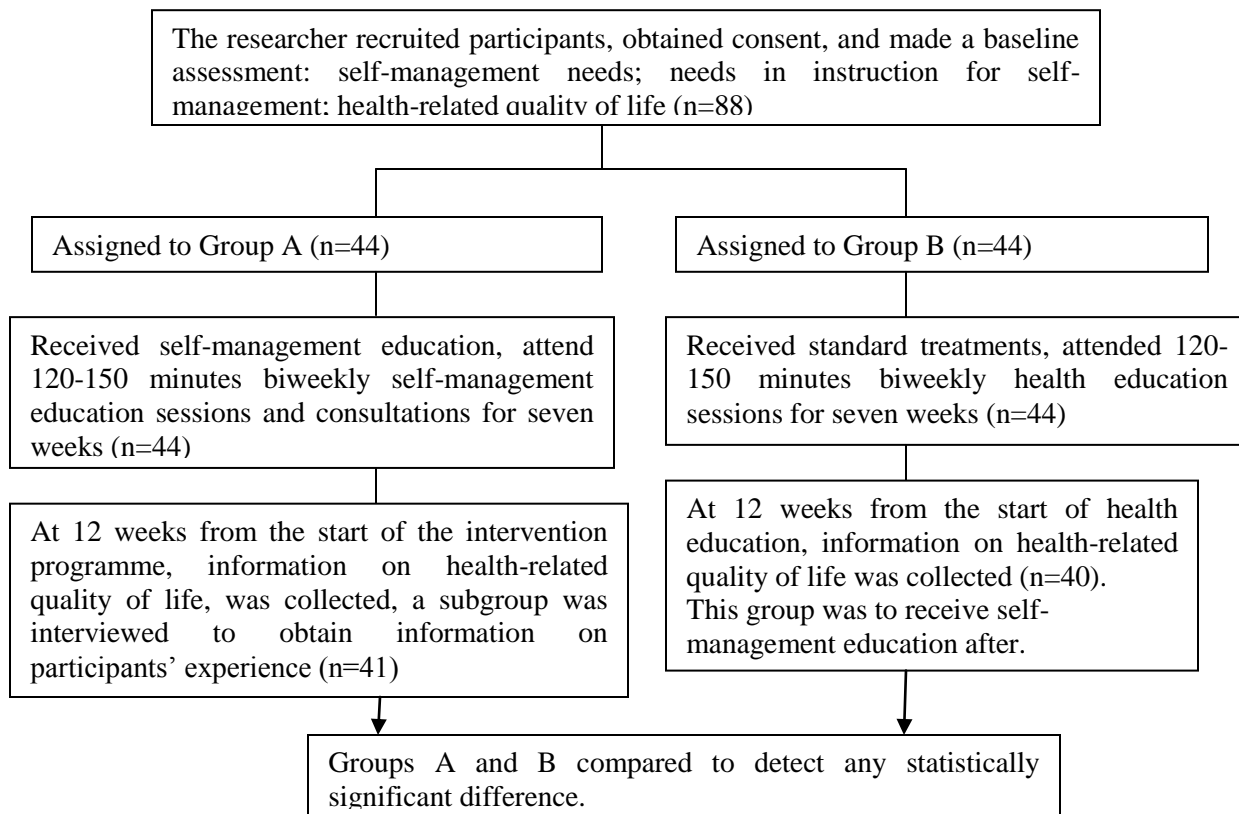


Figure 4.1: Schematic diagram of study design

4.3 INTERVENTION MAPPING (IM)

Intervention mapping has been used to develop health promotion programmes; it produces a framework that links health behaviour theory and performance objectives with specific methods and strategies (Bartolomew, Parcel and Kok, 2002; Hoelscher, Evans, Parcel and Kelder, 2002; Wolff, Young, Beck, Maurana, Murphy and Holifield, 2004). The investigator performed IM to ensure that the intervention addressed the self-management needs of PLWHA, allowed for maximal participation of PLWHA, encouraged community engagement and participation, and maximized the sustainability of self-management programmes in semi-rural KwaZulu-Natal. IM is carried out in a series of steps, from review of relevant data through evaluation, as described by Corbie-Smith, Akers, Blumenthal, Council, Wynn, Muhammad, and Stith (2010). Step 1 involves assessing needs and assets; Step 2 includes developing matrices of change objectives (i.e., intervention goals) and consists of the following tasks: defining health promoting behaviour (i.e., behavioural outcomes); specifying performance objectives for health promoting behaviour; deriving behavioural determinants of performance objectives from theory, literature, and practice; specifying and creating a matrix of learning objectives to link performance objectives with specific determinants.

I established the intervention goals in consultation with PLWHA. The intervention goals for participants were: to develop positive self-care behaviour including: lifestyle (diet and exercise); managing therapy (concordance); using health services effectively; and being able to understand symptoms and problems and respond appropriately to them. Step 3 involves specifying intervention methods and translating methods into practical strategies. Step 4 includes producing programme components. Intervention methods are based on empowerment and social science theories as stated in the conceptual framework; they directly address the determinants of

behaviour in any given intervention. Step 5 involves organizing strategies into a deliverable programme and produces the actual design of the programme, including training manuals and workbooks. As part of this task, the investigator has to determine the programme structure (i.e., scope and sequence), theme, channels for delivery, and programme materials. Intervention methods are techniques for influencing change in those determinants. Strategies, on the other hand, are practical techniques for applying the appropriate methods to the target population and the planned intervention. The investigator again uses subgroups of academic and professional partners to match intervention methods to the learning objectives. The feasibility of the programme was assessed by measuring compliance with the design and purposes of the intervention, participants' attendance and adherence, and their reactions to the programme. See Table 4.3.1 below.

Table 4.3.1: The Intervention Mapping Process

| The Intervention Mapping Process | |
|--|--|
| Step 1 Needs and asset assessment | <ul style="list-style-type: none"> • Plan needs assessment and problem analysis. • Assessment of health, quality of life, behaviour, and environment. • Assessment of participants' capacity. • Establishment of programme outcomes. |
| Step 2 Matrices of Learning Objectives | <ul style="list-style-type: none"> • Establish expected changes in behaviour and environment. • Specify performance objectives. • Specify determinants of the target behaviour of groups A and B. • Create matrices of change objectives. |
| Step 3 Theory-based methods and practical strategies | <ul style="list-style-type: none"> • Review programme design with participants. • Identify theoretical methods. • Choose programme methods. • Select or design strategies. • Ensure that strategies match objectives. |
| Step 4: Produce Programme Components and Materials | <ul style="list-style-type: none"> • Consult with intended participants and implementers. • Create programme scope, sequence, theme, and materials list. • Develop design documents. • Review available materials. • Develop programme materials. • Pre-test programme materials with target groups; implement and oversee materials production. |
| Step 5 Adoption and implementation plan | <ul style="list-style-type: none"> • Identify adopters and users. • Specify adoption, implementation, and sustainability of the programme objectives. • Specify determinants and create matrix. • Select methods and strategies. • Design interventions to affect programme use. |
| Step 6 Evaluation | <ul style="list-style-type: none"> • Describe the programme. • Describe programme outcomes and possible answers to questions. • Write questions based on matrix. • Write process questions. • Develop indicators and measures. • Specify evaluation designs |

4.4 RESEARCH SETTING ENTRY NEGOTIATION PROCESS

The research setting has the potential to influence the expected intervention outcomes, and may modify the way the intervention is implemented. The context in which the intervention has been made has created evident bias in some nursing studies (Burns and Grove, 2009). The context can serve as a moderating variable, either by facilitating or impeding implementation of the intervention by muting or intensifying intervention effects (Conrad and Conrad, 1994). Linked with the setting are the resources needed to carry out the activities of the intervention. Resources include: (1) equipment, (2) space for the intervention, (3) the availability of adequately educated

professional assistants with the experience needed to implement the intervention, (4) adequate support staff, (5) a political-social environment that welcomes the intervention, and (6) access to telephones and computers (Sidani and Braden, 1998). A researcher should consider these resources and tread carefully during entry negotiations for a research setting, as they have the potential to enhance or prevent the entire research process.

Strategies to support entry include: approaches to stakeholders, that is, the authorities, community members and existing healthcare professionals and PLWHA in the area. These groups and individuals should be helped to understand the nature of the proposed intervention and its relationship to the healthcare services already in place. Key colleagues should be introduced, leadership responsibilities delegated and commitment to policies and practices that support advanced nursing practice made clear (Bryant-Lukosius and DiCenso, 2004). An important first step in carrying out any field research is gaining entry into the research field (Upvall and Hashwani, 2001).

The process of gaining entry into a research field can be a cumbersome process fraught with many obstacles, which the researcher must be willing to recognize and overcome (Thompson, 2000, Upvall and Hashwani, 2001). This is more the case when research requires contact with PLWHA and their families, because the stigma attached to HIV/AIDS makes such issues sensitive (Akintola, 2004). According to Murphy, Spiega and Kinmonth (1992), systematic strategies for gaining entry to research settings can be summarized as follows:

- Identify stakeholders (participants/those with external interests).
- Consider stakeholders' potential response to the project.

- Consult external stakeholders where appropriate.
- Identify gatekeepers.
- Identify local champions.
- Supply adequate and appropriate information.
- Contact gatekeepers.
- Negotiate (avoid irrational refusals/slow down premature agreement).
- Ask for cooperation and make practical arrangements.

Fundamental to the strategies outlined above is the belief that the quality of the access negotiated has a direct effect upon the quality of the eventual research data, and good quality access also minimizes the risk of cooperation being withdrawn at a later stage when considerable time and effort has been invested in the project (Murphy et al., 1992). Aware of these potential problems, I started the entry negotiation process in January 2010 by making contact with nurse managers in the areas identified in my proposal, which had already been approved by the University of KwaZulu-Natal (UKZN). At the first attempt however I was unable to gain entry due to the non-cooperation of the secretaries of the nurse managers, who were unwilling to allow me access.

After many attempts, I was forced to abandon the project in the particular areas which I had first selected. I then began a new search for a research setting that would fulfil the criteria in the proposal. In the process, I met a stakeholder who was a proprietor of a nursing college and presented my proposal with the supporting letter from my supervisor, ethics approval from UKZN and a letter of permission from the Department of Health. The stakeholder became

interested in the research study and was willing to help me. She offered me as a researcher a part-time job as clinical facilitator to help my entry into the health care facilities.

I was posted to a comprehensive health centre on the south coast of KZN, a centre that met the criteria for the research setting. I reported at the clinic, briefed the nursing officer-in-charge about the study but did not stress the issue further. Apart from my facilitating job, I offered, since I am a qualified nurse, to assist in provision of care. This afforded me the opportunity of further assessing the settings' suitability for the study, since the clinic was used by PLWHA, and possessed facilities for the care of these people. I also established a collaborative relationship with the staff of the clinic and assessed their perceptions of the needs for self-management education for PLWHA in their clinic. I was able to develop a cordial relationship with them, and eventually received permission to conduct my research. So cordial was the relationship with the staff members that I was allowed to participate in all their care giving activities. I was able to draw upon my previous experience in community health nursing and community mobilization in Nigeria. After three weeks of working there, I was able to ascertain that the clinic had adequate facilities for PLWHA, being a HAART roll-out centre that also provided treatment for patients with tuberculosis. I then submitted a letter of intent accompanied by necessary documents seeking permission to conduct study and was given the letter of permission to conduct the study.

The nursing officer-in-charge assured me of full support from all members of staff and gave me the opportunity to liaise with the Voluntary Counselling Testing Unit's staff, which had already started seeing me as a colleague. Persistence, humility, patience and social sensitivity were some

of the major attributes used to facilitate my entry and indeed to take the entire research process forward.

4.5 RESEARCH ACTIVITIES

The research activities comprised three phases:

4.5.1. Assessment Phase

Baseline assessment data were collected to establish the self-management education needs and baseline information on health-related quality of life of the participants. Consultation and assessment was conducted in the first visit. Thereafter focus groups discussions (FGDs) were conducted. Content analysis of qualitative data from focus groups discussions was used to refine the HIV/AIDS self-management education intervention package. Data obtained were analyzed to provide information concerning the intervention phase. Instruments 1 and 2 were administered to provide baseline data and obtain information about the self-management education needs of the participants (groups A and B). Instrument 2 plus the interview schedule was to be used in the final evaluation of the intervention.

4.5.2. HIV/AIDS Self-Management Education Programme

The term ‘intervention research’ is increasingly used by nurse researchers to describe a research approach distinguished not so much by a particular research methodology as by a distinctive process of planning, developing, implementing, testing, and disseminating results (Sidani and Braden, 1998; Whittemore and Grey, 2002). Nursing intervention studies either question existing care practices or test innovations in care that are shaped by the values and goals of nursing, guided by a strong theoretical basis, informed by advances in science, and designed to improve

the quality of care and health of individuals and society (Naylor, 2003). The intervention process involves an in-depth understanding of the problem and the people for whom the intervention is being developed; careful, collaborative planning with a diverse team; and the development of an intervention theory to guide the enquiry.

The HIV/AIDS Self-Management Education Programme (HASMEP) was developed by me in 2010 in response to the self-management education needs. It applies empowerment theory and the HIV/AIDS self-management conceptual framework, incorporating the general principles of good chronic care for PLWHA. HASMEP was designed to encompass both individual and group engagements working towards the empowerment of PLWHA.

Group engagement has many advantages; in this case the group is engaged in self-management education. First, a group provides a setting in which people living with HIV/AIDS can be in touch with others with similar problems. Second, group engagement can help PLWHA gain better understanding of their situation and problems. Third, PLWHA can be taught effective coping skills and self-management strategies. Fourth, cooperation and interaction between participants allows members to gain experience and profit from the successes of other group members as well as the knowledge of group leaders and the researcher. HASMEP consists of fourteen bi-weekly sessions (120 to 150 minutes per session) and emphasises participants' central role and responsibility in managing their illness. The sessions consisted of supervised dialogue, physical activity and education. The programme aims to enable PLWHA in self-management techniques such as the medical management of the disease; changing, and creating

new and meaningful behaviour (role management), and dealing with the emotional consequences of living with HIV/AIDS (Lorig and Holman, 2003).

The main goal was for PLWHA to gain knowledge and skills to self-manage and improve their health-related quality of life. Acquisition of knowledge and skills was to be driven by behaviour change goals, not by a fixed curriculum. However, the topics for the sessions include: goal setting, increasing emotional capacity, increasing knowledge of HIV/AIDS, positive living and self-management, active antiretroviral therapy, nutrition, water, control of infection, hygiene, physical exercise, self-management strategies, networking and communication. Self-management educational material used as homework was included.

These self-management techniques are taught by means of skills mastery through weekly action planning and feedback on progress, modelling of self-management behaviour and problem-solving strategies, reinterpretation of physiological symptoms, and social persuasion through group support and guidance for individual self-management efforts (Lorig et al., 2001, Lorig and Holman, 2003). I compiled a self-management handbook, based on findings from the assessment, which was distributed to members of Group A to be used as a reference source for the material covered in the sessions. They received this book at the first session of the programme.

The programme comprises a 'professional leader' (myself) and 'peer leaders' (PLWHA), acting as role models for the other PLWHA in the study. The reason was that a programme which is led by at least one professional leader is easier to implement in regular health care than a programme

led by lay leaders only (Gifford and Sengupta, 1999). Another reason was that HIV/AIDS is a serious condition with unexpected complications and underlying health problems. This means that peer-group leaders may only be able to conduct the programme for a limited period, which could form a threat to continuity. The ten prospective leaders underwent four days of intensive training, following a curriculum set out in the HASMEP leaders' manual. The leaders' manual outlined HASMEP in detail, including visual aids, group teaching activities, scripts and other curricular elements.

This leader training included discussion of the goals of HASMEP, detailed presentation and demonstration of the HASMEP curriculum and orientation of prospective leaders according to the manual. The training concluded with practice teaching experiences by the ten prospective leaders. These practice sessions were evaluated, and corrective feedback was provided. The nurse master trainer (the researcher) also conducted several classes with these leaders. Groups A and B consisted of equal numbers of PLWHA. The comparison groups received no self-management education, but received standard treatment from their primary care providers as well as traditional health education on HIV/AIDS, which I myself reinforced. Group A participants met twice weekly for seven weeks to receive interactive self-management education twice a week and completed a structured curriculum that taught self-management skills and information. Symptom assessment and management, medication use, physical exercise, relaxation, communication of health problems to healthcare providers, and nutrition were all taught to Group A, who learnt self-management strategies and skills that could be used in everyday life. Group A also learnt a behavioural therapy process designed to meet the individual needs of the participants.

In this study, the PLWHAs' current problems and the reasons they occurred were also focused upon, recorded, and assessed continually throughout the programme, using the conceptual framework and incorporating the principles of good chronic care. Treatment goals and objectives were specified by the participants and recorded. Each PLWHA's expectations of the costs and benefits of the changes they were making and confidence in their ability to achieve their goals were measured at each visit. The intervention was based on their needs at the time. With regard to compliance, the leaders recorded after each session whether group members had exceeded specified time limits, or whether they had used different training techniques from those specified in the protocol. In addition, they recorded preparation time, travel time, time spent on the session, and activities resulting from the session. They reported on patient attendance and adherence at group level. Absent participants were phoned by the investigator to ask about the reasons for their absence. After completing the programme, both leaders and PLWHA reported on the overall performance (i.e. PLWHA's efforts during the sessions) with regard to homework assignments (e.g. did group members achieve the weekly targets?).

4.5.2.1 Intervention procedure

Participants were provided with information about the purpose and method of the study, the fact that participation was voluntary and that confidentiality was guaranteed. Assessments were made to assess direction and trend of the intervention. Conducting self-management education for PLWHA is not always a straightforward affair; a number of clinical issues can arise. Among these are problems relating to PLWHA's expectations: anger and emotional distress may be emphasised. I was careful above all to ensure a consistent positive relationship with the participants, showing concern, acceptance, sincerity and empathy. I was alert to any potential

factors that might compromise group collaboration. Good record keeping and the use of a report form for monitoring and measuring change that might occur was adhered to. Self-awareness and self development was emphasized, as was emotional support for both peer leaders and participants. Individuals with specific problems identified during sessions were referred to me for individual interactive sessions. At the initial consultation I assessed: PLWHA's knowledge, beliefs, concerns, daily behaviour, goals, clinical status; I identified and classified relevant treatments and gave advice using non-judgmental language, correcting any inaccurate beliefs and supplying gaps in the PLWHA's understanding of his or her condition. I reinforced in group teaching the advice given to individuals within consultations, putting that advice into a wider context, suggesting further sources of information, and helping the recipient to gain more from the healthcare system. In developing treatment plans I discussed the options available with PLWHA, relating them to specific concerns, and evaluating the importance each PLWHA gives to the indicated treatment, as well as his or her readiness to adopt the recommended behaviour change. I negotiated the selection from different options, agreed upon goals that reflect PLWHA's priorities, ensured that the negotiated goals were clear, measurable, realistic, under the PLWHA's direct control and limited in number. I also provided a written or diagrammatic summary of the plan, and liaised with the clinic staff to provide prescribed medications. In addition I provided nursing care where necessary, provided skills and tools to assist with self-management, addressed obstacles, provided psychological support and links to other kinds of support. I arranged for follow-ups to monitor progress, reinforced key messages and scheduled group sessions.

During follow-up consultations, in order to improve both health and health literacy which increases an individual's capacity to understand basic health information and services and make appropriate health-related decisions, I assessed the PLWHAs' needs for consultation, and their clinical status. I also assessed the risk factors, the understanding of the treatment plan, and later assessed adherence to treatment plan (by asking, counting pills, checking pharmacy records), and compared my findings with those from previous consultations. I acknowledged the patient's efforts and successes with self-management, even if they were limited. At each consultation I repeated key information concerning the PLWHA's condition and its treatment, reinforcing what PLWHA need to know to self-manage. Where necessary I negotiated changes in the plan, discussed problems and developed strategies to overcome them in the future. I also arranged follow-up to monitor progress, reinforced key messages, and scheduled group sessions or support groups, recording what happened during the session and evaluating the intervention process and the PLWHA's condition.

4.5.2.2 A summary of HIV/AIDS self-management education programme

The aim of the self-management education was to increase participants' level of knowledge about HIV/AIDS, its treatment (medication regimen including benefits of therapy, adverse effects, scheduling of dosing, drug interactions, storage recommendations, and what to do if the dose was missed), symptom management strategies, as well as support seeking and networking.

The programme: (a) explicitly engaged PLWHA as active participants in their healthcare; (b) facilitate development of skills and knowledge necessary to collaborate with their healthcare providers and implement treatments effectively and (c) enable PLWHA to develop confidence to put their knowledge and skills into practice.

The health information was written in plain language with enough depth and substance to allow self-management group participants to weigh all the options for prevention and treatment. The sessions were tailored to the skills and interests of the participants and allow time for individual exploration. For the sessions various methods such as presentations, role plays, discussions and networking meetings were employed to facilitate acquisition of self-management behaviours. The self-regulation skills comprises of: (1) self-monitoring, (2) goal-setting, and (3) enlistment of self-incentives. The purposes of self-monitoring were to self-diagnose health problems, self-evaluate progress towards goals, and enhance self-regulatory efficacy.

A single implementer, assisted by the technical staffs provides intensive guidance in facilitating self-management education. The leader's manual (appendix 8) comprises of detailed information about HIV/AIDS self-management education programme (HASMEP). The objectives of each session, activities and the expected outcomes targeted during the sessions are summarised below (Table 4.5.2.2).

Table 4.5.2.2: Objectives, activities and outcomes

| OBJECTIVES | ACTIVITIES | OUTCOMES |
|--|--|--|
| Session one Make the participants feel valued by the team, to alleviate their fear make them feel relaxed, to know the nature of the program and what is expected of them. | Welcome, Introductions, expectations, programme objectives and ground rules. The researcher greets everyone warmly and praises them for attending the program. We want to care for you and we will have to work together. So we need your cooperation. This course will give you information and skills to live with HIV/AIDS and build new supportive friendships. Expectations from the participants (P. 14 leader's manual) | Helped everyone to get to know each other's name and helps to break the ice. |

| OBJECTIVES | ACTIVITIES | OUTCOMES |
|---|---|--|
| <p>Session two</p> <p>Becoming an active self-manager</p> | <p>Self-management tasks includes: (1) taking care of your illness; (2) carrying out your normal activities; (3) managing your emotional changes. Good self-management practice are: (1) decide what you want to achieve; (2) look for alternative ways to achieve this goal; (3) make a short-term action plan; (4) carry out your action plan; (5) check your results; (6) make changes as needed; and (7) reward yourself (Lorig, Holman, Sobel, Lauret, Gonzalez and Minor, 2006; EPPCIC, 2007). Positive living and self-management (P. 20 leader's manual).</p> | <p>Participants demonstrate understanding of self-management concept.</p> |
| <p>Session three</p> <p>Help participants to come to terms with the fact that they have HIV.</p> | <p>Give everyone a piece of paper and ask them to draw a picture. This picture should depict:</p> <ul style="list-style-type: none"> • Who you were before you knew you had the virus. • Who you are now that you know you have the virus. • Who you wish you could be. <p>Encouraged to use whatever they feel comfortable with to express themselves. Dealing with stigma and making self important (P. 16 leader's manual)</p> | <p>Helped participants to come to terms with the fact that they have HIV, understand the emotional and physical impact that HIV has had on them. It gives them an opportunity to express their feelings about what has happened to them. Participants began to share their</p> |

| OBJECTIVES | ACTIVITIES | OUTCOMES |
|--|---|--|
| | | stories. |
| Session four Increase knowledge and how to improve their health functioning. | Participants were provided detailed guides on how to improve their health functioning. Personalised reports include feedback of progress toward sub goals. The feedback also provides guides on how to manage troublesome situations and new goals to realise. Participants were encouraged to utilise self-management strategies, share their strength and resources. Increasing knowledge about HIV/AIDS (P. 17 leader's manual) | Participants demonstrated adequate knowledge about HIV/AIDS and commitment to health information utilisation and sharing. |
| Session five Improving adherence to antiretroviral medications and keeping immune system as strong as possible. | The self-management strategies includes: (1) integrate your regimen into your daily routine; (2) keep a checklist of doses taken; (3) use a daily planner; (4) plan ahead for weekends and vacations; (5) keep your medications with you when travelling; (6) plan ahead for privacy; (7) keep a diary; and use a support network of friends or family" (Smith et al., 2003). Information about highly active antiretroviral therapy is on p. 23 leader's manual. | Participants reported taking all their prescribed antiretroviral medications in accordance to time and dosage. Self-monitoring ensures adherence and generated expected benefits |
| Session six Identify nutritious foods in the locality and prepare them to meet their nutritional needs; have adequate knowledge of the | Prior to facilitating the session, the researcher finds out more about the dietary habits in the community, varieties of local food, hindrances that prevent healthy eating. Start presentation with the basics of food and nutrition. Ask the participants why do we eat? Why is good nutrition essential for all humans? Show the presentation slides, | Participants were responsible for showing that they understand the three foods groups and hydration by |

| OBJECTIVES | ACTIVITIES | OUTCOMES |
|--|---|---|
| relationship between nutrition and HIV/AIDS. | <p>which list all the things good nutrition does for the body.</p> <p>Ask participants what constitutes a nutritious diet? Ask if it is OK to only eat the same thing all the time? Ask them what food they think may be bad for the body? Ask participants to explain the different food groups and what type of food fit within the different groups. Write down the answers on the whiteboard. Show the power point slide with explanations on the food groups and what they do.</p> <p>Ask participants if it is important to drink fluids such as water. Also ask how much water a person should consume in a day (2litres). Show the slide that reviews why hydration is important. Relationship between nutrition and HIV is on P. 26 leader's manual.</p> | dividing up the locally procure foods correctly. |
| Session seven Encouraging food, water safety and hygiene practices. | Participants are encouraged to carry out: personal hygiene, food hygiene for animal products, hygiene in the kitchen, and sanitary disposal of faeces. Detail P. 27 leader's manual. | Participants demonstrated adequate knowledge of personal, food, water and environmental hygiene. |
| Session eight Understanding and managing symptoms I: anxiety, depression, forgetfulness and insomnia. | <p>Anxiety and depression: contact your physician or nurse.</p> <p>Strategies (try-relaxing or stress-reducing activities, consider attending a support group, avoid stimulants, take your medications as prescribed, go for a walk at your own pace, keep a diary to record your thoughts and feelings.</p> <p>Strategies for managing forgetfulness and insomnia are on P. 88 and 96 of self-management handbook (appendix 9)</p> | Participants develop skills in symptom management and techniques to manage their own health. This was |

| OBJECTIVES | ACTIVITIES | OUTCOMES |
|--|--|-----------------------------------|
| | | reported during group interviews. |
| Session nine Understanding and managing symptoms II: constipation, diarrhoea and nausea. | Contact your physician or nurse. Strategies for managing constipation, diarrhoea and nausea are on P. 82, 84 and 90 (appendix 9). | |
| Session ten Understanding and managing symptoms III: shortness of breath, dizziness, loss strength (fatigue) and fever. | Contact your physician or nurse. Strategies for managing: dizziness and fever (P.86 and 87), shortness of breath (P. 92 and 93), and loss of strength (P. 89). | |
| Session eleven Understanding and managing symptoms IV: cough, night sweats, pain and swellings. | Contact your physician or nurse. Strategies for managing cough (P. 83), night sweats and neuropathy (P. 91), swellings (P. 96). | |
| Session twelve Understanding and managing symptoms V: skin abscesses, blisters and rashes. | Contact your physician or nurse. Strategies for managing skin abscesses, blisters and rashes (P. 93, 94 and 95). | |
| Session thirteen Understanding and managing symptoms VI: weight loss (unplanned), oral | Contact your physician or nurse. Strategies for managing weight loss (P. 98), genital itching, burning and discharge (P. 94). | |

| OBJECTIVES | ACTIVITIES | OUTCOMES |
|--|---|---|
| trush, genital itching, burning and discharge. | | |
| Session fourteen Encourage seeking social supports and networking. | Ask the group if anyone would like to share how it felt to meet new people. How has hearing the experiences of others changed the way they felt about themselves and their illness? Explain that we are designed to interact with other people. We cannot live in isolation. The most damaging aspect of HIV disease is that it isolates us through stigma, lack of information and fear. Explain that in order to gain support, skills, love and positive input, we need to choose friendships that will build us up and help us to stay strong and focused. One of the ways to do this is to continue friendship with those we have met. Another way is to become involved with a spiritual support group, like a church. Explain that as we play a part in helping others, we in turn will receive help when we need it. | The group spends some time sharing addresses, phone numbers and contact details with people they have met. suggested the formation of a support group |

4.5.3 Measuring the ‘Dose’ of Programme Intervention

Information about the ‘dose of programme intervention’ is very important for a nurse researcher who wants to engage in evidence-based practice. “The dose of behavioural intervention is defined as a specified unit amount of a treatment or therapy. It is measured in terms of what is prescribed, what is perceived to have occurred by either party, or as the actual quantity that is delivered” (Huber, Sarrazin, Vaughn and Hall, 2003: 276). “Because the production of the desired outcomes and subsequent assessment of effectiveness and value is dependent in part on

knowing how to deliver the intervention, when to deliver it, and the amount of intervention to deliver, dose determination is an urgent issue for behavioural interventions” (Huber et al., 2003: 277).

The four components of dosage of nursing interventions are: amount, frequency, duration and breadth (Sidani and Braden, 1998; Huber, Hall and Vaughn, 2001). These were considered and measured so as to ensure they were equal for Groups A and B. “Amount is the quantity of nursing intervention delivered at one point in time. Frequency is the number of times the intervention is delivered over a specified time period. Duration is the entire length of time over which the intervention is delivered. Breadth is number of different activities that occurred.” (Sidani and Braden, 1998; Huber et al., 2003; Reed, Titler, Dochterman, Shever, Kanak and Picone, 2007).

Engagement was examined as a potential variable. It was observed that, “with a behavioural intervention, the degree to which a client engages with the provider will vary according to the client’s personal characteristics, the therapist’s characteristics, the circumstances, and the motivation” (Huber et al. 2003: 279).

In this study, I seek to ascertain that the prescribed interventions were delivered and that the desired outcomes were achieved as a result. I also attempted to ensure that the dose of intervention were equal for all, that is, Groups A and B, so that participants in Group B did not feel that they were being devalued as compared to Group A. I took steps to create equality between the two groups by providing health education for Group B, ensuring that the dose of

intervention were equal. For example, if Group A is engaged for 90 minutes during session one, Group B is also engaged for 90 minutes.

4.5.4. Evaluation (Phase Three)

Process, impact and outcome evaluations were conducted. Data for the impact and outcome evaluations were first collected at baseline and then at the end of 24 weeks from the start of the programme. Data for the process evaluation were collected from the participants by means of group interviews conducted by the investigator in the 24th week of intervention. A sample of Group A participants were interviewed for 30-40 minutes.

I was concerned to identify themes grounded in PLWHAs' experiences, rather than my questions. The interview guide therefore had general questions placed at the beginning and targeted questions about specific components of the programme at the end. This was done to permit open-ended, unbiased elicitation of subjects' experiences, while still allowing for data collection about key programme elements.

4.6 RESEARCH SETTING DESCRIPTION

KwaZulu-Natal (KZN) is the third smallest province in terms of land space (34,361 square meters) in South Africa, but is the largest in terms of population, with an estimated 10 million people (Start SA, 2009), translating to 27.9% of the total population of South Africa. The province is divided into eleven health districts, each of which is governed by its own district health authority. According to the national HIV/AIDS Plan (South African National AIDS

Council, 2007), each district has at least one HAART-roll out site provided by the government health service, and these sites are situated in state clinics or Hospitals.

The semi-rural settings include those areas where black people are located either from birth or by land acquisition near urban settings. One of the functions of the semi-rural settings is to cater for rural people, but these semi-rural settings also cater for some of the needs of people from urban areas. One distressing legacy of past policy is that semi-rural settings where black people live are often poor and decaying; they have become places which are a trap for old and young. The legacy of poverty and neglect in these places is far from being eliminated. Semi-rural, semi-urban areas such as Danganya, Umugababa and Ilfracombe are a mixture of city-like suburbs, locations in which rural people have some but not all the facilities which are usually available in urban areas.

The realities faced by people, especially people living with HIV/AIDS, in rural settings cannot always be addressed by policy made elsewhere. Therefore, PLWHA in rural communities have to devise methods of managing their affairs, and develop social networks and cultural practices that will impact positively on their social well-being. Chapter 5 includes an assessment of the self-management education needs of PLWHA.

Inclusion criteria for research setting

According to Campbell et al (2007) the finding of trials of complex interventions should be generalizable if they are performed in the setting in which they are likely to be implemented. In this study, the inclusion criteria for research setting were: (1) health settings involved in HAART

roll-out, (2) part of the public health services set up to meet the needs of PLWHA, (3) likely to have an interest in addressing the issues of self-management education, and (4) willing to allow for monitoring outcomes in terms of CD4count and HAART uptake (For which non-HAART settings would not do). The public health services are the relevant sites for this study since health care of the population in South Africa are mainly provided by government. Danganya cilinic was selected for the study since it met the above criteria.

Danganya Clinic

Danganya clinic is a comprehensive health centre under the Department of Health, situated on the outskirts of Durban in Danganya, between Umugababa and Ilfracombe, along the R 102 south, about 40 km south of Durban. The vision of the clinic is to achieve optimal health status for all persons in the Primary Health Care services under Danganya clinic. The mission is that all personnel in the Primary Health Care will be committed to developing sustainable, coordinated, integrated and comprehensive health services at level I (the lowest level of health care service delivery) and referral to the next level. Danganya is a semi-rural situation, underdeveloped but with access to the Metrorail; commercial taxis are available on the R 102. The clinic serves a catchment area of more than 85 000 people, mostly Zulu-speaking, and caters primarily to the healthcare needs of the very poor. The clinic serves as one of Prince Mshiyeni Hospital ARVs down-referral clinics and also serves as down-referral clinic for Addington Hospital and Charles James Hospital. Supplies of ARVs for all the down-referred patients are supplied from these hospitals. Patients from the areas served by the clinic are down-referred for ARVs provided: viral load is less than 25 and there is no sign of clinical deterioration. Blood monitoring and evaluations of the down-referred patients are done at the clinic and if there is deterioration in

their clinical status before the end of a six month period, CD4 count and viral load are repeated on the motivation of the doctor at the clinic. There are rules such as: for viral load greater than 1000, or a fall/decrease in CD4 count: make sure the patient is adherent, and re-enforce adherence; repeat viral load and CD4 count. If viral load is still greater than 1000, refer patient back to referral hospital for further management. For any acute or chronic illness that needs referral to a tertiary health institute, the normal referral pattern is followed. The clinic keeps statistics of patients who exit the programme for any reason and inform Prince Mshiyeni and Charles James Hospital pharmacy as soon as possible. Patients diagnosed with TB whilst on ARVs are started on anti-TB therapy and need to have their liver function test done before anti-TB therapy. Services offered in the clinic include:

- Clinical management of HIV, AIDS, STIs and TB (HAST)
- A laboratory service for screening blood for HIV and sputum smears for AFB.
- Voluntary counselling and testing services.
- Antiretroviral treatment.
- Health education for PLWHA and TB patients, families, staff and communities.
- Primary health care services, including immunization, treatment for sick infants and adults.
- Prescribed treatment for chronic conditions down-referred from district hospitals and other tertiary health institutes. Danganya clinic is one of the 17 clinics attached to Prince Mshiyeni Hospital.

Prince Mshiyeni Memorial Hospital, has been designated a district and regional hospital. It is a 1200-bedded facility that serves the surrounding area, up to and including part of the Eastern Cape. The hospital offers health services to the community at regional and district levels. Services provided at regional level of care can use the expertise of general specialists for

managing inpatients and outpatients referred from district hospitals. Services provided at the district level of care are non-specialist and are offered to patients referred from local clinics for inpatient and outpatient generalist care. District health services are jointly provided by the Provincial Department of Health and the Local Government authority, with former contributing 60% and the latter 40%.

4.7 TARGET POPULATION

My study is concerned with PLWHA in semi-rural KwaZulu-Natal. For the study an information-rich sample was selected, using inclusion and exclusion criteria.

4.8 SAMPLING TECHNIQUE AND SAMPLE SIZE

An advertisement was placed at the Danganya Clinic to assist in the recruitment of PLWHA who were identified as eligible to participate in the project. PLWHA who express verbal interest in participating were assessed by me on presentation for consultation and were given the participant's information sheet and a consent form.

The inclusion criteria were: over 18 years of age, HIV-positive, in WHO stage 3 or more of HIV/AIDS, on antiretroviral medication for at least three months prior to the study, not a participant in any similar programme for the prior three months, medical approval and personal consent to participate, and able to complete the study instruments in English or isiZulu. Exclusion criteria were: too ill to participate, and exposed to similar programme in the three months prior to the study.

Following institutional approvals, the study sample was recruited from all patients (138 PLWHA) attending the clinic for routine care for eight weeks in April-May, 2010. Of the 138 clinic patients approached, 114 met the study criteria. Eligible participants who had written consent were randomly allocated into either Group A or Group B, using a random numbers table. For the qualitative part, a list of participants in Group A was prepared and one out of every five was randomly selected.

4.8.1 Recruitment and retention of participants

Hellard, Sinclair, Forbes and Failey (2001) studied methods to improve the recruitment and retention of subjects in clinical trials and suggested that the four most important strategies were: (1) to use nonaggressive recruitment methods, (2) to maintain regular contact with the participants, (3) to ensure that the participants are kept well informed of the study's progress, and (4) were constantly encouraged to continue participation.

Retaining acquired subjects is critical to achieve an acceptable sample size and requires the researcher to consider the effects of the data collection strategies on subject attrition. The researcher is required to invest considerable energy in developing strategies to maintain the sample. Power analysis (see P 119) was calculated according to the number of participants expected to complete the study. To compensate for attrition over-sampling by 10% was done during recruitment. Screening logs were kept during the recruiting period to record data on patients who met the criteria but were not selected to form part of the study.

In addition to defining the number of subjects and the time set aside for recruitment, short-term recruitment goals were fixed to maintain a constant rate of participant entry. Some of the factors that influence a subject's decision to participate in a study were the attitudes and ethics of the researcher, the subject's need for treatment, the subject's interest in the study topic, fear of the unknown, time and travel constraints, financial compensation (A stipend of R30 per session of the educational programme was paid to each participant), and the question of informed consent (Madsen et al., 2002, Papadopoulos and Lee, 2002, Sullivan-Bolyai et al., 2007) The researcher's initial approach to a potential participant usually strongly affects his or her decision about participating in the study (Burns and Grove, 2009).

I did my best to maintain a pleasant, informative and nonaggressive approach, and explained the importance of the study, clarifying exactly what the participants would be asked to do, how much of a participant's time would be involved, and what the duration of the study would be. Participants' names, addresses, cell and home telephone numbers and at least two family member's cell phone numbers were obtained when they enrolled in the study. Refreshments and lunch were also provided on session days. Ice-breakers and other kinds of games are an important part of the programme and serve two basic purposes: (1) they serve as metaphorical introductions to the topic of the session and (2) as lively exercises to bring the energy back into the group when they are feeling tired or too serious. Participants played games and watched videos and documentaries of long-term survivals of HIV/AIDS.

4.9 POWER CALCULATION

To ensure the intended sample was large enough to have a statistical power of 0.80, statistical advice was sought from the UKZN College of Health Sciences statistician. It was necessary that the findings of the study should have ‘power’, that is, the capacity to detect differences or relationships that actually exists in the population. To be expressed this in another way, “power is the capacity to correctly reject a null hypothesis” (Burns and Grove, 2009: 357). An *a priori* power analysis was conducted, assuming the Type I error rate to be .05 and for the smallest size of effect that could usefully be detected, 80 participants with complete data were required. The power analysis was performed using PASS 2000 (Hintze, 2002). The methods elected to determine the power for this study is accepted, validated, and have been previously used by numerous investigators. To compensate for expected attrition and missing data, over- sampling by about 10% was applied. A sample of 88 adults PLWHA was therefore recruited from the clinic.

4.10 Instrumentation for Data Collection

4.10.1 Research Instruments and variables measured:

Three instruments and consultations were used in this study.

A. Assessment phase instruments:

1. HIV/AIDS Self-management Education Needs Survey

This instrument was adapted from Health and Self-Care Learning Needs Survey, developed by Mendias and Paar (2007) for assessing the self-care learning needs of outpatients with HIV/AIDS. The survey was reformatted to make it more user-friendly without modifying the

content of the original questions or the answer options. The original survey was translated to isiZulu. The translator tried to replicate the original instrument as much as possible for the purposes of cross-cultural comparisons and to adapt the instrument to the local socio-economic and cultural setting. Translation was reviewed by two independent healthcare providers who were proficient in both English and isiZulu and the accuracy of translation was certified. The survey was translated into isiZulu, the language of the participants, in order to minimize the problems of error or distortion that might occur; it was then translated back into English and compared with the original English version; adjustments were made where necessary.

Pilot testing of the HIV/AIDS Self-Management Education Needs Survey on PLWHA recruited for the pilot study was carried out before data collection for the main study commenced. A purposive sample of 20 PLWHA in an HIV/AIDS support group at a site that was not part of the study was recruited for pilot testing and I administered the instruments to them. This allowed me to identify problems in the design of questions, sequence or procedure of recording responses. Data from the pilot survey was reviewed and the instruments were further refined, but no major changes were needed. Participants seemed to understand the instruments and were able to give information that was required.

Content validity was addressed through a literature review on PLWHAs' health concerns and needs. In addition, expert clinicians from the School of Nursing at UKZN reviewed items for content, clarity and readability. These clinicians also considered the appropriateness of terminology, based on words commonly used with and by patients in the clinic, and suggested

items for inclusion. Clinic patients were informally questioned, prior to survey development, concerning patient interest in self-management education programmes.

My survey includes (a) biographical data (six items); (b) general health data (11 items); (c) self-management education needs scale (74); items related to perceived self-management education needs; barriers to programme attendance; and preferred modalities for learning, using a five-point Likert-type scale ranging from 'Very much' to 'Not at all'. An additional question was: "What one thing would be most helpful in meeting your current self-management needs?" Cronbach's coefficient alpha, calculated as a measure of reliability for the total scale was .984. Alphas on the subscales ranged from .837 to .969. These values support high internal consistency within the total scale and within subscales (Mendias and Paar, 2007).

2. SF-36 Questionnaire

SF-36 Questionnaire is considered to be one of the best instruments for measuring the health-related quality of life (HRQOL) of general and specific populations, patients with acute and chronic diseases in clinical practice under different circumstances (Ware et al., 2001, Joshi et al., 2001). The SF-36 questionnaire, directed towards the respondent's experiences, feelings, beliefs and convictions about health-related quality of life, consists of eight scales and two summary measures (physical and mental health). The eight multi-item scales that were used are: (a) limitations in physical activities because of health problems; (b) limitations in social activities because of physical or emotional problems; (c) limitations in role performance because of physical health problems; (d) bodily pain; (e) general mental health; (f) limitations in role

performance because of emotional problems; (g) degree of vitality; and (h) general health perceptions (Ware and Sherbourne, 1992: 473-483).

The content validity of the SF-36 questionnaire has been confirmed by systematic comparisons that indicate that this questionnaire includes eight of the most frequently represented health concepts in the measurement of health-related quality of life (Ware et al., 2001: 3). Both the internal and constructed validity of SF-36 instrument have also been confirmed through various studies (Petr, 2001; Möller and Petr, 2002; Strassnig, Brar and Ganguli, 2003).

Recently, to evaluate how distinct each scale of SF-36 was from the other scales in the same matrix, correlations among all scales were computed. “Pearson bivariate correlation showed moderate correlations between the SF-36 scales. Internal reliability was estimated using Cronbach’s α . Cronbach’s α was greater than 0.70 for six out of eight multi-item scales, with value ranging from 0.6298 to 0.8860 for all scales, with .06500 for VT and 0.6298 for GH indicating good internal reliability of SF-36” (Abera, Gedif, Engidawork and Gebre-Mariam, 2010: 35). These values have demonstrated that SF-36 is a reliable and valid instrument for the assessment of quality of life in PLWHA.

B. Evaluation phase instruments:

Evaluation instruments include SF-36 questionnaire, an in-depth interview guide and a document review checklist.

In-depth Interview guide

The instrument for the in-depth group interview was an interview guide adapted by me from the instrument previously used by Gifford and Sengupta (1999) to identify themes grounded in PLWHAs' experiences. The interview guide had general questions at the beginning and targeted questions about specific components of the programme at the end. This was done to permit unbiased elicitation of participant's experiences, while still allowing for data collection about key elements of the programme.

The interview guide was reformatted to make it more user-friendly without modifying the content of the original questions or answer options. The original interview guide was translated into isiZulu. The translator tried to replicate the original instrument as much as possible for purposes of cross-cultural comparisons whilst adapting the instrument to the local socio-economic and cultural setting. Translation was reviewed by two healthcare providers from Danganya who were proficient in both English and isiZulu and the accuracy of translation was certified by language expert.

Examples of questions which were asked are indicated below:

1. In general, what did you think was most helpful about the programme?
2. If you could only keep two of the things in the programme, which two things would you keep?
3. If you had to throw two things out of the programme, what would you throw out?
4. What would you do differently if you were to design the programme?
5. What would you like to be added to this programme in future?

6. Are there things that you do now to improve your health that you didn't do before the programme?
7. Are there changes in your health and functional ability since you've attended the programme?
8. What did you think about the self-management education handbook?
9. What did you think about the participants in your group?
10. What did you think about the facilitators of the programme?
11. What experiences did you gain from participating in the programme?
12. How did the programme impact on your life as a result of attending?

The interviews provided exploratory data on experiences of participants

Document review checklist

The document review process provides a systematic procedure for identifying, analyzing, and deriving useful information from the existing documents. The advantages of the document review process are: (1) Information contained in the extant document(s) is independently verifiable; (2) the document review process can be done independently, without needing extensive input from other sources; and (3) document review is typically less expensive than collecting the data afresh. The disadvantages include (1) Information in the document(s) may represent a perspective that is not aligned with the needs assessment project; (2) data in the document source(s) may not be exactly what you want for the needs assessment; (3) obtaining and analyzing necessary documents can be a time consuming process; (4) the investigator has no control over the quality of data being collected and must rely on the information provided in the document(s) to assess quality and usability of the source(s).

4.10.2 Breakdown of the Instruments

Table 4.10.2 HIV/AIDS Self-Management Education Needs Survey

| VARIABLES TO BE MEASURED | DESCRIPTION OF SUBSCALES | PLWHA | EXISTING SCALE |
|--|--|--------------|-----------------------|
| Biographic and health data | Gender, age, education, diagnosis with HIV or AIDS, rating of current health, HIV/AIDS medications currently prescribed daily, perception of difficulty living with HIV/AIDS, perception of difficulty taking prescribed medications correctly and use of complementary or alternative therapies | | |
| Self-management needs | One thing that would be most helpful in meeting self-management needs | | |
| Self-management education needs | Overall health and wellbeing, nutrition and HIV/AIDS management | | |
| Barriers to participation in self-management education | Distance, transport, stigma, costs, hours of classes, confidentiality, ill health, poor vision, family and work obligations | | |
| Methods of learning | Pamphlets, bulletin, group and individual classes, video library, telephone, mailed newsletter and computer resources | | |

Table 4.10.3 SF-36 questionnaire

| QUALITY OF LIFE SUBSCALES | DESCRIPTION OF SUBSCALES | PLWHA | EXISTING SCALE |
|--|---|--------------|-----------------------|
| Physical functioning (PF) | Extent to which PLWHA are able to perform moderate to vigorous activities as influenced by physical condition e.g. running, lifting heavy objects, participating in strenuous sports, climbing several flights of stairs, walking more than a kilometre, bending, kneeling, stooping and dressing themselves. | | |
| Role limitation due to physical health(RP) | Extent to which performance of their roles in daily activities is impeded by their physical state of health. e.g. lifting heavy objects, moving a table or pushing a vacuum cleaner. | | |
| Role limitation due to emotional problem(RE) | Extent to which their emotional condition: feeling depressed or anxious limits their daily functioning and ability to perform roles. | | |
| Vitality (VT) | Energy /fatigue: feeling energetic or tired. | | |
| Mental health (MH) | Emotional well being: feeling full of energy, calm and peaceful, being happy, being very nervous | | |
| Social functioning (SF) | Social activities and interaction with significant others such as friends, neighbours and other social relations | | |
| Bodily pain (BP) | Extent to which experience of body pain hinders performance of daily activities. | | |
| General health (GH) | Perception of general health in terms of concepts such as excellent, very good, good, fair or poor. | | |

4.10.3 Measures to Improve Validity and Reliability of Data

A number of measures were taken to address the potential limitations of the study and ensure the validity and reliability of data. The nature and sensitivity of the research precluded the use of a probability sampling technique. The generalizability of these findings is supported by use of purposive sampling technique, but the selection criteria does not allow for sampling across the disease trajectory.

Issue of linguistic fluency

According to Axinn et al., (1991) the issue of linguistic fluency is critical to instrument construction, which assumes shared linguistic interpretation by respondents and investigators especially when studying societies that are ‘alien’ to the investigator, such as the circumstances of this study. I do not speak isiZulu but made efforts to learn it whilst negotiating the study setting. I had not learned enough vocabulary, however, to be able to conduct in-depth interviews in isiZulu; so a purposive sample was used for the in-depth interviews. I lived amongst the people and attended isiZulu speaking church to acquire enough vocabulary to facilitate the interactive sessions. Two trained technical staff who were fluent in isiZulu and English participated in this study. What I learnt was useful in following the flow of the sessions during my intervention.

Recruitment and training of peer leaders and technical staffs

Ten prospective leaders, who appeared to be respected by others, fluent in isiZulu and English, and willing to devote time to the study were recruited from the sample after the assessment. The ten prospective leaders underwent four days of intensive training, following a curriculum set out

in the HASMEP leaders' manual, which included visual aids, group teaching activities, scripts and other curricular elements.

Leader training included discussion of the goals of HASMEP, detailed presentation and demonstration of the entire HASMEP curriculum and orientation of prospective leaders in terms of the leaders' manual. The training concluded with the ten prospective leaders undergoing practice teaching experiences. These practice sessions were watched and evaluated, and corrective feedback was provided by the investigator. I developed a plan for the supervision and follow-up of peer group leaders to increase their accountability. The technical staff consists of volunteers from the community where the research setting is situated, who receive a small stipend (R600 for participating in the programme, which lasted about twenty-four weeks including follow-up).

Measures taken to prevent diffusion of treatment

I am aware that diffusion of treatment can serve as threat to internal validity of the study. If participants in Groups A and B communicate with each other, this communication can influence how both groups score on the outcomes. I therefore tried to keep Groups A and B as separate as possible. Sessions were scheduled on different days of the week and different venues were used for the groups and this proved to be useful.

Measure taken to reduce methodological limitations

The qualitative data on self-management needs were derived from an open-ended questionnaire item which gave participants an opportunity to respond as they wished, unconstrained by pre-determined categories, and enabling the consideration of all matters of importance to them. A limitation of these data is that they were derived from a single questionnaire item and, given the complex and dynamic needs of people living with HIV/AIDS, such data may not provide details of what and why these things were important to participants. Another section of the instrument was used to assess participants' self-management education needs, perceived barriers to attending the programme, and preferred method of learning. Also, the variations in responses may have occurred because no specific areas were identified for respondents.

In the absence of a specific context, some respondents may have identified a cure as the one thing that would most help them, not because they believed this to be possible but because it would be the only thing that could meet all their needs. The responses provide an insight into the range of interventions, care and support that PLWHA reported to be important to them, but not a hierarchy of care requirements. A further limitation was the possible effect of a response bias since participants were already known to the clinic, and might be unwilling to say anything which could affect their care. While this might have slightly biased the responses; it is unlikely to have influenced the identification of the categories, which were broad and likely to be applicable to other PLWHA. A criticism sometimes levelled against social science research is that there are many factors that can affect outcomes, and sometimes it is difficult to claim that outcomes are solely based on an intervention (Ncama, 2004). This is not a specific weakness of this study, but of social science in general. I tried to exclude extraneous variables at baseline and

there was generally no interference of confounding variables evident. The findings of this study cannot be universally generalized but may be transferred to similar situations or participants. The context, procedure and analysis have been described as accurately as possible to help the reader to determine the level of trustworthiness and transferability of the study (Holloway and Wheeler, 2002).

4.11 DATA COLLECTION PROCESS

To avoid bias, I invited every client who met selection criteria to participate when they had finished their health consultations with their standard care providers. Before beginning, participants were given information about the study, both verbally and by means of information sheets, following which written consent was obtained. Both quantitative and qualitative data were collected concurrently.

The overall data collection was made up of three steps:

Step 1: Establishing the self-management education needs and baseline information on health-related quality of life.

Step 2: Establishing the effectiveness of the self-management education intervention and its impact on self-management ability and quality of life.

Step 3: Evaluating the intervention and refining the conceptual framework to develop a model.

4.11.1 Quantitative Data Collection

The questionnaires were administered by me before the programme commenced and again upon completion after 24 weeks in the Centre's private room during opening hours. All participants were given verbal explanations on how to complete the survey. They completed questions on

biographical and health characteristics as well as the open-ended question on what would be most helpful in meeting their current self-management needs. The participants responded to questions in the instruments indicating how applicable each item was to them.

4.11.2 Biological Markers

The results of viral load should be interpreted in conjunction with CD4 counts and the patient's clinical status. A result of lower than the detectable limit cannot be presumed to be negative for HIV-1 RNA. There are three methods of collecting data on CD 4 count and viral load: blood drawing for laboratory analysis; chart abstraction of the most recent laboratory test results; and self-report accounts of the most recent test results. Although blood drawing and chart abstraction provide the most reliable methods of collecting biological markers, these methods are relatively expensive and can create considerable barriers to research participation (Kalichman, Rompa and Cage, 2000). Alternatively, collecting CD4 cell counts and viral load data via self-report measures provides convenience, non-invasiveness, low-cost, and confidentiality but there are likely to be threats of unreliability of self-reported health behaviour and health-risk factors.

In this study I nevertheless used comparative results measures combined with chart abstractions with the aid of a document review checklist to ensure that the data collected were reliable. Participants' CD4 cell count and viral load results were retrieved from the clinic records and participants were asked to state their most recent result if they could remember.

4.11.3 Qualitative Data Collection

In-depth group interviews were conducted with a sample of eight participants selected from the intervention group and their response was audiotape and field notes were taken. All interviews were conducted in a private room to ensure privacy. The in-depth group interviews were conducted by me during the twenty-fourth week of the intervention. The use of focus group interviews relies on interaction within the group based on topics that the researcher and members of the group decide to explore further. The potential value of the focus group is to be found because it gives the respondents the opportunity to raise matters that they choose. The researcher becomes more of a coordinator than a conventional interviewer.

When used properly, the focus group offers potential for getting participants to share, compare and explain their self-reported behaviour with other members of the group (Morgan, 1997). It has been observed that one-to-one interviews limit the number of views and options available to the researcher. They effectively restrict the number of voices that can be heard and the range of views that can be included within a research project. Group interviews, however, provide a practical solution to this. By interviewing more than one person at a time the researcher is able to increase the number and range of participants involved in the research (Descombe, 2007). The use of the focus groups provided the participants and me the opportunity to learn from one another and to brainstorm new ideas for programme development.

4.12 ACADEMIC RIGOUR

For the quantitative aspect of the study, internal validity, reliability, objectivity and external validity were ensured. Good qualitative work is both descriptively sound and explicit, and interpretively rich and innovative (Polit and Beck, 2008: 539). Lincoln and Guba (1985) suggest five criteria for developing the trustworthiness of a qualitative inquiry: credibility, dependability, conformability, transferability and authenticity.

Credibility is an evaluation of whether or not the research findings represent a trustworthy conceptual interpretation of the data drawn from the participants' original responses (Lincoln and Guba, 1985: 296). To achieve credibility, the study was carried out in a way that enhanced the believability of the findings and steps were taken to convince external readers.

Dependability is the verdict that the quality of the integrated processes of data collection, data analysis, and theory generation is acceptably high; it refers to the stability of the data in the study. To ensure dependability, data quality checks, peer review of coding, and consultation of qualitative research experts was done.

Confirmability is a measure of how well the inquiry's findings are supported by the data collected. It refers to the objectivity of the research process and its outcomes, the degree to which data confirms the findings, and the researcher's freedom from bias. The conclusions must depend on the subjects and condition of enquiry rather than on the prejudices of the investigator. This was promoted by detailed field notes, tape recording interviews, transcribing interviews verbatim to identify variations in responses and making field notes available for audit checks.

Transferability is the degree to which the findings of this inquiry can be applied beyond the bounds of the project. It refers to the application of the study to the context from which data were derived and the possibility of their application in other, similar contexts. This was ensured by the use of purposive sampling and provision of detailed description of the context.

Authenticity refers to the extent to which the researcher fairly and faithfully shows his findings, culled from the reports by and on the participants. The study report conveyed the tone of participants' lives.

The interpretation presented in this study is the most defensible interpretation of the facts which were made available through the intervention. I was aware of the hypotheses which I had formed on the basis of previous knowledge as a nurse researcher, but tried to be as open as possible to the text by continually and critically reflecting on my changing interpretations. I realise that a researcher is tempted to come to conclusions related to his or her pre-understanding while interpreting a text (Lindseth and Norberg, 2004). While interpreting the interview text I broadened my pre-understanding by studying relevant literature. My findings are illustrated with quotations from the interview transcripts.

4.13 DATA ANALYSIS

Data yielded from the qualitative and quantitative elements of the study and from the various sources were analyzed simultaneously.

4.13.1 Quantitative Data Analysis

Before the statistical analysis was conducted, the assumptions underlying the statistical methods were also checked. The Statistical Package for Social Sciences (SPSS) Windows 15.0 was used for quantitative data analysis. Descriptive statistics were generated for biographic and health variables to explore floor and ceiling effects and to determine the extent of missing data resulting from participants' omissions. Statistical methods such as frequencies and percentages were used to describe participants' demographic and health characteristics. All continuous variables were expressed as means (standard deviation, SD) and categorical variables were summarized by percentages.

Responses to the questionnaires were transcribed, coded, and entered into the Statistical Package for Social Sciences (SPSS) Windows 15.0 for data analysis. The standard method for scoring SF-36 was used in calculating the mean scores for the eight domains (Ware et al., 2001). The One-Sample Kolmogorov-Smirnov Test was performed to check for normality in the data. The test revealed the normal and skewed curves on the graph, which required different tools for analysis. Independent Samples Test or Mann-Whitney Tests were carried out, depending whether the data was normally distributed or skewed.

Mann-Witney Test also known as Wilcoxon Rank-Sum Test (a nonparametric statistical test for comparing paired groups, based on the relative ranking of values between the pairs) was used for the analysis of data where the scores were not normally distributed. Paired T-test was used for the normally distributed data. Based on the design and purpose of the study, a repeated measure of analysis of variance (ANOVA) was performed to determine any differences between the two

groups. Time and group interaction effects determined the significance of Group A versus Group B changes over time.

Comparisons between pre- and post-intervention scores were performed using paired T tests (for normally distributed continuous variables), non-parametric test results from related samples (for non-normally distributed variables). A p value < 0.05 was considered statistically significant. All probabilities were two-tailed.

4.13.2 Qualitative Data Analysis

All interviews were audio taped, with supplementary handwritten notes taken by the investigator. Audiotapes were transcribed to text files, which were read by me to identify themes. Evaluation of trustworthiness of the results was done by presenting them during focus group discussion to other HASMEP participants and peer leaders.

Content analysis of qualitative data was done; an active and interactive process was used to carefully scrutinize data. I established with the help of my supervisor, Professor Busisiwe Ncama, a first-language speaker of isiZulu, that transcriptions were accurate, that they validly reflect the totality of the interview experience, and that they were suitable for analysis. Once a list of appropriate categories had been developed, data were read in their entirety and coded, organized, account for and explained, to make sense in terms of the participants' definition of the situation, noting patterns, themes, categories and regularities.

4.13.2.1 Qualitative data on self-management needs

For qualitative data on self-management needs, the investigator employed qualitative content analysis following a nine-step procedure described by Feher, Waltz et al., (1991).

Step 1. Define the universe of content (identified as all the relevant responses) examined.

Relevance was determined by the presentation of an identifiable self-management initiative or request.

Step 2. Identify the suggestions and requests which occurred in participants' responses to the questionnaire. PLWHA perceived these to be most helpful in meeting their self-management needs.

Step 3. Select the unit of analysis to be employed in the coding process. The primary units of analysis were codes, defined as neutral labels that described the content of responses.

Step 4. Develop a sampling plan. All relevant responses were included in the analysis and no sampling was necessary.

Step 5. Develop a scheme for categorizing the content. Each response was coded on the basis of the substantive propositions articulated. Once the data were coded, they were assigned to categories (a group of codes that share a common characteristic). Categorization was undertaken at two levels:

- Sub-category level: codes were organized on the basis of a common characteristics (e.g. codes relating to access to HAART, adherence, and management of side-effects were categorized as “disease modifying therapy”);
- Category level: sub-categories were then grouped to summarize the areas of care identified (e.g. disease modifying therapy was organized at category level as “medical care”).

- Step 6. Develop explicit coding and scoring instructions. Initially, I reviewed the responses with the supervisor and generated prototype codes. These prototypes were then discussed until agreement was achieved over each code, and a coding schedule produced.
- Step 7. Pre-test the categories and coding instructions. To test the coding schedule, the statistician coded the raw data using the coding schedule. No difficulties were encountered.
- Step 8. Train coders and establish an acceptable level of reliability. The data were independently coded by me and the statistician: 92% agreement was achieved. Disagreements were reviewed by my supervisor and codes agreed.
- Step 9. Perform the analysis. The analysis was undertaken following the coding schedule. Categorization of codes to sub-category and category levels was done via the same interactive process outlined in step 6.

4.13.2.2 Qualitative data analysis on experiences of the participants

In this study, I employed thematic structural analysis, that is, a way of identifying and formulating themes as described by Lindseth and Norberg (2004). This is a method of identifying, analysing and reporting themes within data (Braun and Clarke, 2006: 79). “A theme is a thread of meaning that penetrates text parts, either all or just a few. It is seen as conveying an essential meaning of lived experience”(Lindseth and Norberg, 2004: 149).

Data analyses were performed in three steps to extract the meaningful content of participants’ experiences. During the first step (i.e. naïve reading), I attempted to understand, through their responses, what the participants perceived. The units of meaning are read and reflected on

against the background of naïve understanding. Then they are condensed and the essential meaning of each unit is expressed in everyday words as concisely as possible. All condensed units are read through and reflected on regarding similarities and differences. They are then sorted and all that are similar are further condensed. During the structural analysis I tried to view the text as objectively as possible.

The second step involved a number of structural analyses performed inductively to grasp the most probable explanation of parts of the text, at the ‘common sense’ level. The text was read again as a whole with the naïve understanding and the validated themes in mind, and with as open a mind as possible.

The final step in the analysis process is the theoretical level and this is described in the discussion section. I tried to think of associations, especially with relevant literature. I also performed the analysis of the text and synthesis of findings. The main themes and illustrative quotations were discussed with my supervisor, who read several of the isiZulu interviews to validate my inductive analyses (Tobin and Begley, 2002). Expert clinicians who care for participants at Danganya Clinic reviewed the themes for content and clarity and for appropriateness of terminology, based on words commonly used with and by participants.

Data analyses continued until the point was reached where no new issues were being raised and matter was simply being repeated. After the qualitative analysis, the quotations chosen to illustrate the various themes were translated into English, and back-translated to isiZulu by my technical staff.

4.14 ETHICAL CONSIDERATIONS

4.14.1 Introduction

“Ethical issues in health promotion and education have garnered increasing attention as an important topic in academic research and professional practice” (Bastida, Tseng, McKeever and Jack, 2010: 16). Exploring the importance of ethical issues in community-based participatory research (CBPR), Bastida et al., (2010) discussed ethical issues such as the importance of community involvement in research, ensuring that communities benefit from the research, sharing leadership roles, and issues regarding data collection and sharing.

I adhered strictly to the six principles identified by Bastida et al., (2010). The principles were: (1) respect, (2) fiduciary transparency, (3) fairness, (4) informed consent (always voluntary), (5) reciprocity, and (6) equal voice and disclosure.

First, the principle of respect for persons was considered. Throughout the period of study, I respected and gave full attention to participants’ comments and built on these, making it a rule never to contradict participants. I organized sessions on stigma reduction, conflict avoidance and management in preparation for the programme. Also stressed were the importance of keeping all personal matters and possible biases separate from the task at hand (Bastida et al., (2010). I remained neutral in exchanges with participants unrelated to the content of the intervention.

Secondly, I endeavoured to maintain a high level of transparency. Every effort was made to conduct the programme as planned. Thirdly, in fairness to all, I carefully explained the inclusion and exclusion criteria. Emphasis was given to the importance of principles of fairness when working with minority populations who have not been the recipients of fairness in our society (Bastida et al., 2010), such as people living with HIV/AIDS.

Fourthly, I ensured that the consent form was translated to the language of the participants and that the technical staffs were fluent in isiZulu and English. In general, I repeatedly emphasised the participants' rights, that their participation is voluntary, and that they have the right to withdraw from participation at any time.

Fifthly, I ensured that all participants fully understood their commitment and their anticipated contribution to the study. All transactions which occurred during the programme and all interactions were considered reciprocal. Participants' time and efforts were acknowledged as being especially valuable. This meant acknowledging their contributions in terms of travel time and other related expenses.

Lastly, all the participants were accorded the same time and acknowledgement regardless of the group they belonged to in the study. All ideas were entertained, and I also disclosed my academic interests. In conducting this study, I quickly learned that I had to take a leadership role in moving the study forward and adhering to the scientific principles that guided the study.

In summary, my ethical competence with regard to the six principles is based on adherence to the code of conduct from beginning to end. Relevant ethical standards were adhered to during the study and permission was sought from all participants and organizations involved. I obtained ethical approval from the University of KwaZulu-Natal Ethics Committee and permission was also obtained from the Department of Health of South Africa as well as from the Nurse in Charge of Danganya Clinic.

I also paid attention to the following ethical codes:

4.14.2 Respect for autonomy

The principle of respect for persons holds that persons have the right to self-determination and freedom to participate or not in research (Burns and Grove, 2009:188). This principle holds that because humans are capable of self-determination, they should be treated as autonomous agents who have the freedom to conduct their lives as they choose. The participants were provided with information about the purpose and method of the study, the fact that participation was voluntary and that confidentiality was guaranteed. All participants were assured that information supplied by them would remain confidential to the researcher and that they would remain anonymous. No invasive therapy or placebos were used in this study. During the initial focus groups discussions, participants were notified that the interviews would be taped for transcription purposes only. For confidentiality and anonymity, no names or identifying data were collected on study forms. Pseudonyms were used so that participants' names could not be traced. All interviews were conducted in a private room to ensure privacy. All transcribed data were kept on a password-protected computer and I myself kept the tapes.

4.14.3 Beneficence

The principle of beneficence requires the researcher to do good and “above all, do no harm” (Burns and Grove, 2009:188). The investigator strove to be honest, respectful and sympathetic towards all participants. Both Groups A and B continued to receive their standard treatment from primary care providers. The participants in these groups had no contact with each other to avoid ill feeling and contamination of data. Permission for the use of the instruments was obtained

from the appropriate authorities. Participants were given a statement containing details of the study as well as verbal explanations.

The participants in the study could be viewed as a vulnerable group. Their physical and emotional needs therefore were regarded as paramount throughout and informed consent to participate was constantly negotiated, with participants being reminded that they could withdraw at any time. They also received R30 for their travel expenses and as a token of appreciation of their time and for the completion of the baseline questionnaires.

4.14.4 Justice

The principle of justice holds that human subjects should be treated fairly. Participants received both oral written information about the study at admission, and written consent was obtained before participation. Group B was also exposed to a self-management education programme immediately after the study and they also received the self-management handbook. The project was approved by the Institutional Review Board at the University of KwaZulu-Natal.

4.15 DATA MANAGEMENT AND STORAGE

Data were stored in a password-protected computer and external hard drive. Papers used to transcribe data were kept under lock and key. Tapes used to record interviews were also kept under lock and key. All data collected were kept confidential. The data was captured from the original questionnaires using the Census and Survey Processing System (a computer software programme). A database was designed with range restrictions to ensure that data capture was

never out of range and data cleaning procedures were implemented. Duplicate records were identified and removed.

Extensive internal consistency checks against the original questionnaire were carried out to ensure data accurately reflected the data captured in the field. Internal data errors, such as a respondent mistakenly recording his/her gender, were recorded as missing. Other internal inconsistencies were left intact, reflecting the right of persons to refuse to answer particular questions and the natural errors that occur in face-to-face interviews. Data will be disposed of by incineration after a period of five years.

4.16 CONCLUSION

This chapter has described the approach used to gather the relevant data needed to provide the information for the development HIV/AIDS self-management education model. The purpose of the study influenced the choice of the methodology. The complexity of the task at hand determined the choice of a mixed methods approach. For the present study, the task at hand was the developing testing and refining of a model for self-management education. Since the task was threefold, the methodology chosen took into consideration developing, testing and refining. Evaluation research design was found to be the most suitable method for the study. A conceptual framework developed from literature was used to guide the study. During each phase of evaluation, the objectives of the study were used as basis for decision making. Although this study is an exercise in academic research, it has presented a framework for the successful implementation of research in practice.

CHAPTER FIVE

RESULTS OF THE ASSESSMENT PHASE

5.0 INTRODUCTION

In this chapter, all data collected and analyzed during the assessment phase are reported. While the research questions guide the collection of data, the study objectives form the basis for data analysis. The results of this assessment phase have been analyzed to highlight their influence on the next phase. The chapter therefore presents the manner in which the self-management education model was developed.

To assist PLWHA through the self-knowing process, it was necessary to explore their pre-intervention situation, which would work as a baseline as well as guide for care planning. At programme entry I assessed each participant's profile. The profiling was deemed important for me to be able to develop a comprehensive documentation system. Much time and effort has been devoted to the participant profiling component, and it contains all the data elements required for an educational record, including demographic characteristics, health perceptions, self-management needs, learning needs, preferred method of learning, perceived barriers to participating in a self-management education programme as well as behavioural assessment and biological indices such as CD4 cell counts, viral load and health-related quality of life.

The plan was to collect data that could be used for need assessment and outcome evaluation. These data would serve as the baseline for comparison to post-programme evaluation, providing a measure of participants' responses and programme outcomes.

5.1 NEEDS, ASSETS AND PROBLEMS ASSESSMENT

This assessment was done to establish how PLWHA perceived their health and what they found most helpful towards meeting their self-management needs. Their self-management education needs, preferred methods of learning, and perceived barriers to participating in self-management education programme were assessed, as well as the health-related quality of life of the participants prior to the intervention. Self-Management Education Survey and SF-36 Questionnaire (discussed in chapter four) were used for assessing the variables mentioned above.

5.2 PRESENTATION OF ASSESSMENT PHASE RESULTS

The aim of this chapter was to present the findings of the study in a form which would allow for their use by nurses, other health personnel and other consumers, for the implementation of self-management education programmes.

5.2.1 Describing Data through Statistics

An important probability distribution in statistics is the normal distribution (Gaussian distribution or bell-shaped curve). The reason is that many phenomena either have such a distribution or closely approximate to it. A normal distribution is symmetrical, unimodal, and not too peaked. The standard normal distribution serves as a standardization tool in inferential statistics since any normal distribution can be converted into such a distribution (Maree and Pieterse, 2008). The only difference between the standard normal distribution and any other normal distribution is that the standard normal distribution has a mean of 0 and a standard deviation of 1, whereas other normal distributions can have any mean or standard deviation. The skewedness of a distribution is a measure of how far the distribution deviates from symmetry. If

the data is more spread out to the upper end of the scale, in other words it has a longer “tail” to the right, the distribution is said to be skewed to the right or positively skewed. If, however, the data is more spread out to the left or lower end of the scale, the distribution is said to be skewed to the left or negatively skewed (Maree and Pieterse, 2008).

For this study, the One-Sample Kolmogorov-Smirnov Test was performed to check for normality in the quantitative data. This test provides information about the distribution of data. The test revealed the normal and skewed data, requiring different tools for analysis.

5. 2. 2 Assessments of Personal and Environmental Factors

5.2.2.1 Biographic characteristics of PLWHA

Biographic data included gender, age, highest education level and whether or not the participant had been diagnosed with AIDS (Table 5.1). The proportion of female participants exceeded that of male participants due to the fact that many males stated that they were not comfortable being interviewed during the recruitment process. Another reason was that the majority of the people attending the antenatal and tuberculosis clinics are female.

Table 5.1: Biographic characteristics

| Characteristics | Frequency | | Valid Percent | |
|--------------------------------------|------------------|--------------|----------------------|---------------|
| | n | % | n | % |
| Gender | | | | |
| Male | 19 | 21.6 | 19 | 22.09 |
| Female | 67 | 76.1 | 67 | 77.91 |
| Missing | 2 | 02.3 | - | - |
| Total | 88 | 100.0 | 86 | 100.00 |
| Age categories in years | | | | |
| 18 – 25 | 19 | 21.6 | 19 | 22.09 |
| 26 – 35 | 31 | 35.2 | 31 | 36.05 |
| 36 – 45 | 21 | 23.9 | 21 | 24.42 |
| 46 – 55 | 11 | 12.5 | 11 | 12.79 |
| 56 and above | 4 | 4.6 | 4 | 4.65 |
| Missing | 2 | 2.3 | - | - |
| Total | 88 | 100.0 | 86 | 100.00 |
| Highest educational level | | | | |
| Primary | 26 | 29.5 | 26 | 30.95 |
| High school | 47 | 53.4 | 47 | 55.95 |
| College/University | 11 | 12.5 | 11 | 13.10 |
| Missing | 4 | 4.6 | - | - |
| Total | 88 | 100.0 | 84 | 100.00 |
| Diagnosis with AIDS | | | | |
| Yes | 78 | 88.6 | 78 | 92.86 |
| No (HIV positive, no AIDS diagnosis) | 6 | 6.8 | 6 | 7.14 |
| Missing | 4 | 4.6 | - | - |
| Total | 88 | 100.0 | 84 | 100.00 |

A majority, 77.91% (n=67), of the study participants were females and 22.09% (n=19) were males; and the majority (82.5%) was between 18 and 45 years old. Over half, 55.95% (n=47), reported high school education; about three quarters, 30.95% (n=26), reported primary education, and the remainder, 13.0% (n=11) reported some college/university education. Almost all, 92.9% (n=78), reported diagnosis with AIDS, with 7.1% (n=6) being HIV positive with no AIDS diagnosis (Table 5.1).

Gender of PLEWHA

There were more females than males in this study. There were 67 females and 19 males. This meant that female formed 77.91% of the study participants and males formed only 22.09% (see figure 5.1)

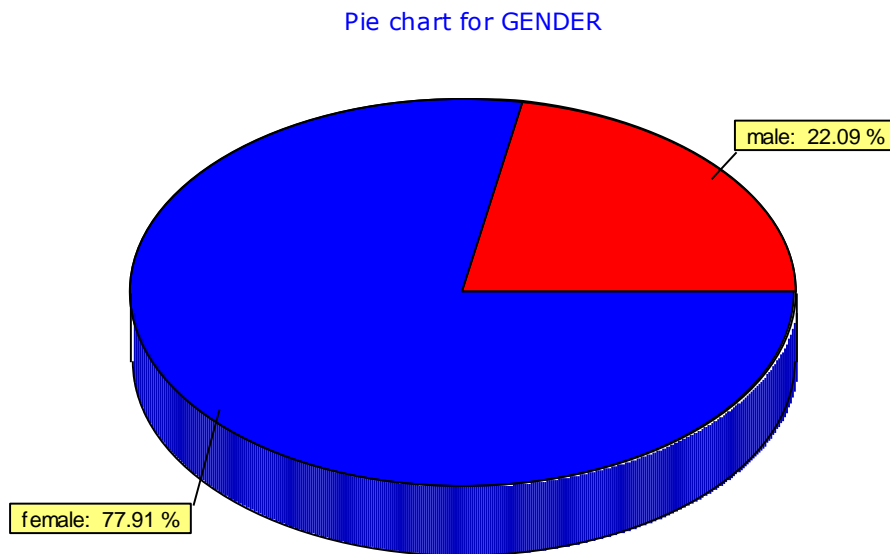


Figure 5.1: Description of PLWHA according to their gender

Age of PLWHA

Only people of 18 years and older were included in the study, and the sample was grouped into five categories: see figure 4.2 below. The figure shows that 36.05% (n=31) of PLWHA were in the age range 26-35 years, followed by 24.42% (n=21) in the age range of 36-45 years and 22.09% (n=19) in the age range 18-25 years, with 12.79% (n=11) within the age range of 46-55 years, while only 4.65% (n=4) were 56 years and above in age.

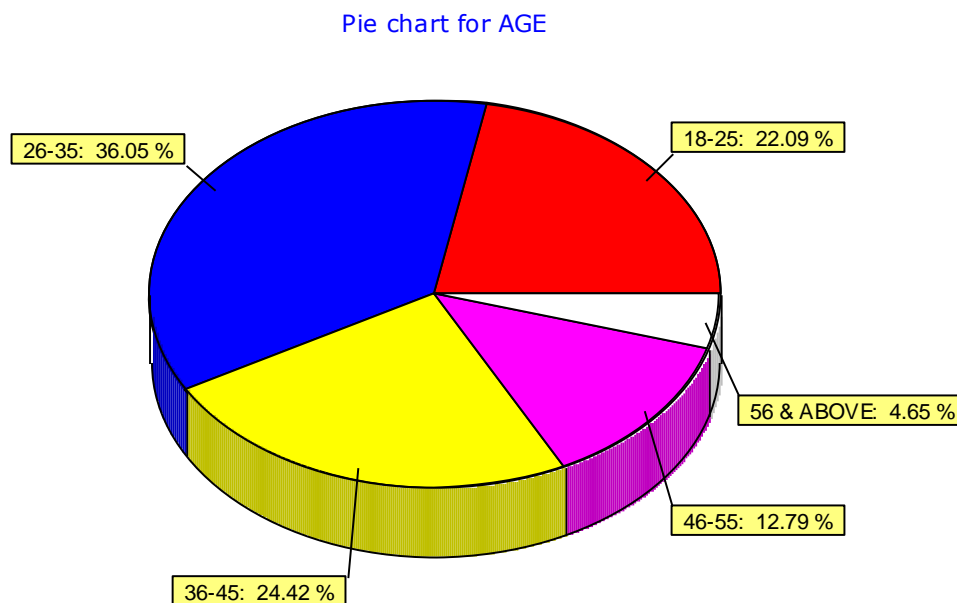


Figure 5.2: Description of PLWHA according to Age

Education of PLWHA

Over half of the participants, 55.95% (n=47) reported high school education; 30.95% (n=26) reported primary education and the remainder 13.0% (n=11) reported some college/university education. See figure 4.3 below.

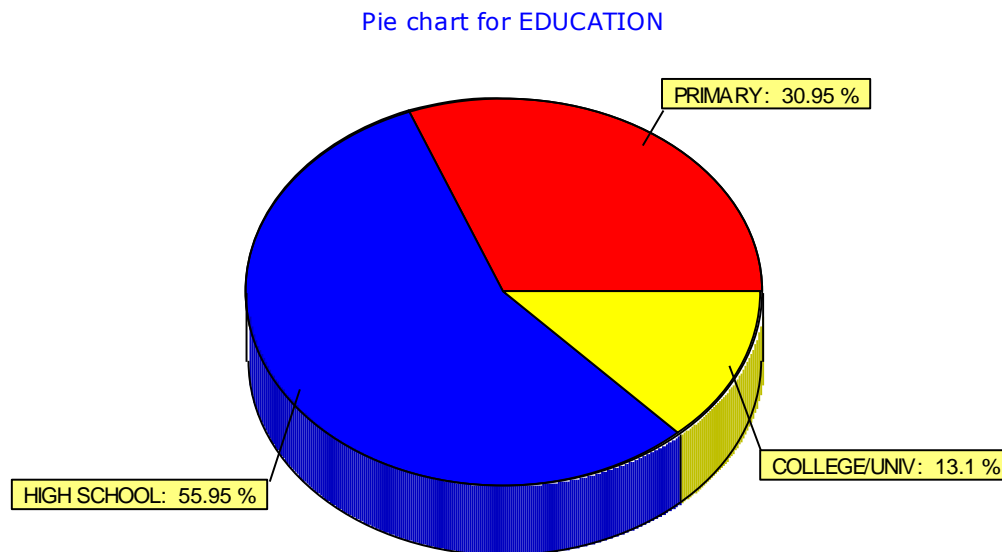


Figure 5.3: Description PLWHA according to level of education

Diagnosis with HIV and AIDS

Almost all, 92.86% (n=78), reported diagnosis with AIDS, with 7.14% (n=6) being HIV positive with no AIDS diagnosis (see figure 4.4 below).

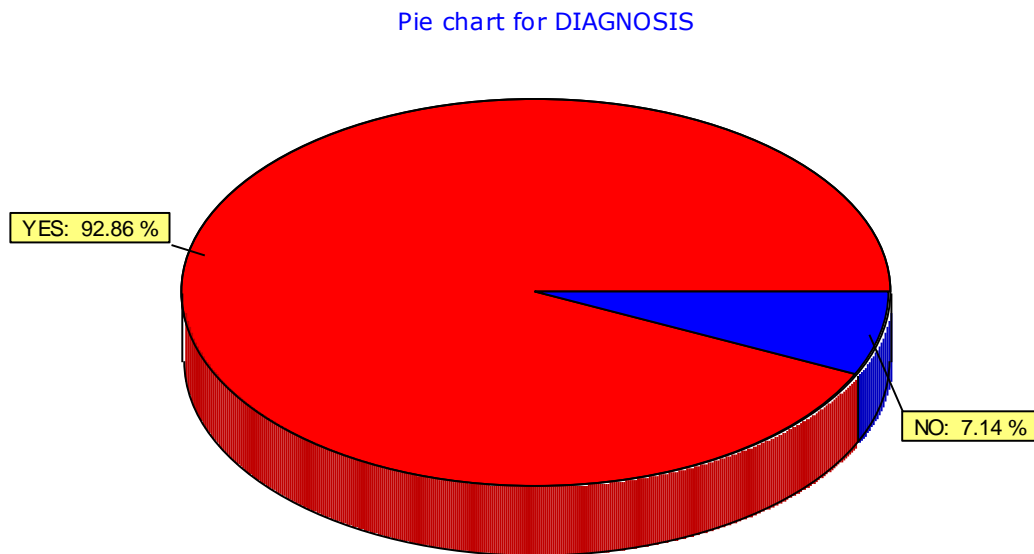


Figure 5.4: Description of PLWHA according to diagnosis with HIV and AIDS

5.2.2.2 Health characteristics of PLWHA

Participants were requested to provide personal health information, selecting from available descriptions in the questionnaire the one that best matched their perception of their health, difficulty in living with HIV/AIDS, difficulty in taking prescribed medications and use of alternative/complementary therapies (Table 5.2).

Table 5.2: Health characteristics

| Characteristics | Frequency | | Valid Percent | |
|--|-----------|--------------|---------------|---------------|
| | n | % | n | % |
| Perceived current health status | | | | |
| Excellent | 5 | 5.7 | 5 | 5.88 |
| Good | 18 | 20.5 | 18 | 21.18 |
| Fair | 38 | 43.2 | 38 | 44.71 |
| Poor | 24 | 27.2 | 24 | 28.24 |
| Missing | 3 | 3.4 | - | - |
| Total | 88 | 100.0 | 85 | 100.00 |
| Perceived difficulty living with illness | | | | |
| Not at all difficult | 15 | 17.0 | 15 | 17.65 |
| Somewhat difficult | 44 | 50.0 | 44 | 51.76 |
| Difficult | 14 | 16.0 | 14 | 16.47 |
| Very difficult | 12 | 13.6 | 12 | 14.12 |
| Missing | 3 | 3.4 | - | - |
| Total | 88 | 100.0 | 85 | 100.00 |
| Perceived difficulty taking medications correctly | | | | |
| Not at all difficult | 17 | 19.3 | 17 | 19.77 |
| Somewhat difficult | 39 | 43.3 | 39 | 45.35 |
| Difficult | 12 | 13.6 | 12 | 13.95 |
| Very difficult | 18 | 20.5 | 18 | 20.93 |
| Missing | 2 | 2.3 | - | - |
| Total | 88 | 100.0 | 86 | 100.00 |
| HIV/AIDS medications currently prescribed daily. | | | | |
| Regimen 1A (Tenofovir, Lamivudine/Emtricitabine and Efavirenz) | 35 | 39.7 | 35 | 42.17 |
| Regimen 1B (Tenofovir, Lamivudine/Emtricitabine and Nevirapine) | 18 | 20.5 | 17 | 20.48 |
| Regimen 1C (Zidovudine, Lamivudine and Efavirenz) | 10 | 11.4 | 10 | 12.05 |
| Regimen 2A (Tenofovir, Lamivudine/Emtricitabine and Lopinavir) | 7 | 8.0 | 7 | 8.43 |
| Regimen 2B (Zidovudine, Lamivudine and Lopinavir) | 14 | 15.9 | 14 | 16.87 |
| Missing | 4 | 4.5 | - | - |
| Total | 88 | 100.0 | 84 | 100.00 |
| Use of alternative or complementary medicines | | | | |
| Yes | 3 | 3.4 | 3 | 3.90 |
| No | 74 | 85.2 | 74 | 96.10 |
| Missing | 11 | 11.4 | - | - |
| Total | 88 | 100.0 | 77 | 100.00 |

Of those who responded, only 5.88% (n=5) reported themselves to be in excellent health, while three-quarters, 65.89% (n=56), reported fair to good health, and 28.24% (n=24) reported poor health. While 17.65% (n=15) of respondents indicated no difficulty living with HIV/AIDS, 51.76% (n=44) reported some difficulty, and 30.59% (n=26) found it difficult or very difficult. Less than half, 42.17% (n=35), of respondents were taking what the clinic coded as regimen 1A (Tenofovir, Efavirenz and Lamivudine/Emtricitabine), 20.48% (n=17) were on 1B (Tenofovir, Lamivudine/Emtricitabine and Nevirapine), only 12.05% (n=10) were taking 1C (Zidovudine, Lamivudine and Efavirenz), with 8.43% (n=7) and 16.87 (n=14) taking regimen 2A (Tenofovir, Lamivudine/Emtricitabine and Lopinavir) and 2B (Zidovudine, Lamivudine and Lopinavir) respectively. 11.4% (n=11) of the participants chose not to answer questions about alternative/complementary therapies. Almost all respondents to this question, 96.2% (n=74), reported not using alternative or complementary medicines (Table 5.2).

Missing data

Some participants did not respond to all items, but, as failure to respond occurred at random, no participant was excluded due to missing data. Participants' responses are discussed, supplemented by tables that also report missing data.

PLWHA's perception of health status

Of those who responded, only 5.88% (n=5) reported themselves to be in excellent health, 21.18% (n=18), reported good health, less than half, 44.71% reported fair health, and the remaining 28.24% (n=24) reported poor health. See figure 4.5 below.

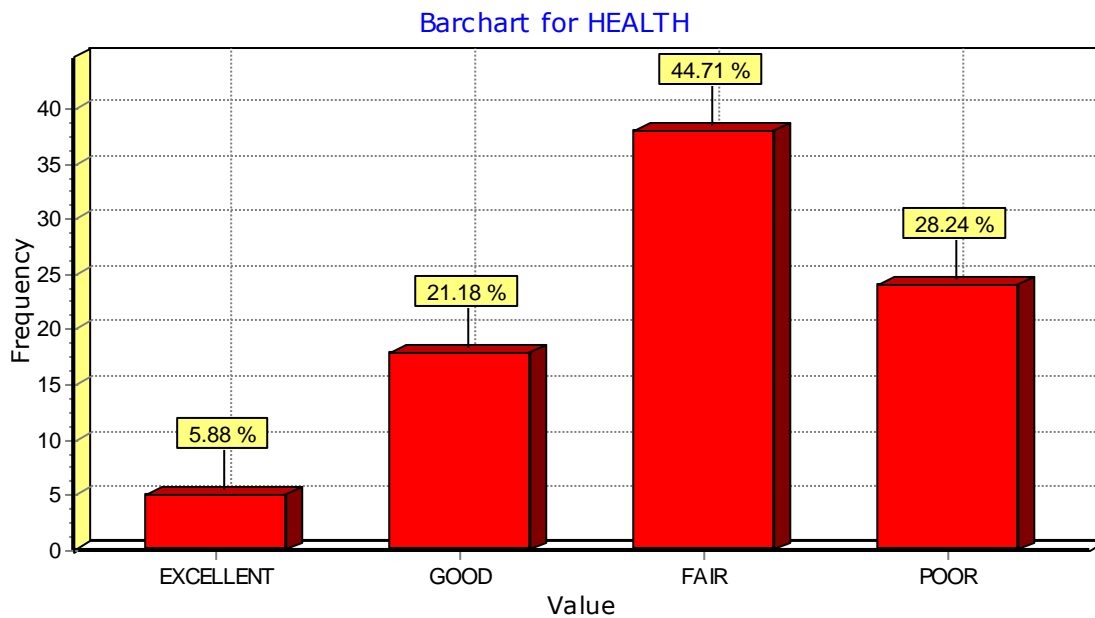


Figure 5.5: Describing PLWHA according to their perception of health status

Perception of difficulty living with HIV/AIDS among PLWHA

Slightly above half, 51.76% (n=44) of participants reported some difficulty, 17.6% (n=15) of participants indicated no difficulty living with HIV/AIDS, 16.47% (n=14) found it difficult and 14.12% (n=12) very difficult. See figure 4.6 below.

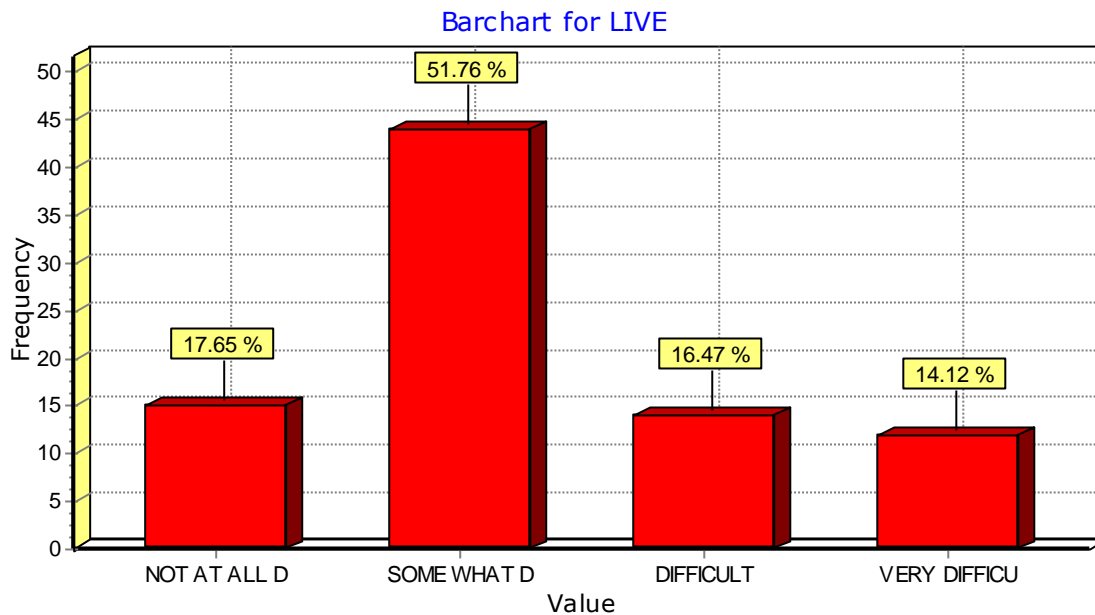


Figure 5.6: Describing PLWHA according to their perception of difficulty living with HIV/AIDS

PLWHA's Perception of difficulty taking prescribed medications

Slightly less than half, 45.35% (n=39) of participants perceived taking prescribed medications somewhat difficult, followed by 20.93% (n=18) who perceived it as very difficult, 19.77% (n=17) not at all difficult and the remaining 13.95% (n=12) perceived it difficult. See figure 4.7 below.

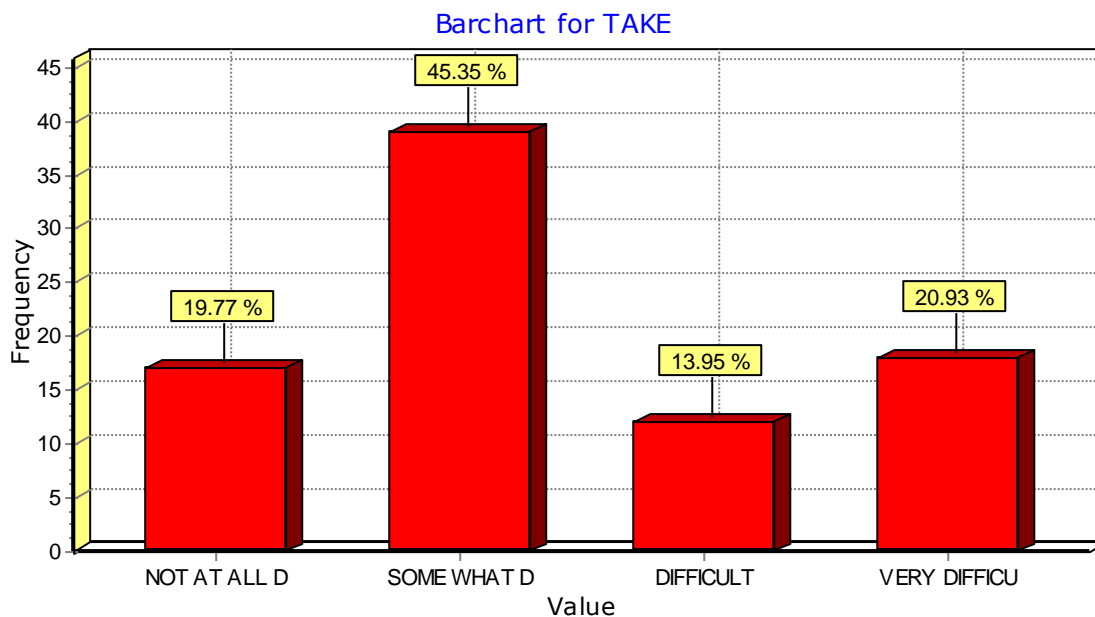


Figure 5.7: Describing PLWHA according to their perception of difficulty taking prescribed medications

HAART Regimen for PLWHA

The HAART regimen is divided into five categories: 42.17% (n=35) of respondent were taking what the clinic coded as regimen 1A (Tenofovir, Efavirenz and Lamivudine/Emtricitabine), 20.48% (n=17) were on 1B (Tenofovir, Lamivudine/Emtricitabine and Nevirapine), only 12.05% (n=10) are taking 1C (Zidovudine, Lamivudine and Efavirenz), with 8.43% (n=7) and 16.87% (n=14) taking regimen 2A (Tenofovir, Lamivudine/Emtricitabine and Lopinavir) and 2B (Zidovudine, Lamivudine and Lopinavir) .

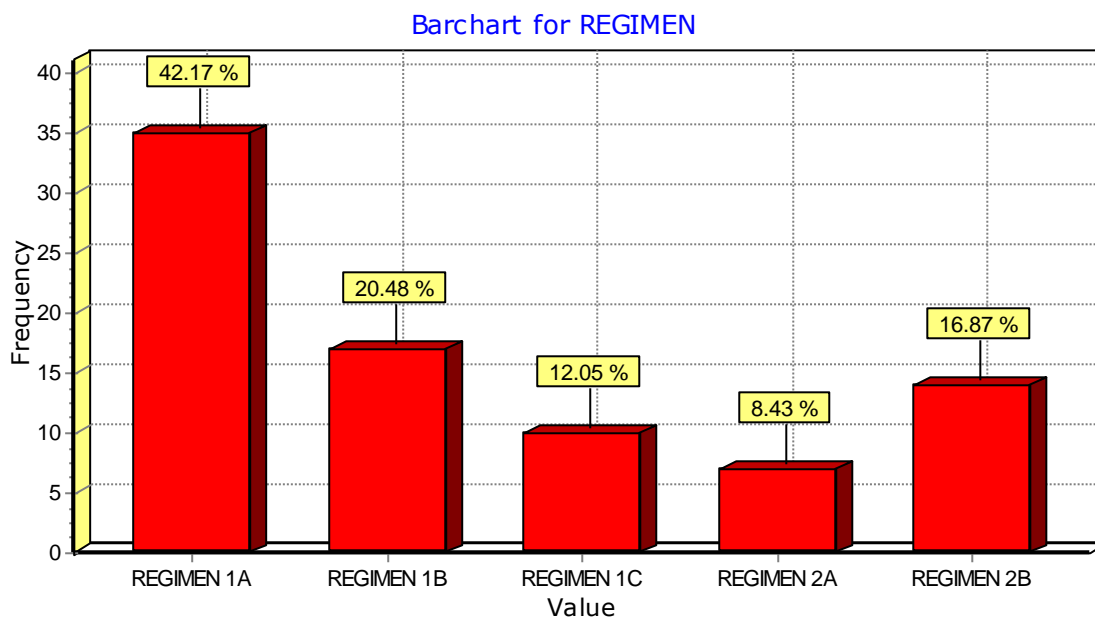


Figure 5.8: Description of PLWHA in terms of prescribed HAART regimen

Use of alternative or complementary therapies among PLWHA

11.7% Of the participants chose not to answer the question about alternative or complementary therapies. Almost all participants 96.1% (n=77) reported not using alternative or complementary medicines, while 3.9% (n=3) reported using alternative or complementary therapies (See figure 5.9 below).

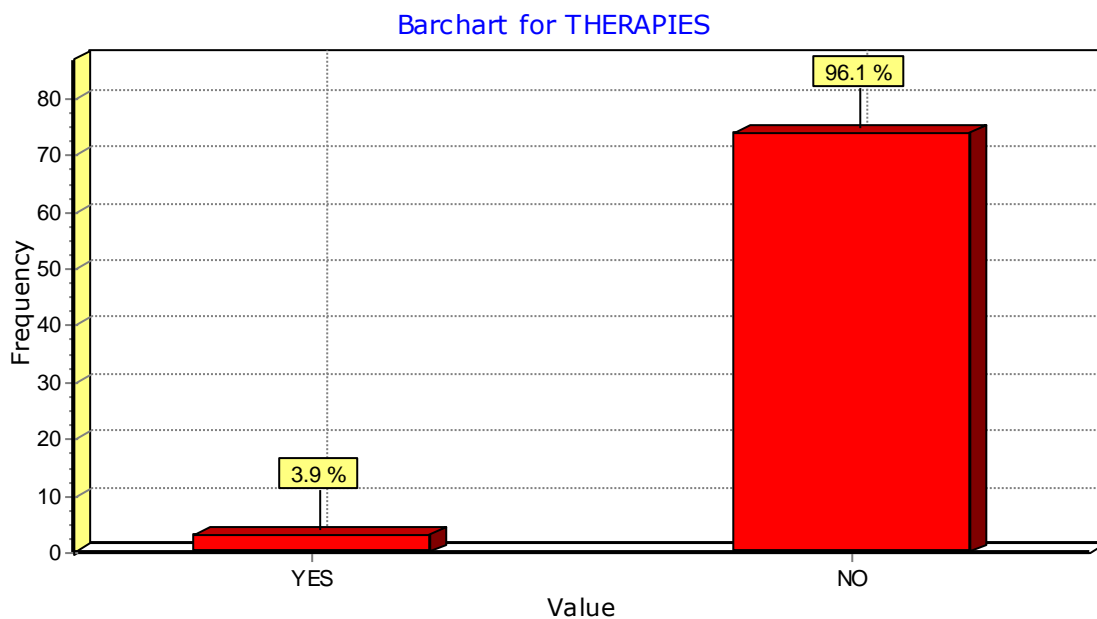


Figure 5.9: Describing PLWHA according to use of alternative or complementary therapies

RESEARCH QUESTION ONE:

What are the educational needs for the understanding of health, and the undertaking of self-management, for PLWHA?

5.3 SELF-MANAGEMENT EDUCATION NEEDS OF PLWHA

Participants are interested in self-management education, but they expressed various levels of interest in the topic. To determine the degree of interest, items are ranked using a five-point Likert scale ranging from 1(not at all) to 5 (very interested). Participants indicated the degree of their interest by checking an option from ‘very much’ through ‘not at all’. Descriptive statistics were generated for each item to explore maximum and minimum interest and to determine the extent of missing data where there is no response. A small number of discrete data points were missing in each data set; all cases in the original data sets were retained for analysis.

Of the 33 items on self-management education needs, the most highly rated indication of interest in self-management education (expressed by two third of the participants and above) included understanding viral load and CD4 cell count (n=74), understanding HIV/AIDS transmission, (n=72), understanding HIV/AIDS medications and how they work (n=71), understanding HIV/AIDS (n=70), managing HIV/AIDS medications (n=64), sex and HIV/AIDS (n=63), managing side-effects from medications (n=61), how to talk to others about HIV/AIDS (n=59), how to disclose HIV status to others (n=58), how to live positively whilst being HIV positive (n=58), exercise for health and well being (n=57), how to come to terms with HIV status (n=55), and how to cook meals to help people living with HIV/AIDS (see Table 5.3 and Table 5.4).

Table 5.3: Health, well-being and nutrition of PLWHA

| Overall health and well-being | Very much | | Much | | Some | | A little | | Not at all | | Missing |
|---|-----------|-------|------|-------|------|-------|----------|-------|------------|-------|---------|
| | N | % | N | % | N | % | N | % | N | % | |
| Recommended health screening for adults | 48 | 55.17 | 19 | 21.84 | 10 | 11.49 | 8 | 9.20 | 2 | 2.30 | 1 |
| Recommended immunizations (shots) for adults | 38 | 44.19 | 10 | 11.63 | 20 | 23.26 | 13 | 15.12 | 5 | 5.81 | 2 |
| Recommended skin test for Tuberculosis | 36 | 40.91 | 16 | 18.18 | 10 | 11.36 | 18 | 20.45 | 8 | 9.09 | 0 |
| Women's health concerns | 50 | 53.82 | 21 | 24.71 | 5 | 5.88 | 5 | 5.88 | 4 | 4.71 | 3 |
| Men's health concerns | 39 | 44.83 | 19 | 21.84 | 12 | 13.79 | 8 | 9.20 | 9 | 10.34 | 1 |
| Healthy aging | 38 | 46.34 | 24 | 29.27 | 8 | 9.76 | 5 | 6.10 | 7 | 8.50 | 6 |
| Nutrition | | | | | | | | | | | |
| Food groups and their importance | 47 | 54.85 | 32 | 37.21 | 4 | 4.65 | 1 | 1.16 | 2 | 2.33 | 2 |
| Relationship between nutrition and HIV | 52 | 59.09 | 30 | 34.09 | 1 | 1.14 | 3 | 3.41 | 2 | 2.27 | 0 |
| Reasons why PLWHA become undernourished | 41 | 48.24 | 30 | 35.29 | 6 | 7.06 | 2 | 2.35 | 6 | 7.06 | 3 |
| Cooking meals to help PLWHA | 55 | 63.95 | 19 | 22.09 | 6 | 6.98 | 4 | 4.65 | 2 | 2.33 | 2 |

Table 5.4: Management of HIV/AIDS

| Management of HIV/AIDS | Very much | | Much | | Some | | A little | | Not at all | | Missing |
|--|-----------|-------|------|-------|------|-------|----------|-------|------------|-------|---------|
| | N | % | N | % | N | % | N | % | N | % | |
| Understanding HIV/AIDS | 70 | 80.46 | 12 | 13.79 | 1 | 1.15 | 2 | 2.30 | 2 | 2.30 | 0 |
| Understanding viral load and CD4 cell counts | 74 | 84.09 | 11 | 12.50 | 1 | 1.14 | 0 | 0 | 2 | 2.27 | 0 |
| Understanding HIV transmission | 72 | 81.82 | 14 | 15.91 | 2 | 2.27 | 0 | 0 | 0 | 0 | 0 |
| Understanding HIV/AIDS medications and how they work | 71 | 80.68 | 10 | 11.36 | 6 | 6.82 | 1 | 1.14 | 0 | 0 | 0 |
| Managing HIV/AIDS medications (how to take them to best effect) | 64 | 72.73 | 7 | 7.95 | 11 | 12.50 | 5 | 5.68 | 1 | 1.14 | 0 |
| Managing side effects from HIV/AIDS medications | 61 | 69.32 | 9 | 10.23 | 4 | 4.55 | 12 | 13.64 | 2 | 2.27 | 0 |
| How to come to terms with your HIV status | 55 | 63.22 | 22 | 25.29 | 5 | 5.75 | 3 | 3.45 | 2 | 2.30 | 1 |
| Dealing with stigma | 46 | 57.50 | 18 | 22.50 | 9 | 11.25 | 7 | 8.75 | 0 | 0 | 0 |
| Increasing awareness of the importance of self | 51 | 57.95 | 20 | 22.73 | 9 | 10.23 | 7 | 7.95 | 1 | 1.14 | 0 |
| How to live the fullest whilst being positive | 58 | 66.67 | 21 | 24.14 | 4 | 4.60 | 4 | 4.60 | 0 | 0 | 1 |
| Recognizing emergencies | 36 | 41.38 | 20 | 22.99 | 12 | 13.79 | 2 | 2.30 | 17 | 19.54 | 1 |
| Coping with fatigue | 38 | 44.19 | 20 | 23.26 | 24 | 27.91 | 3 | 3.49 | 1 | 1.16 | 2 |
| Coping with stress | 34 | 38.64 | 25 | 28.41 | 25 | 28.41 | 0 | 0 | 4 | 4.55 | 0 |
| Coping with loss | 35 | 40.23 | 22 | 25.29 | 26 | 29.89 | 2 | 2.30 | 2 | 2.30 | 1 |
| Coping with uncertainty | 28 | 34.57 | 17 | 20.99 | 29 | 35.80 | 4 | 4.94 | 3 | 3.70 | 7 |
| How to talk to others about HIV/AIDS | 59 | 67.05 | 20 | 22.73 | 4 | 4.55 | 4 | 4.55 | 1 | 1.14 | 0 |
| How to disclose your HIV status to others | 58 | 66.67 | 15 | 17.24 | 9 | 10.34 | 5 | 5.75 | 0 | 0 | 1 |
| Exercise for health and well being | 57 | 66.28 | 16 | 18.60 | 6 | 6.98 | 5 | 5.81 | 2 | 2.33 | 2 |
| Sex and HIV/AIDS | 63 | 73.26 | 13 | 15.12 | 4 | 4.65 | 4 | 4.65 | 2 | 2.33 | 2 |
| Using community resources | 42 | 48.28 | 14 | 16.09 | 17 | 19.54 | 12 | 13.79 | 2 | 2.30 | 1 |
| Seeking social support | 36 | 41.86 | 28 | 32.56 | 12 | 13.95 | 7 | 8.14 | 3 | 3.49 | 2 |
| Managing work and home life with HIV/AIDS | 50 | 56.82 | 17 | 19.32 | 9 | 10.23 | 10 | 11.36 | 2 | 2.27 | 0 |
| Legal issues for persons with HIV/AIDS | 36 | 41.86 | 18 | 20.93 | 6 | 6.98 | 6 | 6.98 | 20 | 20.23 | 2 |

RESEARCH QUESTION TWO

What are the, barriers to participation in self-management education and the preferred learning methods of PLWHA in a semi-rural African setting?

5.3.1 Barriers to Participating in Self-Management Education

Participants responded to all the eleven barriers listed, as indicated by the fact that few data were missing (see Table 5.5). Items were recorded as affecting participation “very much” through “not at all”. Potential barriers indicated by the majority of respondents include confidentiality (n=59), the hours at which classes are offered (n=33), and distance from the clinic (n=28). Other potential barriers include transport to and from the clinic (n=32), “don’t feel well enough” (n=30), and cost of travel or supplies (n=25). Potential barriers that least affect participation were poor vision, family and work obligations (see Table 5.5).

Table 5.5: Barriers to participating in self-management education

| Barriers or obstacles | Very much | | Much | | Some | | A little | | Not at all | | Missing |
|-----------------------------------|-----------|-------|------|-------|------|-------|----------|-------|------------|-------|---------|
| | N | % | N | % | N | % | N | % | N | % | |
| Distance from clinic | 28 | 31.82 | 16 | 18.18 | 6 | 6.98 | 6 | 6.98 | 29 | 32.95 | 0 |
| Transportation to and from clinic | 13 | 14.94 | 32 | 36.78 | 6 | 6.90 | 10 | 11.49 | 26 | 29.89 | 1 |
| Stigma attached to the clinic | 12 | 13.95 | 22 | 25.58 | 14 | 16.28 | 9 | 10.47 | 29 | 33.72 | 2 |
| Costs of travel or supplies | 15 | 17.44 | 25 | 29.07 | 14 | 16.28 | 11 | 12.79 | 21 | 24.42 | 2 |
| Hours classes are offered | 33 | 38.37 | 18 | 20.93 | 21 | 24.42 | 8 | 9.30 | 6 | 6.98 | 2 |
| Confidentiality | 59 | 71.08 | 14 | 16.87 | 3 | 3.61 | 3 | 3.61 | 4 | 4.82 | 5 |
| Don’t feel well enough | 14 | 15.91 | 30 | 34.09 | 18 | 20.45 | 15 | 17.05 | 11 | 12.50 | 0 |
| Other health limitations | 10 | 11.76 | 22 | 25.88 | 19 | 22.35 | 12 | 14.12 | 22 | 25.88 | 3 |
| Poor vision | 4 | 4.71 | 12 | 14.12 | 11 | 12.94 | 13 | 15.29 | 45 | 52.94 | 3 |
| Family obligations | 7 | 7.95 | 18 | 20.45 | 18 | 20.45 | 16 | 18.18 | 29 | 32.95 | 0 |
| Work obligations | 10 | 11.76 | 11 | 12.94 | 14 | 16.47 | 11 | 12.94 | 39 | 45.88 | 3 |

Table 5.6: Preferred methods of learning

| Methods of learning | Very much | | Much | | Some | | A little | | Not at all | | Missing |
|--|-----------|-------|------|-------|------|-------|----------|-------|------------|-------|---------|
| | N | % | N | % | N | % | N | % | n | % | |
| Pamphlets and handouts available at the clinic. | 59 | 67.05 | 13 | 14.77 | 10 | 11.36 | 3 | 3.41 | 3 | 3.41 | 0 |
| Clinic bulletin board (current health information, changed every 2-3months) | 49 | 57.65 | 7 | 8.24 | 9 | 10.59 | 6 | 7.06 | 14 | 16.47 | 3 |
| Individual classes on appointment days. | 56 | 65.12 | 19 | 22.09 | 1 | 1.16 | 2 | 2.33 | 8 | 9.30 | 2 |
| Individual classes on schedule days | 50 | 57.47 | 20 | 22.99 | 9 | 10.34 | 4 | 4.60 | 4 | 4.60 | 1 |
| In-clinic group classes on appointment days | 55 | 63.95 | 17 | 19.77 | 6 | 6.98 | 3 | 3.49 | 5 | 5.81 | 2 |
| In-clinic group classes on scheduled days | 50 | 58.14 | 19 | 22.09 | 9 | 10.47 | 4 | 4.65 | 4 | 4.65 | 2 |
| In-clinic videos | 16 | 19.05 | 11 | 13.10 | 3 | 3.57 | 0 | 0 | 54 | 64.29 | 4 |
| Group classes at UKZN (but not in the clinic) | 5 | 5.88 | 7 | 8.24 | 7 | 8.24 | 9 | 10.59 | 57 | 67.06 | 3 |
| A video library (could be borrowed for use at home) | 22 | 25.58 | 6 | 6.98 | 3 | 3.49 | 2 | 2.33 | 53 | 61.63 | 2 |
| Mailed newsletter | 10 | 11.76 | 15 | 17.65 | 5 | 5.88 | 2 | 2.35 | 53 | 62.35 | 3 |
| Mailing in question with response by mail | 12 | 14.12 | 11 | 12.94 | 8 | 9.41 | 1 | 1.18 | 53 | 62.35 | 3 |
| Individual telephone calls by appointment | 53 | 61.63 | 13 | 15.12 | 5 | 5.81 | 3 | 3.49 | 12 | 13.95 | 2 |
| Computer resources: Electronic newsletter | 4 | 4.76 | 7 | 8.33 | 3 | 3.57 | 8 | 9.52 | 62 | 73.81 | 4 |
| Computer resources: Emails | 5 | 5.75 | 3 | 3.45 | 6 | 6.90 | 9 | 10.34 | 64 | 73.56 | 1 |
| Computer resources: Chat rooms | 4 | 4.65 | 5 | 5.81 | 4 | 4.65 | 9 | 10.47 | 64 | 74.42 | 2 |
| Computer resources: On-line resources | 3 | 3.53 | 4 | 4.71 | 5 | 5.88 | 4 | 4.71 | 69 | 81.18 | 3 |
| In-community group classes | 19 | 22.35 | 18 | 21.18 | 5 | 5.88 | 7 | 8.24 | 36 | 42.35 | 3 |
| Home visits | 21 | 24.42 | 27 | 31.40 | 7 | 8.14 | 6 | 6.98 | 25 | 29.07 | 2 |
| Other | 7 | 10.00 | 2 | 2.86 | 7 | 10.00 | 5 | 7.14 | 49 | 70.00 | 18 |

5.3.2 Preferred Methods of Learning

Preferred learning methods were also rated as preferred “very much” through “not at all”. Participants indicated multiple preferred learning methods at various levels. ‘Very much preferred learning methods’ as expressed by the majority of the participants included pamphlets and handouts available at the clinic (n=59), in-clinic group classes on appointment days (n=55) and individual telephone calls by appointment (n=53). Also, more than half of the participants ‘very much’ preferred individual classes on scheduled days (n=50), in-clinic group classes on scheduled days (n=50) and clinic bulletin board (current health information, changed every 2-3months) (n=49). The least preferred methods were the computer resources and group classes elsewhere (see Table 5.6 above).

5.3.3 Categories of Self-Management Needs of PLWHA

A qualitative content analysis following a nine-step procedure described by Feher Waltz, Strickland and Lenz, (1991) was performed. Five categories emerged: medical care; physical care; psychosocial care; socioeconomic and environmental care; health literacy information (see Table 5.7). The categories are further discussed below:

Medical care

The medical care category incorporates a range of content relating to AIDS care interventions, including requests for improvements in the availability of highly active antiretroviral therapy (HAART). Experts in HIV/AIDS need to collaborate with care providers, and continuity of care must be ensured. The commonest response related to the provision of greater access to an HIV/AIDS specialist nurse. The need for nurses with greater knowledge of HIV/AIDS and the skills needed for its management were identified. The need for continuous provision of HAART,

its administration and how to cope with the side-effects, and drugs for opportunistic infections were frequently expressed by the respondents as were the need for supportive prophylaxis and the desire for prompt treatment in cases of emergencies. Medical needs identified were as follows: *if only HIV/AIDS medicine can be made available on appointment days ...more accessible healthcare providers especially nurses, it's okay... regular supply of HIV/AIDS drugs including medicine for cough and drugs for watery stool to stop. Can't I get a cure for this thing? I need something to stop this troubling chest pain and cough. Information about HIV/AIDS medications including their side-effects will help me to manage myself. Guaranteed follow-up healthcare services (PLWHA).*

Physical care

The term “physical care” was used for all responses relating to requests for support with self-care activities such as bathing, brushing hair and teeth, washing, cooking and feeding (activities of daily living) and home care. Participants also stress the need for response to special needs such as provision of condoms. The need for provision of supplies for caregivers at home, hospice or hospital, including the provision of legal advice and home-based nursing care services was also identified. Physical needs also included provisions such as nutritional supplements, sufficient clothing, and decent housing. Here are some illustrative examples:

My major need is food for me and my children, clothing and a decent house. Somebody or machine to assist me with washing, cooking and other jobs in the house can help me to cope better. Law to protect me and my children, my neighbours don't like me, they can kill me. Somebody to help me care for my children and look after them when I am gone...somebody to care for me at home when I cannot come to the hospital (PLWHA).

Psychosocial care

The psychosocial care category comprised requests for access to help with emotional problems, particularly for spiritual care, how to disclose status to relations and overcome stigma, how to communicate HIV/AIDS to others, having somebody to talk to and the need to see a professional counsellor. Participants stress the need for counselling regarding interpersonal relationships, sexuality and sexual issues. Provision of facilities for crisis management, terminal and funeral rights was also touched. Spiritual counselling and support in preparation for dying, and necessary arrangements for children were also identified. Also included is the clarification of issues related to personal and family confidentiality. The needs for psychosocial care were expressed as follows:

Need people to love, accept me and help me deal with this thing. I am alone in this world. I need someone to talk to at least...concern about the future of my children. Who will take care of them? They know I am infected and coping with the virus. Worried about how my funeral will look like. I need a counsellor or psychologist to talk to about my problems...to know how to disclose my status to people (PLWHA).

Socioeconomic and environmental care

This category comprises care activities centred on socioeconomic and environmental issues that affect PLWHA. Enhancement of the living standard through provision of accommodation means of transport and recreational facilities are included in this category. Food and shelter, child care, financial support and income-generating activities were also mentioned. The majority of responses relating to financial support identified the need for disability grants and child welfare grants. The need for employment opportunities, occupational therapy, and greater involvement of

PLWHA in community life and engagement of PLWHA was also identified. Highlighted here are some of the needs:

If only government can provide us permanent decent house. Access to disability grants and child welfare grants...its right... financial supports in term of job opportunities. Money for food and transportation to the clinic is my problem. I have run out of money to buy my groceries and pay house rent (PLWHA).

Health literacy information

The majority of responses within the health literacy information category identified the need for information about HIV/AIDS, its treatment and the available HIV/AIDS care services. A few respondents reported a need for information targeted at families, communities and the wider society to improve understanding of HIV/AIDS and reduce the stigmatisation of PLWHA. The provision of HIV/AIDS literacy programmes for PLWHA, both the affected and their significant others was highlighted as being important to self-management. Some of the participants expressed health literacy needs:

Our people need education relating to accepting campaigns to de-stigmatize us is necessary. Let my people know about this sickness, its treatment and available care services... if they know about it may be they will accept me... health campaign is fine (PLWHA)

SELF-MANAGEMENT NEEDS OF PLWHA

Table 5.7: Overview of categories

| Category | sub-categories | Item codes | Raw data |
|--|--|---|---|
| Medical care (n=36) | Disease modifying therapy (n=9) | Access to HAART and supportive.(n=5) Managing side-effects of HAART (n=4) | "HIV/AIDS medicines" "How to use drugs correctly and management of side-effects" |
| | HAART (n=4) | Continued access to HAART (n=4) | "Continued access to AIDS drugs" |
| | Symptom management (n=8) | Pain Cough Diarrhoea Nausea Fatigue Skin rashes Anxiety Depression | "Something to relieve pain" "Treatment for cough" "Something to stop diarrhoea" "Stopping nausea" "A treatment to get energy" "Creams to remove rashes" "Something to make me relaxed" "A medicine to stop depression" |
| | Access to treatment (n=3) HIV/AIDS nurse (n=4) | Drug treatment(n=3) Access to HIV/AIDS nurse | "Not to wait for long time the medicines" "A HIV/AIDS nurse" |
| | Expertise in care coordination (n=2) | Care coordinator (primary nurse) | "One nurse to coordinate all my needs". |
| | Regular assessment and care (n=1) | Regular health care reviews (n=1) | "Regular checking of my viral load, CD4 count and other tests" |
| | Cure (n=2) Control of disease progression (n= 3) | Cure (n=2) Control of progression from HIV to AIDS (n=3) | "A cure for this disease" "To get no worse" |
| Physical care (N=18) | Home-based care(n=10) | Home care (n=10) | "Help at home with heavy chores" "Help with self-care" "Extra home help" |
| | legal services (n=3) Supplies for caregivers(n=5) | Legal advice (n=3) Supplies for caregivers (n=5) | "Legal advice on my rights" "Materials for careers at home" |
| Psychosocial care (n= 13) | Formal psychosocial support (n=7) | Formal psychosocial support (n= 7) | "Talking to a trained counsellor" "Help with emotional problems" |
| | Informal psychosocial support (n=6) | Informal psychosocial support (n=6) | "Somebody to talk to" "Something to reduce loneliness" "Arrangements for my children" "Arrangements for my funeral" |
| Socioeconomic and environmental care (n=12) | Infrastructures (n=3) | Accommodation (n=2) Good road (n=1) | "House near the clinic" "Help with recreational activities" |
| | Financial support (n=4) | Financial assistance (n=4) | "Money for transport to and from clinic" "Disability grant" "Child welfare" |
| | Risk management (n=2) Occupational therapy (n=3) | Ambulance services (n=2) Occupational therapy (n=3) | "Emergency services" "To earn money" |
| Health literacy information (n=9) | PLWHA information (n=5) | General information (n=2) Treatment information (n=2) Disease information (n=1) | "Written information on HIV/AIDS" "Information regarding treatment, drug side-effects and prognosis" "Information on HIV/AIDS-related conditions and issues" |
| | Public and family information (n=4) | Service information (n=2) Public information (n=1) Family information(n=1) | "Information on what help is available" "People understanding HIV/AIDS" "My family have a greater understanding of HIV/AIDS" |

5.4 Health-Related Quality of Life (H-RQOL) of PLWHA

RESEARCH QUESTIONS THREE:

What is the health-related quality of life of PLWHA before selection into A and B Groups?

5.4.1 Distribution of Data

One-sample Kolmogrov-Smirnov Test Result:

The result shows the distribution of the data on mean scores for the eight domains of health-related quality of life and the standard deviation for the scores. The data for VT (vitality), BP (bodily pain), and GH (general health) are normally distributed while data for PF (physical functioning), RP (role limitation due to physical health), RE (role limitation due to emotional problems), MH (mental health) and SF (social functioning) are skewed (see Table 5.8 below).

Table 5.8 One-Sample Kolmogorov-Smirnov Test

| | | PF | RP | RE | VT | MH | SF | BP | GH |
|--------------------------|----------------|----------|----------|----------|----------|----------|----------|----------|----------|
| N | | 88 | 88 | 88 | 88 | 88 | 88 | 88 | 88 |
| Normal Parameters(a,b) | Mean | 27.8886 | 39.7727 | 38.3030 | 41.6477 | 52.0455 | 53.5511 | 53.9489 | 44.4129 |
| | Std. Deviation | 24.38026 | 38.58793 | 36.93533 | 16.99766 | 12.07630 | 19.78230 | 24.88110 | 18.13334 |
| Most Extreme Differences | Absolute | .179 | .224 | .224 | .124 | .158 | .155 | .120 | .082 |
| | Positive | .179 | .224 | .224 | .084 | .104 | .155 | .120 | .082 |
| | Negative | -.126 | -.151 | -.150 | -.124 | -.158 | -.145 | -.119 | -.065 |
| Kolmogorov-Smirnov Z | | 1.677 | 2.098 | 2.101 | 1.160 | 1.478 | 1.454 | 1.121 | .773 |
| Asymp. Sig. (2-tailed) | | .007 | .000 | .000 | .136 | .025 | .029 | .162 | .588 |

a Test distribution is Normal.

b Calculated from data.

A majority of the participants reported decreased social, emotional, functional and physical well-being as reflected by the scores for all the eight domains of SF-36. Considering the sample as a whole the mean scores were: physical functioning, 27.89%; role limitations due to physical health, 39.77%; role limitations due to emotional problems, 38.30%; vitality (energy/fatigue), 41.65%; mental health (emotional well-being), 52.05%; social functioning, 53.55%; bodily pain, 53.95%; and general health, 44.41% (see Table 5.8 above). Since a score of 100 represents

optimal functioning with no problems (Ware et al. 2001) these findings suggest that the majority of participants were experiencing decreased physical functioning, role limitations, loss of energy, some fatigue, reduced social functioning, pain, and poor health.

5.4.2 Groups A and B compared before the intervention

RESEARCH QUESTIONS FOUR:

Is there a significant difference between Groups A and B in terms of age, gender and health-related quality of life of PLWHA before intervention?

The age, gender, and SF-36 mean scores were cross-tabulated by intervention/comparison status to examine for possible baseline differences between the groups. The participants' mean age was 33.35 and the standard deviation (SD) was 10.77. The age of participants ranged from 18 to 60 years. The mean age for participants in Group A was 34.95 while the mean for participants in Group B was 31.75 (see Table 5.4.1).

Table 5.4.1: Ages of Members of the A and B Groups

| GROUPS | MEAN | STANDARD DEVIATION |
|---------------|-------------|---------------------------|
| GROUP A | 34.95 | 11.35 |
| GROUP B | 31.75 | 10.18 |

The ages of participants showed normal distribution; an Independent Samples Test was therefore performed. The t test for independent groups shows there is no significant difference between the means of the two groups. Here the p value is 0.167, which is larger than 0.05 (Table 5.4.2). This suggests that there is no statistically significant difference between the means of the two groups. The two groups are not statistically significantly different in terms of their mean scores on age ($t=1.394$; $df=86$; $p=0.167$).

Table 5.4.2 Independent Samples Test Results

| | t-test for Equality of Means | | | |
|-----------------------------|------------------------------|--------|---------------|-----------------|
| | T | Df | Sig(2-tailed) | Mean Difference |
| Age Equal variances assumed | 1.394 | 86 | .167 | 3.205 |
| Equal variances not assumed | 1.394 | 84.990 | .167 | 3.205 |

5.4.2.1 Gender of members of the A and B Groups

There were more females than males in both groups in this study. There were 34 females and 9 males in the intervention group. This meant that females formed 79.07%, of the study participants and males formed only 20.93% in the intervention group. There were 33 females and 10 males in comparison group. This meant that females formed 76.74% of the study participants and males formed only 23.26% in the comparison group (see Table 5.4.3 below). One of the participants in each group did not indicate their gender. The groups are also similar in terms of gender composition.

Table 5.4.3: The A and B Groups' Genders Compared

| GROUPS | GENDER | | TOTAL |
|---------|------------|-------------|-----------|
| | MALE | FEMALE | |
| GROUP A | 9 (20.93%) | 34 (79.07%) | 43 (100%) |
| GROUP B | 10 (23.26) | 33 (76.74) | 43 (100%) |

5.4.2.2 SF-36 Mean Scores and SD for Groups A and B before the intervention.

The mean scores and standard deviation for Groups A and B before the intervention are presented below.

Table 5.4.4 Group statistics for normally distributed data before the intervention

| Experimental group | N | Mean | Standard Deviation (SD) | Std. Error Mean |
|--------------------|----|---------|-------------------------|-----------------|
| VT GROUP A | 44 | 39.5455 | 15.35692 | 2.31514 |
| GROUP B | 44 | 43.7500 | 18.43042 | 2.77849 |
| BP GROUP A | 44 | 51.8182 | 24.72737 | 3.72779 |
| GROUP B | 44 | 56.0795 | 25.13567 | 3.78934 |
| GH GROUP A | 44 | 45.6439 | 19.60434 | 2.95547 |
| GROUP B | 44 | 43.1818 | 16.66887 | 2.51293 |

An Independent Samples Test was performed for the normally distributed data. The result shown below (Table 5.4.5) revealed that there is no statistically significant difference between groups in terms of VT, BP, and GH before intervention. The p values are larger than 0.05.

Table 5.4.5 Independent Samples Test Result for normal data before the intervention

| | t-test for Equality of Means | | | |
|-----------------------------|------------------------------|--------|---------------|-----------------|
| | T | Df | Sig(2-tailed) | Mean Difference |
| VT Equal variances assumed | -1.163 | 86 | .248 | -4.20455 |
| Equal variances not assumed | -1.163 | 83.288 | .248 | -4.20455 |
| BP Equal variances assumed | -.802 | 86 | .425 | -4.26136 |
| Equal variances not assumed | -.802 | 85.977 | .425 | -4.26136 |
| GH Equal variances assumed | .635 | 86 | .527 | 2.46212 |
| Equal variances not assumed | .635 | 83.832 | .527 | 2.46212 |

Table 5.4.6 Ranks for skewed data (non-normally distributed data)

| Experimental group | | N | Mean Rank | Sum of Ranks |
|--------------------|---------|----|-----------|--------------|
| PF | GROUP A | 44 | 44.84 | 1973.00 |
| | GROUP B | 44 | 44.16 | 1943.00 |
| | TOTAL | 88 | | |
| RP | GROUP A | 44 | 43.59 | 1918.00 |
| | GROUP B | 44 | 45.41 | 1998.00 |
| | TOTAL | 88 | | |
| RE | GROUP A | 44 | 45.78 | 2014.50 |
| | GROUP B | 44 | 43.22 | 1901.50 |
| | TOTAL | 88 | | |
| MH | GROUP A | 44 | 43.93 | 1933.00 |
| | GROUP B | 44 | 45.07 | 1983.00 |
| | TOTAL | 88 | | |
| SF | GROUP A | 44 | 43.38 | 1908.50 |
| | GROUP B | 44 | 45.63 | 2007.50 |
| | TOTAL | 88 | | |

A Mann-Whitney Test was done for skewed data. The result showed that there is no statistically significant difference between groups at baseline. The p values are greater than 0.05 (See Table 5.4.7 below).

Table 5.4.7 Mann-Whitney Test Results for skewed data before the intervention

| | PF | RP | RE | MH | SF |
|-----------------------|----------|----------|----------|----------|----------|
| Mann-Whitney U | 953.000 | 928.000 | 911.000 | 943.000 | 918.500 |
| Wilcoxon W | 1943.000 | 1918.000 | 1901.000 | 1933.000 | 1908.500 |
| Z | -.126 | -.347 | -.492 | -.211 | -.424 |
| Asymp.sig. (2-tailed) | .900 | .729 | .623 | .833 | .672 |

Baseline assessment findings revealed that there were no differences in background and demographic data between Groups A and B. At baseline (before intervention) the differences between Groups A and B in terms of age, gender, and health-related quality of life were not substantial or statistically significant. The hypothesis that there is significant difference in health-related quality of life of intervention and comparison group before intervention was therefore rejected.

RESEARCH QUESTION FIVE: Is there a significant difference in the CD4 cell counts and viral loads of Groups A and B before intervention?

A One-sample Kolmogorov-Smirnov Test was performed. The result revealed that the CD4 counts and viral loads data were normally distributed.

5.4.2.3 Groups A and B's CD4 cell counts and viral load before intervention

Table 5.4.8 A and B Groups' CD4 cell counts before the intervention

| Group | | N | Mean | Std. Deviation | Std. Error Mean |
|------------|---------|----|--------|----------------|-----------------|
| CD4 before | GROUP A | 44 | 187.27 | 133.913 | 20.188 |
| | GROUP B | 44 | 177.41 | 104.949 | 15.822 |

Table 5.4.9 Independent Samples Test Results for CD4 counts before the intervention

| | t-test for Equality of Means | | | |
|------------------------------------|------------------------------|--------|---------------|-----------------|
| | T | Df | Sig(2-tailed) | Mean Difference |
| CD4 before Equal variances assumed | .385 | 86 | .702 | 9.864 |
| Equal variances not assumed | .385 | 81.353 | .702 | 9.864 |

The two groups are not statistically significantly different in terms of their CD4 count mean scores before intervention ($t=.385$; $df=86$; $p=.702 > 0.05$). See Table 5.4.9 above.

Table 5.4.10 A and B Groups' viral loads before the intervention

| Group | | N | Mean | Std. Deviation |
|-----------|---|----|-------|----------------|
| VL before | A | 44 | 1.136 | 0.347 |
| | B | 44 | 1.159 | 0.370 |

Table 5.4.11 Independent Samples Test Results viral loads before the intervention

| | t-test for Equality of Means | | | |
|-----------------------------------|------------------------------|--------|---------------|-----------------|
| | T | Df | Sig(2-tailed) | Mean Difference |
| VL before Equal variances assumed | -0.297 | 86 | 0.767 | 0.023 |
| Equal variances not assumed | -0.297 | 85.653 | 0.767 | 0.023 |

The t test for independent groups shows whether there is a significant difference between the means of two groups. Here the p value is 0.767, which is larger than 0.05 (see Table.5.4.11). This suggests that there is no statistically significant difference between the means of the two groups. The two groups, therefore, are not statistically significantly different in terms of their mean scores on viral load before the intervention ($t=-0.30$; $df=86$; $p=0.767$). The hypothesis that there is a statistically significant difference between Groups A and B in terms of their CD4 cell counts and viral loads before intervention was therefore rejected.

5.5 CONCLUSION

This Chapter culminates in the assessment of self-management education needs, preferred methods of learning, barriers to implementation, as well as biological markers. It provides baseline information that can be used in implementing self-management education. This information formed the basis for decision-making in the successive phases. The key elements that emerged during this phase were:

- The participants have medical, physical, psychosocial, socioeconomic and environmental care needs, as well as a need for health literacy information.
- The majority of participants are experiencing decreased physical functioning, role limitations, loss of energy, some fatigue, reduced social functioning, pain, and poor health.

- The differences between Groups A and B in terms of age, gender, health-related quality of life mean CD4 cell counts and viral loads were not substantial or not statistically significant.
- All the participants were interested in self-management education, but they expressed various levels of interest in the topics. The highest rated self-management education needs included understanding viral load and CD4 cell counts, understanding HIV/AIDS transmission, understanding HIV/AIDS medications and how they work, understanding HIV/AIDS, managing HIV/AIDS medications, sex and HIV/AIDS, managing side-effects from medications, how to talk to others about HIV/AIDS, how to disclose HIV status to others, how to live positively, exercise for health and well being, how to come to terms with HIV status, and cooking meals suitable for people living with HIV/AIDS.
- Potential barriers most often indicated (“very much affects participation”) include confidentiality, hours at which classes are offered, and distance from the clinic. Other potential barriers that affected participation included transport to and from the clinic, “don’t feel well enough”, and cost of travel or supplies.
- Participants indicated many different preferred learning methods. “Very much preferred learning methods,” as expressed by the majority of the participants, included pamphlets and handouts available at the clinic, in-clinic group classes on appointment days and individual telephone calls by appointment. More than half of the participants “very much preferred” individual classes on scheduled days, in-clinic group classes on scheduled days, and current health information, changed every 2-3months to appear on the clinic bulletin board.

To the knowledge of the investigator, no single instrument was available to measure the multidimensional HIV/AIDS self-management behaviour or factors that affect PLWHA. These data will serve as a baseline for comparison to post-programme data, providing a measure of participant and programme outcomes.

Specifically, I shall in Chapter 6 conduct an assessment of knowledge, facilitate the necessary education, and document the assessments and educational processes. This documentation will focus on the knowledge required to achieve the desired behavioural change. My scheme for the acquisition of knowledge was driven by behaviour change goals, not by a fixed curriculum. Behaviour change and maintenance of the new pattern of behaviour is essential to HIV/AIDS self-management education. The programme should therefore focus on behaviour change and lifestyle management.

CHAPTER SIX

THE RESULTS OF THE IMPLEMENTATION AND TESTING PHASES

6.0 INTRODUCTION

In this Chapter I shall describe the empirical implementation, including the testing and refining, of the self-management education model, with attention to issues of reliability, validity, and sensitivity to change. During the development phase I conducted a search for a suitable site for the programme, as described in Ch.4. Of the institutions that met the criteria for inclusion, only one was accessible and expressed interest in hosting the programme.

The implementation was specifically designed to focus on PLWHAs' motivation to achieve self-knowing and self esteem, which in turn result in the individual's empowerment as a self-manager. The implementation phase will be divided into three stages: input, process and product evaluations. Input evaluation involves decisions about what structures would be put in place and how these will be organized. It is also concerned with the development of human resources to implement the self-management education programme.

Process evaluation deals with the actual implementation process. It involves issues like whether the implementation of the programme is going according to plan, whether there are problems with implementation and whether the proposed guidelines for self-management education implementation are actually being followed. Product evaluation is concerned with the actual testing of the programme. These will be discussed separately, except for the discussion on human resources development, which was dealt with under recruitment and training of peer group leaders in Chapter 4.

Chapter 6 will be arranged in the following manner: first the input evaluation will be discussed; results from this evaluation will be summarized and then the process evaluation will be discussed, with a summary of results. Lastly, the product evaluation results will be analysed and the Chapter will end with a summary of the input, process, and product evaluation.

6.1 Input Evaluation

In preparation for the self-management education programme, I had to draw on my previous experiences in curriculum development and facilitation of educational programmes as a nurse lecturer. In formal education, a curriculum is the set of courses, the course work, and the content offered at an educational establishment. A curriculum has two aspects: the range of courses and the specific learning programmes. The learning programmes should provide a description of the teaching, learning, and assessment materials available for each course of study.

Instructional design includes teaching methods, materials, and assessment procedures. Curricula are developed using classic principles of instructional design. They are developed collectively, ensuring communication among management, curriculum developers, editors, production coordinators, and stakeholders.

The term pedagogy refers to the human or personal elements of education and must be found not in abstract theoretical discourse or analytic systems, but in the personalities of the teachers who will implement the curriculum. The more we understand ourselves and can articulate reasons for our choices in teaching, the more meaningful our curriculum will be.

Empowerment through formal learning is an interactive process of meaning making within particular historical, cultural and economic contexts. When participants share the burden of the classroom dialectic, classrooms become incubators in which ideas are germinated, shared, nurtured, argued, acted upon, and often transformed by teacher and participants alike.

The practice of the group is based upon theory, that the social world is very deeply embedded in each person, that the group will develop norms, which move it towards the healthy and away from the unhealthy. What matters in the group is that people should learn to communicate from deep within themselves to deep within another person; the role of the teacher is to facilitate this, and sometimes to model this also (Tubert-Oklander and Hernández-Tubert, 2011).

Based on my prior work and experience in developing health teaching programmes and my theoretical approach to individual and group teaching, I attempted to show how individual and group processes can be integrated into the participating group. This integration offers an understanding of individuals' needs and plans in relation to the collective. My practical experience in furthering the self-help movement and my knowledge of how it works are the background for the development of self-management education programme, to mobilise self-development of PLWHA, without new dependencies.

Kolb's (1976) theory of experiential learning posits that knowledge is continuously gained through personal and environmental experiences where certain abilities are required. The learner must be willing to be actively involved in the experience; be able to reflect on the experience; possess and use analytical skills to conceptualize the experience; possess decision-making and

problem-solving skills to use the new ideas gained from the experience. To provide for the active engagement required in self-management education, the course was conducted by means of seminars in which learning proceeds from interactions. This dialogic focus is intended to help the individual relate ideas to his or her situation and, in the case of myself as teacher, to help me to determine how, in personal and professional situations, I can act upon some of the ideas and issues discussed.

I was aware that the teaching group as a whole may neglect individual experience and expectancies, especially when the group is seen as an entity, an interactional network. From this viewpoint my interest must be in the quality and quantity of interactions between the members, and the reciprocal feedback.

A group does not achieve its goal because every member shares that goal but because each group participant's goal reflects some of the other members' attitudes and behaviour patterns. Since a concern with the self is a preliminary to concern with the group, some participants can profitably speak to each other, or the teacher can speak to an individual member, and the others can profit from it. The point is never reached where all group members at any one moment have a shared goal. On a higher level of relationship, one or several individuals who experience the group as a whole as a great caring mother may have mutual concern for each other's welfare. This degree of mutual concern will differ in each member and will demand that the group facilitator pay close attention to individual members and the group situation. I tried my utmost to do this throughout the intervention.

Development of a self-management education conceptual model continued over a period of nine months. Meetings were scheduled on a biweekly basis, with members of Groups A and B meeting at different times. On average, ten people were present at any one time and each group met only once, all the participants met at the end of the intervention. The reason for this was the difficulty involved in coordinating group members; nevertheless, working in this manner was found to be effective.

From programme entry I maintained a positive, informative and non-aggressive approach. I explained the importance of the study, and clarified exactly what the participants would be asked to do, how much of the participant's time would be involved, and what the duration of the study would be. In order to establish contact and win trust I employed a non-judgmental appreciation of the position of participants, and tried to connect with them and their world. Throughout the intervention, I recognised and praised the qualities and achievements of participants.

The empowerment theory which I have explained earlier guided the design and development of this self-management education conceptual model. I strongly encouraged participants to become autonomous. The meetings were interactive and focussed on building skills, sharing experiences, and providing mutual support.

The conceptual framework outlined in Chapter 3 was used to structure the interventions and to evaluate the outcomes of the programme for PLWHA. It was found to be comprehensive and informative, since it produced the desired competencies in six out of the eight objectives. I

deliberated further to determine what should be included in the conceptual model in order to help PLWHA master all the competencies areas required to be a self-manager.

By blending an array of learning and teaching strategies in stimulated real-life contexts, I attempted to expand participants' knowledge by integrating empirics, aesthetics, ethics and personal knowledge into learning activities such as craft art work and role playing. I allowed participants to think critically as well as creatively; they were encouraged to consider fellow participants as well as about themselves.

The focus of the self-management education programme is to enable PLWHA to gain the motivation and skills needed to self-manage their condition. My programme was different from traditional interventions in which participants receive medical advice and information about their condition from healthcare providers (Newbould et al., 2006). This new situation in my intervention created new responsibilities for PLWHA and healthcare providers. The PLWHA became an active partner applying his or her knowledge continuously to the care process. Initially however he or she is inexperienced in this new role, and must learn how to be an effective participant. Healthcare providers now became facilitators, aiding the participant in developing skills related to health practices. Continuity and integration of care by the participating healthcare providers were both essential.

My self-management education programme encompasses activities that empower and prepare PLWHA to manage their health care. The care component reflects PLWHAs' central role in care

and treatment, and stresses the use of self-management support strategies, including assessment, goal setting, action planning, problem solving and follow-up.

The programme placed high value on interdependent and collaborative learning and hence the way learning activities were organised became important. Through these arrangements, participants come to realise the importance of making information available to group members, careful planning, communication and negotiation, coordinated efforts in execution of the plan, critical thinking in cases of unanticipated difficulty and honest evaluation based on facts.

I intended participants entering the programme to learn to understand and accept their position, and felt that this piece of poetry summarised their plight:

“When I was young and quite depressed

Full of loss and pain and grief

I joined a group of troubled souls

All searching for relief.

As told, we tried to share our lives

We sat together twice a week

And though our worlds were quite apart

My dreams began to leak.

I found the group spoke out today

But used the voices of my past

I thought that I had run away

I found my childhood held me fast.

*I'd always thought I owned my self
I now found out I was on loan
A share-point site for needs and ids
Where their bad breasts found comfy homes.
Although, like most, I used to look
Inside my head for solitude
I found, without respect or pay,
My insides served as psychic food.
My group became my other selves
They even seemed to share my skin
I couldn't tell whose mind was whose
And in my turn I sucked them in.
The theories that I've learned about
Are quite inadequate
To tell you how the group worked out
Which parts belonged with what.
But—in a while—I found I could
Without the guilt of being wrong
Decide which parts I wished to own
And which to pass along.
And so, sometimes, I find, these days
That I am really me.”(Brown, 2011: 112-113).*

6.2 Process Evaluation

6.2.1 Self-management education programme implementation

A process analysis is undertaken when there is a need for descriptive information on the process by which a programme is implemented and how it actually functions. “A process analysis is typically designed to address such questions as the following: does the programme operate the way its designers intended? What are the strongest and weakest aspects of the programme? What exactly is the treatment, and how does it differ (if at all) from traditional practices? What were the barriers to implementing the programme successfully? How do staff and clients feel about the intervention?” (Polit and Beck, 2008: 317).

I shall attempt to answer the above questions in the next section. The programme implementation presented here is directed at the most aspects of the self-management education process as described in Chapter 3, it also provides some indication of the level of intended performance. Too often interventions are evaluated without regard to the nature or extent of the the target improvements (Hulscher, Laurant and Grol, 2002). For this study, I used key indicators of quality of self-management education programmes (Nolte, Elsworth, Sinclair and Osborne, 2007) “to check whether the planned improvement activities ha[d] indeed been executed uniformly and whether the target population ha[d] actually been exposed to these activities as planned” (ouwens, wollersheim and hermens, 2005). A valid set of indicators for the self-management education programme can be determined by linking indicators to the elements of this framework. The key indicators in participants, according to Nolte et al., (2007) are: (a) positive and active engagement in life, (b) health-directed behaviour, (c) skills and technique

acquisition, (d) constructive attitudes and approaches, (e) self-monitoring and insight, (f) health service navigation, (g) social integration and support and (h) emotional wellbeing.

For PLWHA, an intervention should lead to enhanced self-reflection which in turn influences health behaviour and eventually health status. PLWHA, having identified their need and rediscovered self, were able to make decisions and engage in behaviour that positively affects their health. It was crucial to involve them in their own care processes. PLWHA and I had a better chance of seeing improvements if we focussed on a specific problem, established realistic goals and developed an action plan for attaining them.

The evidence supporting sustained follow-up shows that PLWHA benefited immensely from the programme and were happy knowing that they had ongoing planned contact with the investigator, even in the absence of a medical crisis.

Conducting self-management education for PLWHA is not always a straightforward affair: a number of clinical issues arose. Among these are problems relating to dealing with PLWHA's expectations; sometimes anger and emotional distress are emphasized. Underlying all considerations that have to do with the technique, I established a consistent positive relationship with the participants, showed concern, acceptance, sincerity and empathy. I was alert to any potential factors that might compromise group collaboration. Good record keeping was adhered to and a report form was used for monitoring and measuring change. Self-awareness and self development were encouraged and emotional support provided for peer leaders and participants.

Individuals with specific problems identified during sessions were referred to me for individual interactive sessions, during which in all cases one of my technical staff acted as an interpreter.

At the initial consultation I assessed: PLWHA's knowledge, beliefs, concerns, daily behaviour, goal for consultation and clinical status. I identified appropriate treatments and advice, using neutral, non-judgmental language, corrected inaccurate knowledge and filled in the gaps in PLWHAs' understanding of their condition. I reinforced advice given to individuals during consultations, putting that advice into a wider context, suggesting further sources of information, and helping the recipient to gain more from the healthcare system.

In developing a treatment plan I discussed with PLWHA the options available, relating them to specific concerns; I evaluated the importance each PLWHA gave to the treatment indicated and his or her readiness to adopt the treatment. I negotiated each person's selection from the different options, agreed upon goals that reflect priorities, ensured that the negotiated goals were clear, measurable, realistic, under the PLWHA's direct control and limited in number. I provided a written or diagrammatic summary of the plan, liaised with the clinic staff to provide medications, provide nursing care, skills and tools to assist with self-management, addressed obstacles, and provided psychological support. I arranged for follow-up to monitor progress, reinforced key messages and scheduled group sessions.

During follow-up consultations in order to improve both health and health literacy which increase an individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health-related decisions. I carried out the following

activities: assessed PLWHAs' clinical status, risk factors, understanding of the treatment plan and adherence to it (by asking, counting pills, checking pharmacy records). I compared findings with those from previous consultation, and acknowledged efforts and successes in self-management, even if they were limited. I repeated key information concerning each PLWHA's condition and its treatment, reinforced what he or she needed to know to self-manage, negotiated changes in the plan as needed, discussed problems and developed strategies to overcome them, arranged follow-ups, scheduled group sessions, recorded what happened during the sessions and evaluate the intervention process and the PLWHA's condition.

There was in the area where my intervention took place little knowledge or experience concerning the benefits of self-management education programmes. This information appeared to be necessary to convince both PLWHA and healthcare professionals of the worth of the programme. I conducted intervention mapping (see Chapter 4) to address issues raised.

Implementation of this programme was not without problems. Interactive teaching methods demand coordination, experienced facilitators, and physical space. There were barriers to implementation at both the participant and programme levels. Problems centered on staffing and reimbursement for the technical staff and participants. I applied to various funding organisations for grants to cover the programme costs, which were not granted. The School of Nursing offered me a part-time teaching job which made the intervention possible. At participant level, problems included funds for transportation, low levels of literacy and need for reimbursement. To address these problems, I gave each participant R30 as reimbursement for transportation at each meeting.

Some of the participants had very little formal education. The instruction materials were translated into their home language by language experts that were fluent in isiZulu and English.

The self-management intervention was well received, being tailored to PLWHAs' needs. It provided continuing personalized guidance that enabled them to control their change. It was a clinic-based programme that did not require special facilities or equipment, but only group meetings related to clinic days. It served large numbers of people simultaneously under the guidance of a single implementer. PLWHA developed skills in monitoring their health and related circumstances; in turn the facilitators showed them how to use proximal goals to motivate themselves. They were provided with an enabling environment, incentives and social support to sustain their efforts. The following were also provided: adequate information, knowledge and skills on how to develop healthy living habits, set themselves short-term goals, and report changes.

The feedback at follow-up sessions provided guidelines on how to manage troublesome situations. There was a decline in request for support among Group A while Group B still expressed needs for support and felt a lack of knowledge and the skills of self-management strategies. Participants were also empowered to take a more active role in managing their illness and improving their quality of life.

6.3 Product Evaluation

Outcome and impact analysis was carried out in product evaluation.

6.3.1 Outcome Analysis

An outcome analysis tends to be descriptive and does not use a rigorous experimental design. Such an analysis simply documents the extent to which the goals of the programme are attained, that is, the extent to which positive outcome occurs (Polit and Beck, 2008: 317). An outcome analysis would document outcomes without making rigorous comparisons. Outcome research represents a response to the increasing demand from policy makers, insurers, and the public to justify care practices and systems in terms of improved patient outcome and costs (Polit and Beck, 2008). Outcomes are defined as personal or organizational changes that follow as a result of consequences of interventions or services (Schalok, 2001).

In this study, outcome evaluation consists of determining the ultimate effects of the intervention on self-management behaviour change among PLWHA.

RESEARCH QUESTION SIX

How effective is the HIV/AIDS Self-Management Education Programme (HASMEP) in improving the ability of PLWHA, in partnership with their health care providers, to manage the physical and psychosocial challenges that they face?

Results of in-depth group interviews

Participants did not remember all the events or exactly when and if things had happened during the intervention, but could talk about their experiences connected with the programme and how it improved their self-management. Knowledge and skills of self-management increased, as did

levels of comfort in talking to health professionals (Campbell, Beer and Wilkins, 2008). Emerging themes from focus group interviews with PLWHA include: healthy living and active engagement in life, self-management skills and strategies acquisition, self-monitoring and self-care, social support, emotional well-being, and partnering health care services.

Healthy living and active engagement in life

Most of those interviewed are now actively engaged in life and are motivated to improve their life circumstances by living positively while HIV positive. Many are engaged in things of interest to them, enjoy their life and actively involve themselves in health promotion activities:

Before, I am tired all the time, feel sad...I am always thinking of my disease. Now, the days are better than before. I am now thinking of my life ahead in the future even if I don't know if... I take care of myself and now wish to live and enjoy my life. I do not get sick like before. I eat good food, do exercise and go for check-up. I've written down more things. I schedule things. I do things when I say to do them.

Self-management skills and strategies

The majority of those interviewed developed skills in symptom management and techniques to manage their own health. Healthcare providers were viewed as only understanding their area of expertise, while PLWHA had to be experts on managing every aspect of their health.

When I have symptoms I've got the skills that help me cope. I avoid things that make me sick and manage my health problems. If others can cope with problems like mine, I can too. My health problems cannot ruin my life; I've got to live like any other person. I do not let my health problem control my life. I know what things can trigger my health problems. I carefully watch

my health and do what is necessary to keep healthy. I know when my lifestyle is creating health problem for me. I of course feel like I know more about HIV/AIDS now. I am not getting sick like before... I manage myself. Know what to eat, do and how to care for myself when I am sick.

Self-monitoring and self-care

Self-monitoring can be defined as awareness of symptoms or bodily sensations, enhanced through periodic measurements, recordings and observations to provide information for improved self-management (Wilde and Garvin, 2007). The interplay between awareness, measurement and observation can enhance self-management by improving individuals' self-monitoring. A majority of those interviewed have identified the benefits of self-monitoring, self-management, setting reasonable targets, and insight into living with HIV/AIDS. A common theme among these participants was that they had a responsibility to be involved in the management of their health.

I started to pay attention to my body. I started to become more aware of subtle signs...such as body rashes, increased body temperature, blurred vision and degree of mental acuity. I learned to know my body and its responses just by really concentrating, by making a concerted effort to recognize that I have to be in control. 'I think that's the name of the game, getting in touch with yourself, and listen and find out what's going on with your body'. I regularly monitor my CD4 cell counts, viral loads and other laboratory results to be able to set realistic expectations.

Social support

Some of those interviewed indicated high levels of social interaction, support, seeking support from others, and low level of social isolation due to illness.

Now I have enough friends who help me cope with my health ... I get enough chances to talk about my health. If I need help, I have plenty of people I can rely on. Overall, I feel well cared for by friends and family. When I feel ill, my family and carers readily understand.

Emotional well-being

Some of participants have high levels of overall health-related positive effect, positive attitude to life, and low levels of anxiety, stress, anger and depression.

Due to my emotions I was no longer socializing. But now I visit friends, family members and attend social gatherings. I feel fine. I spend enough time on my work and other activities do them as careful as usual and accomplish as much as I want.

Partnering healthcare services

Many of the participants have confidence in their ability to communicate with healthcare professionals and good understanding of ways to access healthcare in order to meet their needs. Some of the participants spoke of the importance of understanding their clinical test results, being involved in decisions about medications they were taking, or seeking information from healthcare providers.

I discuss my health problems with healthcare providers now. I see my doctors and nurses regularly and do whatever they tell me to stay healthy. I talk well with doctors and nurses about my health. I have positive relationship with healthcare workers. I confidently give healthcare professionals the information ... getting my needs met from available healthcare resources is no problem. I work in a team with my doctors and other healthcare providers.

The Self-Management Handbook

A majority of participants (over 90%) identified the *Self-Management Handbook for People Living with HIV/AIDS*, as useful for their self-management. Participants had something good to say about every unit of the book.

I thought [the book] ... was good, in fact, perfect...I think (the general information) are good as a resource. It tells me about disability grant... use and applying for disability grant.

Another participant commented:

The (symptom management strategies) are very good sources. When I get any symptom, I just look in the book and it tells me what to do, when to go to see the doctor and all the things like that.

Another participant makes reference to the symptom management and HAART units of the book.

Those units on symptom management and drugs are good sources. It is good to have that book. When I need any information about my drugs I just open the book to the drugs page and it tells me anything I need to know.

Another participant describes learning about reproductive health for people living with HIV/AIDS.

I thought my life is over about having sex. I learnt about how to have safe sex being ... to protect my partner and myself. I learnt that I can even have a child and protect the child from HIV. In fact, the book is very useful in managing my condition.

6.3.2 Impact Analysis

An impact analysis attempts to identify the net impacts of a programme, that is, the impacts that can be attributed exclusively to the programme, over and above the effects of the counterfactual

(e.g., traditional health education). Impact analyses use an experimental or quasi-experimental design because the aim of such evaluation is to attribute a causal influence to the special programme (Polit and Beck, 2008). Performing an impact evaluation of the intervention does not involve much difficulty as the study was specifically designed for this. I performed an impact evaluation six months after the intervention, since allowing for a longer time to elapse would, imply that I was measuring, not the impact itself, but its sustainability.

RESEARCH QUESTION SEVEN

Is there a significant difference between the health-related quality of life of Groups A and B after the intervention?

One-sample Kolmogorov-Smirnov Test was conducted to check for normality in the post-intervention data. Data for PF, VT, MH, BP and GH are normally distributed, RP, RE and SF are skewed.

6.3.2.1 Groups A and B's health-related quality of life compared after the intervention

Table 6.1 Group Statistics for normally distributed data

| | GROUP | N | Mean | Std. Deviation | Std. Error Mean |
|----|---------|----|---------|----------------|-----------------|
| PF | GROUP A | 41 | 65.9756 | 25.79291 | 4.02818 |
| | GROUP B | 40 | 42.3750 | 28.62193 | 4.52552 |
| VT | GROUP A | 41 | 65.6098 | 13.33206 | 2.08212 |
| | GROUP B | 40 | 54.8750 | 15.99229 | 2.52860 |
| MH | GROUP A | 41 | 67.9024 | 18.55775 | 2.89823 |
| | GROUP B | 40 | 62.7000 | 13.98571 | 2.21133 |
| BP | GROUP A | 41 | 68.4756 | 19.81065 | 3.09390 |
| | GROUP B | 40 | 69.1875 | 26.17977 | 4.13939 |
| GH | GROUP A | 41 | 68.5976 | 14.13285 | 2.20718 |
| | GROUP B | 40 | 61.5625 | 15.88687 | 2.51194 |

Of the 88 participants, 81 completed the SF-36 questionnaire after intervention. The remaining seven participants did not complete the SF-36 questionnaire either because they were deceased (n=2) or were acutely ill when contacted (n=5) (Table 6.1).

Independent Samples Test Results

Independent Samples Test was performed for the normally distributed data. The two groups are statistically significantly different in terms of their mean scores on physical functioning ($t=3.900$; $df=79$; $p=0.000 < 0.05$), vitality ($t=3.285$; $df=79$; $p=0.002 < 0.05$) and general health ($t=2.107$; $df=79$; $p=0.039 < 0.05$) post-intervention. The groups are not statistically significantly different in terms of their mean scores on mental health ($t=1.422$; $df=79$; $p=.158 > 0.05$) and bodily pain ($t=-.138$; $df=79$; $p=0.891 > 0.05$) post-intervention (Table 6.2).

Table 6.2 Independent Samples Test Results

| | t-test for Equality of Means | | | |
|-----------------------------|------------------------------|--------|---------------|-----------------|
| | T | Df | Sig(2-tailed) | Mean Difference |
| PF Equal variances assumed | 3.900 | 79 | .000 | 23.60061 |
| Equal variances not assumed | 3.895 | 77.715 | .000 | 23.60061 |
| VT Equal variances assumed | 3.285 | 79 | .002 | 10.73476 |
| Equal variances not assumed | 3.277 | 75.827 | .002 | 10.73476 |
| MH Equal variances assumed | 1.422 | 79 | .159 | 5.20244 |
| Equal variances not assumed | 1.427 | 74.302 | .158 | 5.20244 |
| BP Equal variances assumed | -.138 | 79 | .890 | -.71189 |
| Equal variances not assumed | -.138 | 72.642 | .891 | -.71189 |
| GH Equal variances assumed | 2.107 | 79 | .038 | 7.03506 |
| Equal variances not assumed | 2.104 | 77.454 | .039 | 7.03506 |

Table 6.3 Ranks for skewed data (non-normally distributed data)

| GROUP | | N | Mean Rank | Sum of Ranks |
|-------|---------|----|-----------|--------------|
| RP | GROUP A | 41 | 49.06 | 2011.50 |
| | GROUP B | 40 | 32.74 | 1309.50 |
| | TOTAL | 81 | | |
| RE | GROUP A | 41 | 47.72 | 1956.50 |
| | GROUP B | 40 | 34.11 | 1364.50 |
| | TOTAL | 81 | | |
| SF | GROUP A | 41 | 43.90 | 1800.00 |
| | GROUP B | 40 | 38.03 | 1521.00 |
| | TOTAL | 81 | | |

Mann-Whitney Test Results

A Mann-Whitney Test was done for skewed data. The result showed that there is a statistically significant difference between the groups after intervention in terms of mean scores for role limitations due to physical health ($p=0.001 < 0.05$) and role limitations due to emotional problem ($p=0.007 < 0.05$). There is no statistically significant difference between the groups after intervention in terms of mean scores for social functioning ($p=0.249 > 0.05$) (Table 6.4).

Table 6.4 Mann-Whitney Test Results after the intervention

| | RP | RE | SF |
|-----------------------|----------|----------|----------|
| Mann-Whitney U | 489.500 | 544.500 | 701.000 |
| Wilcoxon W | 1309.500 | 1364.500 | 1521.000 |
| Z | -3.199 | -2.703 | -1.154 |
| Asymp.sig. (2-tailed) | .001 | .007 | .249 |

Out of the eight domains, reflecting health-related quality of life, five show a significant difference between Groups A and B. There is a statistically difference between the groups in terms of their mean scores for PF, VT, GH, RP and RE..

Post-intervention results show that the two groups are statistically significantly different in terms of their mean scores on physical functioning ($t=3.900$; $df=79$; $p=0.000 < 0.05$), vitality ($t=3.285$; $df=79$; $p=0.002 < 0.05$) and general health ($t=2.107$; $df=79$; $p=0.039 < 0.05$), role limitation due to physical health ($p=0.001 < 0.05$) and role limitation due to emotional problem ($p=0.007 < 0.05$). The two groups are not statistically significantly different in terms of their mean scores on mental health ($t=1.422$; $df=79$; $p=.158 > 0.05$), bodily pain ($t=-.138$; $df=79$; $p=0.891 > 0.05$) and social functioning ($p=0.249 > 0.05$) (See Tables 6.2 and 6.4).

RESEARCH QUESTION EIGHT

Is there a significant difference in the CD4 counts and viral loads of the Group A and B after intervention?

One-sample Kolmogorov-Smirnov Test was performed. The result revealed that the CD4 counts and viral loads data are normally distributed.

6.3.2.2 Groups A and B's CD4 cell counts compared after intervention

Table 6.5 Groups A and Bs' CD4 cell counts after the intervention

Group Statistics

| Group | | N | Mean | Std. Deviation | Std. Error Mean |
|-----------|---------|----|--------|----------------|-----------------|
| CD4 After | GROUP A | 41 | 365.36 | 155.708 | 24.026 |
| | GROUP B | 40 | 254.70 | 106.231 | 16.797 |

Table 6.6 Independent Samples Test Results after the intervention

| | t-test for Equality of Means | | | |
|-----------------------------------|-------------------------------------|--------|---------------|-----------------|
| | T | Df | Sig(2-tailed) | Mean Difference |
| CD4 After Equal variances assumed | 3.741 | 80 | .000 | 110.657 |
| Equal variances not assumed | 3.775 | 72.631 | .000 | 110.657 |

The two groups are statistically significantly different in terms of their CD4 count mean scores after intervention ($t=3.741$; $df=80$; $p=.000 < 0.05$). See Table 6.6 above. The hypothesis that there is a significant difference between the two groups in term of CD4 counts after intervention was therefore supported by the findings of this study.

6.3.2.3 Groups A and B's viral loads compared after intervention

The t test for independent groups shows whether there is a significant difference between the mean viral loads of the two groups. Here the p value is 0.708, which is larger than 0.05. (Table 6.8 below) This suggests that there is no statistically significant difference between the means of the two groups. The two groups are therefore not significantly different in terms of their mean scores on viral load after the intervention ($t=-0.38$; $df=86$; $p=0.708$).

Table 6.7 Groups A and Bs' viral loads after the intervention

| Group | | N | Mean | Std. Deviation |
|----------|---------|----|-------|----------------|
| VL after | GROUP A | 44 | 3.023 | 0.590 |
| | GROUP B | 44 | 3.068 | 0.545 |

Table 6.8 Independent Samples Test Results after the intervention

| | t-test for Equality of Means | | | |
|----------------------------------|------------------------------|--------|---------------|-----------------|
| | T | Df | Sig(2-tailed) | Mean Difference |
| VL after Equal variances assumed | -0.375 | 86 | 0.708 | 0.045 |
| Equal variances not assumed | -0.375 | 85.472 | 0.708 | 0.045 |

ANOVA RESULTS

A repeated measures analysis of variance (ANOVA) was done to determine whether the differences between two or more mean deviate from one another significantly or merely by chance.

6.3.2.4 Tests of Between-Subjects Effects

Table 6.9 1 Transformed Variable: Average

| Source | Type III Sum Of Squares | Df | Mean Square | F | Sig. |
|-----------|-------------------------|----|-------------|---------|------|
| intercept | 9447056.652 | 1 | 9447056.652 | 374.735 | .000 |
| group | 130617.043 | 1 | 130617.043 | 5.181 | .026 |
| error | 2016797.152 | 80 | 25209.964 | | |

There is a statistical significance in between-subject effects ($p=0.026 < 0.05$).

Paired t-test results

Table 6.9 2 Group A Paired Samples Statistics

| | Mean | N | Std. Deviation | Std. error Mean |
|-------------------|--------|----|----------------|-----------------|
| Pair 1 CD4 Before | 187.27 | 44 | 113.053 | 17.444 |
| CD4 After | 365.36 | 41 | 155.708 | 24.026 |

Paired Samples Test results shows that there is a statistically significant difference between the CD4 before and CD4 after for Group A ($t=-11.538$; $df=41$; $p=.000 < 0.05$).

Table 6.9 3 Group B Paired Samples Statistics

| | Mean | N | Std. Deviation | Std. error Mean |
|-------------------|--------|----|----------------|-----------------|
| Pair 1 CD4 Before | 177.41 | 44 | 94.442 | 14.933 |
| CD4 After | 254.70 | 40 | 106.231 | 16.797 |

Paired Samples Test results shows that there is a statistically significant difference between the CD4 before after for Group B. ($t=-11.538$; $df=41$; $p=.000 < 0.05$). These findings show a statistically significant difference between the CD4 before and CD4 after in both groups. The differences between before and after means for both groups, however, deviate from one another significantly. Group A shows a higher mean difference.

After the intervention, the two groups are statistically significantly different in terms of their CD4 count mean scores ($t=3.741$; $df=80$; $p=.000 < 0.05$) (Table 6.6). There is a statistically significant difference in between-subject effects ($p=0.026 < 0.05$). Paired Samples Test results show that there is a statistically significant difference between the mean CD4 cell counts pre- and post-intervention for both groups but the differences between means for the groups deviate significantly. For Group A the difference between means is -178.09, while –for Group B, 72.29 is the difference between means (See Tables 6.9.2 and 6.9.3).

6.4 CONCLUSION

The programme resulted in an improved quality of care and ultimately, quality of life for PLWHA. It increased the capacity of PLWHA to live with their disease and promoted care that

is consistent with their own preferences and scientific evidence. The self-management education programme provided an opportunity for PLWHA to assume autonomy. It offers healthcare providers the opportunity to provide relief to overburdened case managers, and reduce investment in some cases, saving funds for other critical services.

Field testing fits the study of unstable social processes, where words and deeds are interwoven, as in this research. It provides evidence that the model can be implemented in clinical settings. I used the results of the tests to further refine the model and improve its clinical application.

Consistent use of this model will enable valid comparisons of efficiency and outcomes of self-management education programmes (Lemmens, Nieboer, van Schayck, Asin and Huijsman, 2008).

CHAPTER SEVEN

DISCUSSIONS, RECOMMENDATIONS AND CONCLUTIONS

7.0 INTRODUCTION

The purpose of my study was to develop, test, and refine a model for implementing a self-management education programme for PLWHA in semi-rural KwaZulu-Natal. The model presented here is directed at various aspects of self-management education programmes, and provides some indication of the level of intended performance. This model provides a heuristic method of understanding how self-management education interventions affect care and health-related quality of life.

7.1 DISCUSSION OF THE CONCEPTUAL MODEL DEVELOPMENT PHASE

The first step was to review existing literature on self-management of chronic conditions and specifically HIV/AIDS. Secondly I read publications on the evaluation of self-management education programmes, reviews of studies of HIV/AIDS self-management education and a number of studies of specific programmes illustrating key components of an evaluation system. I also included publications identifying the outcomes to be evaluated, how they related to one another, and a variety of measurement and analyses issues.

The third resource was a set of theoretical models identifying the key factors targeted by interventions for behaviour change. Their purpose was to identify linkages among the components of the health and behaviour change process: health outcomes, behaviour, barriers to behaviour change, intentions to change behaviour, and triggers for behaviour change, including HIV/AIDS self-management education. My model incorporates insights from many other

behavioural models, including the health belief model, the social-cognitive model, and empowerment theories.

One of the first decisions was to design a model to be used in service organizations. My intent was to make it usable in settings that did not have resources for comprehensive care for PLWHA. Another major assignment was deciding the place of knowledge in the model. While the traditional approach to education places major emphasis on knowledge acquisition, I had identified changed behaviour as the key outcome of HIV/AIDS self-management education. Education facilitators were expected to conduct their own assessment of knowledge, provide the necessary education to the patient, and document the knowledge assessment and education process on the Site Report Form. This documentation should focus on the knowledge required to achieve the desired behaviour change. The acquisition of knowledge was to be driven by behaviour change goals, not by a fixed curriculum.

The third decision was to identify what factors determine behaviour change, for example, which factors education facilitators should be prioritized to enhance behaviour change. The most important factors were the self-management behaviour change goals. I adopted the empowerment or patient-centred approach in which self-management behaviour change goals arise from the participant. In addition to assessing the desire to change, participants were asked what their goals were, and their responses were categorized using the same categories as were used for questions about their current behaviour (e.g., frequency and duration of exercise). Behaviour change intentions were also categorized in terms of readiness to change (e.g., immediately, in the next three months, in the next year, longer).

The next factors to be considered were barriers to implementation of self-management education programme. In addition to specific barriers, I identified recognition of the need for behaviour changes as a necessary prerequisite for change. I decided that each participant's behaviour should drive the assessment of intentions and barriers.

The baseline strategy was designed to minimize the number of questions that a patient had to answer. I placed a high priority on making the model practical to use in the day-to-day operation of HIV/AIDS self-management education programmes.

With the format and general content determined, I set about identifying the specific behaviour that would be the basis for other content. The HIV/AIDS self-management behaviour domains can be summarised as including being active, healthy living, taking medication, monitoring viral load and CD4 cell counts, problem solving (for opportunistic infections and HIV/AIDS related conditions), risk reduction activities and symptom management. Different kinds of self-management behaviour were given names, using participant-friendly and action-oriented terminology. The results of the process and product evaluation revealed that PLWHA require both knowledge and skills to manage their HIV/AIDS, which result in changes in behaviour. An extension of this continuum is that appropriate self-management behaviour, in turn improves clinical indicators and health-related quality of life.

The attitudes, skills and behaviour which allow for self-management were selected as the foundation for outcomes measurement in HIV/AIDS self-management education. The behaviour changes which occurred as a result of the intervention were relatively specific and measurable

and perceived as achievable and compatible with the lifestyles of PLWHA. I intend that “the continuous measurement, monitoring, and management of these behavioural outcomes should guide HIV/AIDS self-management educators in their method of delivery of promoting behaviour change, leading to improved clinical indicators and health status, rather than the traditional approach of documenting learning outcomes” (Mulcahy, Maryniuk, Peebles, Peyrot, Tomky, Weaver and Yarborough, 2003). The participants’ response guided the educational interventions by focusing on what they consider most important.

Although the conceptual model underwent extensive development and testing, it is still not set in stone. It does not assess all possible HIV/AIDS self-management behaviours or all factors potentially relevant to participating in the self-management education programme. However, the model provides education facilitators with a tool ready for immediate use and can serve as an important foundation for future work in the field. Findings from field testing indicated that the model has acceptable reliability, validity, and responsiveness to change. It could be used to guide the delivery of services and to evaluate and enhance programme functioning with the purpose of improving education and care.

7.1.1 DISCUSSION OF THE ASSESSMENT PHASE

7.1.1.1 Self-management education needs and perception of health

The participants in this study were both male and female, but the majority were female. Most of the participants were between 18 and 45 years old. The findings were congruent with previous studies conducted on PLWHA. The majority of the participants finished their formal education with a low level of knowledge and skills which is likely to affect their ability to compete for jobs

in urban areas. This can also explain why they have remained in the semi-rural areas. The study reveals that more than half of the participants reported having some difficulty living with their HIV/AIDS, while one third found it difficult or very difficult. This conforms to Sukati et al (2005: 186), who report that “living with HIV/AIDS poses difficult challenges for infected persons ... due in part to the progressive development of HIV-related symptoms”.

Complementary therapies and alternative medical practices are one way that people with HIV can apparently increase their control of illness (Foote-Ardah, 2003). A survey of PLWHA in Australia found that over half of the respondents were using at least one form of complementary or alternative medicine and the majority were taking antiretroviral therapy for HIV at the same time (Grierson, Thorpe, Saunders and Pitts, 2004). The types of complementary alternative medicine practices used included vitamin and mineral supplements, herbal medicine, traditional Chinese medicine, homoeopathy and physical therapies such as chiropractics massage and shiatsu (Grierson et al., 2004). An unexpected finding in our study was low reported use of complementary alternative therapies. This finding may reflect lack of understanding of the terminology or may be due to taboos, secrecy, and reluctance of patients to explain.

A large proportion of the participants desired medical care, which was expressed as a need for effective therapies, experts, access to care, and collaboration with care providers, “reflecting the view that if the disease were removed or suppressed then the needs arising from the disease would be diminished” (Forbes, While and Taylor, 2007). While there was a trend towards suggesting that availability of medical care was important to the self-management of PLWHA, there may be more benefit from the self-care which anticipates serious illness.

Finding permanent, decent housing is one material need highlighted by some of the participants. It is likely that pressures experienced by PLWHA as they rent houses from private owners and share services with their neighbours compound their problems. Even family members may isolate their close relatives who are living with HIV/AIDS, so that the need of PLWHA for shelter becomes crucial.

Professional counselling and psychological support to mitigate the stress resulting from HIV/AIDS was highlighted. In relation to the psychosocial needs of PLWHA, concern for the future of their children was also emphasised.

Participants also express the need for knowledge about HIV/AIDS and its treatment. This can be explained by the fact that “patients need more information regarding their diagnosis and treatment in order to develop effective symptom management strategies” (Sukati et al., 2005). Previous studies have shown that HIV/AIDS service providers perceive the information needs of their clients as falling into two broad categories: medical information needs and social service information needs (Hogan and Palmer, 2005), but none examines the self-management needs of this group, which was the intent of this study. Community education relating to acceptance of PLWHA and campaigns to de-stigmatize HIV/AIDS need to be adopted by the appropriate government bodies. Any effort towards achieving this should be viewed a response to one of the unmet needs of PLWHA.

Previous studies concerned with the identification of physical care and support report that “the disability experience of persons with HIV/AIDS has shifted from issues related to physical well-being to those concerning performance of daily life activities and broader community participation and living longer with HIV/AIDS, [which] often means dealing with impairments, activity limitations and participation restrictions that range from moderate to severe (Anandan, Braveman, Kielfner and Forsyth, 2006; Rusch, Nixon, Schilder, Braistein, Chan, and Hogg, 2004). Also under the physical care category, participants identified needs for others to assist them with activities of daily living, home-based care and provision of legal advisory services.

Psychosocial care was perceived as a priority for PLWHA, who experience discrimination and/or stigmatization from almost everybody around them and a host of social problems. These call for further exploration to determine the nature of the psychosocial problems experienced, as this will inform the content of psychosocial support that will be provided for PLWHA. The self-management needs of PLWHA require a multidisciplinary approach, establishing formal alliances and networks across the health care continuum; this could generate opportunities to integrate self-management into AIDS care initiatives.

For nurses to be able to meet the immediate needs of PLWHA where resources are scarce and healthcare facilities limited, areas of need should be identified and considered, in relation to current emphasis on disease-modifying therapies and medical care. Nurses have the capacity to promote the health and well-being of PLWHA because of their expertise and closeness to patients; understanding their self-management needs will enable appropriate interventions, preparation for discharge from hospital care and evaluation of health promotion activities.

Combining self-reported needs with physical evaluation will guide future self-management education interventions and practice. The wide-ranging self-management needs reported by PLWHA during my intervention opened new challenges for health care professionals and programme developers. I believe that this study will contribute to the knowledge base on care and management of PLWHA in resource limited semi-rural African settings.

7.1.1.2 Preferred methods of learning and barriers to participation in HASMEP

Participants indicated multiple preferred methods of learning. The most frequently marked were in-clinic pamphlets and handouts, in-clinic group classes on appointment days, individual telephone calls and classes on scheduled days and the clinic bulletin board. The least preferred methods were the computer resources and group classes outside the clinic.

Participants' preferred methods of learning are likely to have been influenced by a range of factors such as: the stage of the disease and their health status, socioeconomic status, literacy level, access to internet facilities, and age. Patients at different stages of disease progression may have different learning needs and preferred methods (Mendias and Paar, 2007). In a previous study of internet use by PLWHA, more than half of the participants reported interest in electronic learning strategies and 47% of the participants reported using the internet for health-related purposes during a 3-month period (Kalichman et al., 2005). This suggests that the choices of the patients participating in my intervention were influenced by the fact few of them had internet access.

Barriers indicated by the majority of the participants include fears concerning confidentiality, inconvenient hours at which classes are offered, and too great duration of instruction, distance from the clinic and transport costs. Barriers indicated in this study are similar to those identified in previous studies (Balamurugan, Rivera, Jack, Allen and Morris, 2006, Jordan and Osborne, 2007).

7.1.1.3 Health-related quality of life (H-RQOL) of participants before division into Groups A and B.

The majority of the participants reported decreased social, emotional, functional and physical well-being, as reflected by the low mean score for all the eight domains of SF-36. The participants attained low scores in all eight domains, with the lowest score on physical functioning. HRQOL is of great significance across the whole spectrum of the human health continuum. Studies have shown that the assessment of quality of life not only sheds light on the experience of people with acute illnesses, but may be of particular importance to people who suffer from chronic diseases (Vosvick, Koopman, Gore-Felton, Thoresen, Krumboltz and Spiegel, 2003; Phaladze, Human, Dlamini, Hulela, Hadebe, Sukati, Makoe, Seboni, Moleko and Holzemer, 2005; Tangkawanich, Yunibhand, Thanasilp and Magilvy, 2008; Skevington, Norweg, Standage and THE WHOQOL HIV GROUP, 2010; Postard, Chasany, Lavignon, Costagliola and Spire, 2010; Robberstad and Olsen, 2010). (Möller and Smith, 2004) have compared the HRQOL of PLWHA with that of with that of police on active duty “It was found that statistically significant differences existed in respect of their scores on all eight of the SF-36 domains” (Möller and Smith, 2004: 31)

The measurement of HRQOL is a subjective assessment of one's well-being - a perception of the degree of contentment with and capability to control all the facets of one's life (Molassiotis, Callaghan, Twinn and Lam, 2001). In order to have an effective self-management education programme for PLWHA, their HRQOL needs to be addressed as well as other determinants of health. In my intervention, the mean score of 27.65% on the physical functioning scale showed that participants were experiencing serious limitations and reflected perceptions of how their quality of life is influenced by their physical condition. Physical functioning refers to the extent to which the participants are able to perform vigorous activities such as running, lifting heavy objects, participating in strenuous sports, climbing flights of stairs and walking more than a kilometre. It entails the performance of moderate activities such as bending, kneeling and stooping, bathing and dressing themselves. The inability to perform roles often leads people to question the value of their lives (Sherman, 2001). A mean score of 40.06%, for emotional roles limitation gives an indication of the extent to which the emotional condition of participants limits their daily functioning, resulting in cutting down on the amount of time spent on work or other activities and accomplishing less than they would like to.

When PLWHA report their experience of physical change, there is usually a parallel cycle of emotional alterations (Möller and Smith, 2004). Uncertainty becomes a chronic and pervasive source of psychological distress, particularly as it relates to ambiguous symptom patterns, exacerbation and remissions of symptoms, and the fear of stigma and ostracism. Such uncertainty is linked to negative perceptions of quality of life and poor psychological adjustment. As a result, PLWHA are at risk for psychological disorders such as depression and anxiety. (Sherman, 2001:8). Engagement in self-management programmes will provide PLWHA with

emotional support, helping them to redefine their situation and develop emotional and problem-oriented coping strategies, which may contribute to a more positive experience of life. Social functioning refers to social activities and interactions with significant others such as family members, friends and neighbours.

The scores indicate to what extent the respondents' experience of bodily pain hinders their performance of daily activities, including work-related duties in the public domain and tasks within the home environment. The experience of bodily pain influences PLWHAs' social functioning and emotional condition. Provision of support to people living with HIV/AIDS will improve their mental well-being, and may further enhance their social functioning.

7.2 DISCUSSION OF THE IMPLEMENTATION AND EVALUATION PHASE

Model evaluation is a process of uncovering structures and the ways in which concepts are related without judging them, without involving our own beliefs and biases, without imposing our own view of the world on to the theory under analysis as far as possible (Theofanidis and Fountouki, 2008). It will allow for a decision as to how useful a theory is for practice, education and research.

7.2.1 Product evaluation

My study has focused on the experiences of PLWHA who participated in a self-management education programme and the impact of their participation on their lives. The post-intervention results were encouraging, considering the benefits the participants stated they received from participation as reported in this study (see Ch 6, pp 196 - 200). According to HRSA HIV/AIDS

Bureau (2006) for PLWHA to be effective self-managers, they must learn about their HIV/AIDS disease, develop effective communication skills, actively partner with providers in decision-making. They must also practice action-planning and problem solving, self-monitor their symptoms and follow treatment directions, seek expert medical care and advice, use family peer community support resources. Finally they must maintain emotional and psychological balance; and practice health-enhancing behaviour. “Increasing evidence shows that self-management support reduces hospitalization, emergency department use, and overall managed care costs” (Coleman and Newton, 2005: 1503). Self-management education complements traditional patient education in supporting patients in their efforts to live the best possible life with their chronic condition. A central concept in self-management is the self-confidence to adopt and persist in behaviour necessary to reach a desired goal.

The experiences of PLWHA in this study suggests that self-management education does impact on participants’ behaviour and health care, and this is consistent with literature about translating research into practice to improve their quality of life and well-being. Evidence from my study suggests that self-management education promotes the active involvement of PLWHA in health promotion activities and improves their emotional well-being as well as their willingness to seek information from healthcare providers..

As a result of their experiences, PLWHA can contribute to better understanding of the needs of other PLWHA and best practices in HIV care programmes. PLWHA are often the best counsellors and educators for others who are HIV-positive and their families, particularly with regard to treatment literacy and symptom management (Thorpe, 2008; Majumdar and Mazaleni,

2010; Campbell, Beer, Wilkins, Sherlock, Merrett and Griffiths, 2010). PLWHAs' involvement in making personal health care decisions and in managing their own care in partnership with their health care providers is widely recognized as having positive effects on their health outcomes and on positive health promotion and disease prevention behaviour. Experience has shown that PLWHA provide a critical and necessary perspective on the development, implementation, and evaluation of programmes and services that are designed to meet their needs (UK Department of Health, 2006).

All care and treatment programmes therefore must make a concerted effort to recruit PLWHA and support leadership roles for them. Support for all PLWHA is important to maintaining an effective health-care delivery to this group of people. This support should address economic and subsistence needs of PLWHA, education and skills development, recognition and access to HIV care (Pearson et al., 2007).

Information about the benefits of self-management education programme and evidence on the impact of such programmes is necessary to convince both PLWHA and professionals of the worth of programmes (Kennedy, Gately and Rogers, 2004). Up to the present time, trials have not provided evidence of the generalizability of the programme, given that men and minority ethnic groups are greatly under-represented in most studies (Warsi et al., 2004; Sheikh, Netuveli, Kai and Panesar, 2004) My own study suffers to an extent from the small number of males who were willing to be involved; the type of encouragement which would persuade them to volunteer should be investigated.

The findings of my study provide evidence that self-management education interventions impact on the self-management behaviours and health care of PLWHA. The study supports the effectiveness of self-management education in improving the health and well-being of PLWHA, even in a resource limited semi-rural setting. The study also provides critical information about the effectiveness of the self-management education programme and information about the extent to which PLWHA can achieve and sustain productive participation.

Implications for the future management of PLWHA in poorly resourced areas of rural South Africa emerge from this study. Using self-management intervention in clinical practice provides continuing personalized guidance that enables PLWHA to exercise control over their condition, enhances disclosure and utilization of health care facilities. It is a clinic-based programme that does not require any special facilities or equipment, other than premises for group meetings tailored along the clinic days.

The conceptual model permitted the emergence of the PLWHA into the health arena as people who understand the world in which they must live, who know how to be agents, who show knowledge, and who reveal the mechanism of health and disease in their vital space. The participants can now become autonomous, wishing to establish interpersonal relations with professionals, sharing health care decisions in partnership.

In a self-management programme, the preponderance of AIDS care and management occurs in the PLWHA's residence and is given by the affected individual and informal care givers, who are often quite separate from healthcare professionals. As a result, self-management has emerged

as a critical component of care for PLWHA. Post-intervention measurements revealed a statistically significant improvement in domains of health-related quality of life of the participants. In my own intervention, there is a statistic difference between Groups A (intervention) and B (comparison) in terms of their mean scores for physical functioning (PF), vitality (VT), general health (GH), limitations in role due to physical health (RP) and limitations in role due to emotional problems (RE). There is no statistically significant difference between the groups' post-intervention scores in terms of mean scores for social functioning, mental health and bodily pain.

My study demonstrated that self-management education impacts positively and significantly on the mean CD4 cell counts and health-related quality of life of PLWHA. The mean CD4 cell counts increased over the period in both groups but the change in mean CD4 cell counts scores deviate significantly from each other. Not only did the health-related quality of life of PLWHA not deteriorate during the course of the study, but it demonstrated progressive improvement in both groups. This is probably due to the fact that both groups are on HAART. My findings are consonant with previous studies, where it was reported that emotional and other forms of support received by patients for maintaining medication schedule can enhance the efficacy of HAART and are useful explanatory variables in the models for CD4 cell counts and quality of life indices (Bhargava and Booysen, 2010).

The results indicate that the use of comprehensive self-management education is important for devising cost-effective policies for improving the health status and quality of life of PLWHA especially in resource-limited rural communities. Healthcare infrastructure and emotional

support are predictors of CD4 cell counts and quality of life indices of patients on antiretroviral treatment (Bhargava and Booysen, 2010).

Higher CD4 cell count is associated with better quality of life, and suggests that CD4 cell counts are likely to be useful measurements for PLWHAs' health status and well-being. The study shows that there is a direct positive relationship between CD4 cell counts and HRQOL among people living with HIV and AIDS after a self-management education intervention.

Pre-intervention measurement reveals that the majority of the participants reported decreased social, emotional, functional and physical well-being as reflected by the low mean score for all the eight domains of SF-36 (Table 5.8). The participant attained low scores in all eight domains with the lowest score on physical functioning. In order to achieve an effective self-management education programme for people living with HIV/AIDS, their health-related quality of life needed to be addressed as well the broader determinants of health.

My study provides useful information on the impact of self-management education programmes on CD4 cell counts and health-related quality of life of PLWHA. It also provides background knowledge about CD4 cell counts as correlates of health-related quality of life of PLWHA in semi-rural KwaZulu-Natal province, as a context for designing self-management education programme evaluation.

The evaluation used qualitative and quantitative approaches. The qualitative evaluation shows how participants perceive and feel about the programme. It provides insight into how competent

the participants perceived themselves to be after the completion of the programme, and information on whether the participants had acquired the expected competencies. The qualitative evaluation results demonstrated that participants showed significant improvement in their health status through acquisition of self-management skills, health practices, and communication with healthcare providers.

The data on participants' CD4 cell counts were obtained from the clinic records at baseline and at 24 weeks after the intervention and comparisons were made, between the average means after the intervention, using the data available on all participants in both groups. Body weight and haemoglobin concentration were not considered for this study though they constituted part of routine check-ups at each visit. The mean CD4 cell counts increased over the period of investigation; paired t-tests for difference between Groups A and B were statistically significant ($p < 0.05$) for these variables.

7.2.2 Guidelines for Implementation of HIV/AIDS Self-Management Education

The self-management programmes for PLWHA in developed countries have been in existence for at least two decades longer than those in African countries. A recent review of literature revealed variations in the design of self-management education interventions even in developed countries. While there were some disease-specific models described, there were no standards to guide HIV/AIDS self-management education programmes. It was nevertheless useful to extract relevant lessons from the American Association of Diabetes Educators (AADE) for African countries. I learnt important matters from the developers of 'The National Standards for Diabetes Self-Management Education' (Funnell, Brown, Childs, Haas, Hosey, Jensen, Maryniuk, Peyrot,

Piette, Reader, Siminerio, Weingner and Weiss, 2008) since these standards were also disease-specific.

The guidelines are hereby listed as follows:

1. *The HIV/AIDS Self-Management Education should be need-based, goal-directed and outcome-focused.*
2. *The HIV/AIDS Self-Management Education should have documentation of its organizational structure, mission statement, and goals and should be recognize as an integral component of HIV/AIDS care.*
3. *The HIV/AIDS Self-Management Education entity should determine the self-management educational needs of PLWHA and identify resources necessary to meet these needs. Demographic variables, such as ethnic background, age, formal educational level, literacy, and barriers to participation in an educational programme should also be considered to maximize the effectiveness of HIV/AIDS Self-Management Education.*
4. *An individual assessment and education plan should be developed collaboratively by the participants and health professionals to direct the selection of appropriate educational interventions and self-management support strategies. This assessment of an education plan, the intervention and the outcomes should be documented in the education record.*
5. *A written curriculum reflecting current evidence and practice guidelines, with criteria for evaluating outcomes, should serve as the framework for the HIV/AIDS Self-Management Education entity. Assessed needs of PLWHA should determine the curriculum content. Practical problem-solving skills, collaborative care, psychosocial issues, behaviour change, and strategies to sustain self-management efforts should be emphasized.*

6. *A facilitator should be designated to oversee the planning, implementation, and evaluation of HIV/AIDS Self-Management Education. The facilitator should have academic or experiential preparation in chronic disease care and education and programme management.*
7. *HIV/AIDS Self-Management Education should be provided by members of the team responsible for designing the curriculum and assisting in the delivery. The team should include the facilitator, the technical staff, and PLWHA.*
8. *The HIV/AIDS Self-Management Education entity should appoint an advisory group to promote quality. This group should include representatives from the health professions, PLWHA, the community, and other stakeholders. Some academic staffs in the School of nursing, and nurse clinicians read through the manuscripts of the manual and make suggestions on how to improve it.*
9. *A follow-up plan for ongoing self management education and support should be developed collaboratively by the participant and the team members. The patient's outcomes and goals and the plan for ongoing self-management education should be communicated by the referring provider.*
10. *The HIV/AIDS Self-Management Education entity will measure attainment of patient-defined goals and patient outcomes at regular intervals, using appropriate measurement techniques to evaluate the effectiveness of the educational intervention.*
11. *The HIV/AIDS Self-Management Education entity should measure the effectiveness of the self-management education programme and determine opportunities for improvement, using a written continuous quality improvement plan that describes and documents a systematic review of the entities' process and outcome data.*

7.3 PRESENTATION OF THE EMERGING MODEL

7.3.1 The description of the model

My model asserts that successful implementation of self-management education is a function of the interplay of six core elements: self, the context in which the programme is to be placed, recognition of persons to be educated, the facilitation process, consciousness-raising and empowerment. Thus, a successful implementation of self-management education programme seems to occur when it is person-centred; the context is receptive when there is appropriate facilitation of the change, using a complementary partnership to improve the skills of both PLWHA and their healthcare providers. Representation of the elements in the model may be used to help self-management programme managers to structure their implementation strategies.

The model clarifies some of the theoretical positions which serve as a checklist for staff to assess what they need to do to implement self-management education programmes successfully, even in poorly resourced semi-rural settings. The model explicitly takes into account the wider organisational, managerial, and other influences working upon the local situation. It also encourages healthcare providers to consider facilitation processes in providing guidebooks and other supports for PLWHA undergoing change. The model can be used to explore some of the more complex theoretical positions around implementing self-management education and as a self-assessment tool for staff to judge what they have to do to successfully implement self-management education programmes.

Although the essential function of care is to meet the immediate needs of persons living with HIV/AIDS and related illnesses, a model for HIV/AIDS care should also be viewed in terms of its long-term and wide-reaching benefits. The model that emerges is goal directed and outcome-focused. In Ch 3 the characteristics of the self-management education processes were discussed and all these can be clearly distinguished in the model.

The ultimate aim of the model was to guide HIV/AIDS self-management educators and policy makers in implementing HIV/AIDS self-management education in semi-rural KwaZulu-Natal province. While the development was based on existing models and self-management programme approaches, the emerging model is unique in the sense that it is based on the strengths of developmental process and the competency approach taking into consideration semi-rural context which is not the case with other models. Developmental processes of: self-recognition, self-understanding, recognition of self-management needs, acquisition of self-management skills, increased in knowledge of self-management strategies and disease condition. The participants develop competencies in self-managing the condition as he or she put into practice the acquired skills. The model was designed to be used by service organizations and the intent was to make it usable in settings that did not have adequate resources to devote to comprehensive care for PLWHA.

The model provides a foundation for understanding the HIV/AIDS self-management education programme. The activity of each individual participant and the facilitator consists of discrete elements that can be analyzed, combined, and summarized to provide information that describes the activity and outcomes of the programme. The self-management education programme data

can then be aggregated, and analyzed. This aggregate data can provide information and knowledge for understanding the effectiveness of HIV/AIDS self-management education programmes and defining what interventions contributed to best practice.

7.3.2 An overview of the emerging model

The model assumed PLWHA's engagement in self-management activities is a function of their predisposition to collaborate with healthcare providers, self-reported health status, perceived levels of stigmatisation and self-management needs, as well as self-regulatory mechanisms determined by predisposing, enabling and reinforcing factors which may affect their engagement positively or negatively. The vectors of explanatory variables included in the model are self-management and education needs, preferred method of learning, readiness and willingness to learn, and perceived barriers to engagement in self-management education programme.

The model corresponds to the three defined domains of care coordination programmes: baseline assessment of the patient care situation (input), coordination mechanisms (process) and outcomes of care (Shonjonia et al., 2006). A needs assessment was conducted for the participants as a group at baseline using instrument 1 (appendix 5), searching for the predisposing, enabling and reinforcing factors within the individual and the environment which could be used during facilitation process. Baseline assessment provides information on the vectors of explanatory variables: needs, preferred methods of learning and possible barriers to implementation of the programme. Information obtained was used to determine the nature of interaction with PLWHA and the process of self-knowing, self-understanding and self-development embedded in the facilitation process.

The interplay of the components of the model results in identification of necessary behaviour change, acquisition of knowledge and skills and confidence in self-managing. Central to this model is the effect of the various concepts on treatment outcomes. The model emphasises improving treatment outcomes including adherence to antiretroviral medication. The arrows represent the relationships between various concepts in the model (See figure 7.1).

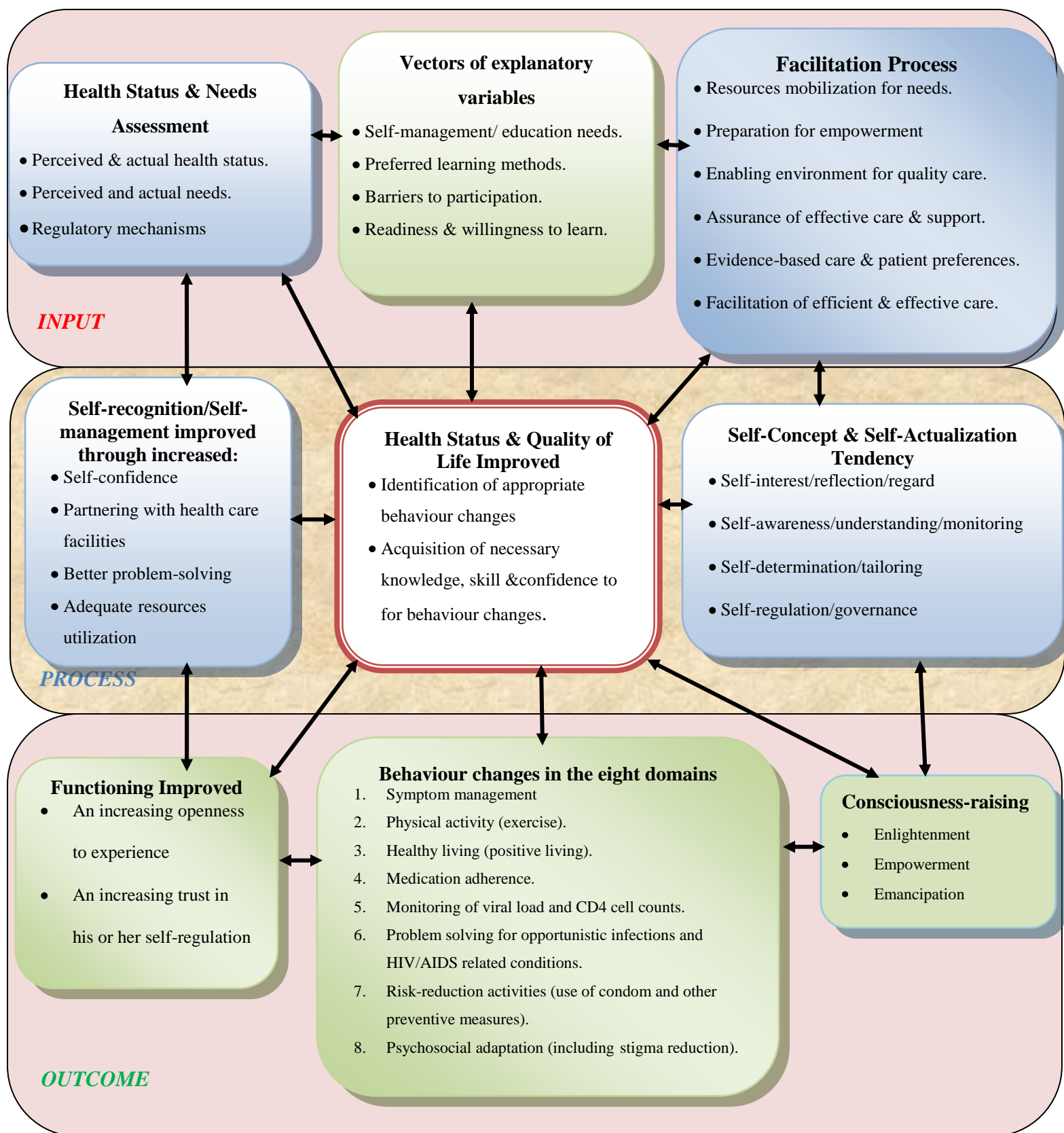


Figure 7.1: Model for implementation of HIV/AIDS Self-management education

7.3.3 The goal of the self-management education programme

The ultimate goal of my self-management education programme was to improve overall health status and quality of life by assisting PLWHA in identifying appropriate behaviour changes necessary for self-management, and in acquiring knowledge, skill, and confidence to make these behaviour changes.

7.4 ELEMENTS OF THE MODEL

7.4.1 The Context

The context is the environment in which the proposed changes are to be implemented. It implies an understanding of the forces at work which give the physical environment a character. This model was developed in a semi-rural setting in KwaZulu-Natal province, where resources are scarce and health care facilities and personnel are limited. This means that the model is suitable for use within the South African Health Care System. It has been developed to fit in with the District Health System, which was deemed by the South African Government to be the most appropriate vehicle for primary health care, and represents the decentralization of health care, which is consistent with the overall policy.

Within the South African context 80% of the population is dependent on the government for health care. There is no government social insurance system. At the end of 2007, there were approximately 5.7 million PLWHA in South Africa, and almost 1,000 AIDS deaths every day (UNAIDS, 2008) in a population of about 43 million. This is a big burden for the Government to carry. The other 20% of the population are on Medical Aids (private insurance schemes often subsidised by employers) and those who can afford to utilize private facilities for health care do

so. Although ARVs have become available to PLWHA, coverage is still limited, hence the emphasis on self-management education and support for PLWHA.

7.4.2 The Target

The target is PLWHA residing in the semi-rural setting who depends solely on government health care facilities for maintenance of their health care.

7.4.3 The Objectives of Self-Management Education

The objectives of the self-management education were to:

1. Explicitly involve PLWHA as active participants in their health care
2. Facilitate acquisition of skills and knowledge necessary to collaborate with their health care providers and implement treatments effectively
3. Enable PLWHA to develop the confidence to put their skills and knowledge into practice.

7.4.4 The Provisions of the Self-Management Education Model

The model provides a means for creating appropriate opportunities, policies, and environments to facilitate self-management. It includes education in self health care; food production, storage, and preparation; understanding human relations, stigma reduction strategies, creating a sense of self-worth, and human rights, and knowing how to participate in health care delivery. The self-management education model seeks to help PLWHA to recognize their inert power, and use this power responsibly—develop an internal locus of control and self-efficacy, and hence learn behaviours that contributed to overall health and health related quality of life.

The self-management education model allows the PLWHA to initiate policy change as they become knowledgeable and capable of utilizing the available health care resources. It helps PLWHA to achieve the desired improved HRQOL through managing their health at the primary health care level in order to develop and sustain improved quality of life and overall health.

The main provisions of self-management education and support are:

1. Education, sanitation, safe water supplies, food storage and preparation, ventilation, and basic cleanliness, including personal hygiene, formed a primary part of the self-management education. The second part includes knowledge about HIV/AIDS, use of medication (ARVs), management of drug side-effects, prevention and management of opportunistic infections, understanding of laboratory results, monitoring of biological markers such as CD4counts and viral load, reproductive health and symptom management.
2. The empowerment of PLWHA through group work and social support, focusing on predisposing, enabling and reinforcing in order to address poverty; increased access to health care, and the overcoming of cultural obstacles to health care.
3. My support strategy emphasised helping PLWHA to utilize health services and make choices regarding healthy behaviour through support seeking strategies and networking with health care agencies and welfare organisations.

7.4.5 Structure of the Model

The structure includes the configuration of the HIV/AIDS self-management education team and methods for delivering the self-management education programme. This structure evolves from the overall mission of the South African healthcare system, the programme design, and the curriculum which I adopted. HIV/AIDS self-management education was provided in individual

sessions, group classes, and a combination of these formats, where appropriate. The frequency of contact between participants and education facilitators and the details of the intervention provided were guided by programme design, referrals, organizational limitations, and participants' needs.

The key team members involved were myself as HIV/AIDS self-management educator; the technical staff (These were PLWHA who had matriculation and who were active and positive in their approach to HIV/AIDS); and PLWHA. Participants and facilitators bring to the team a variety of backgrounds in culture, education, life experience, health beliefs, skill, learning capabilities, and physical and economic limitations. Self-management education was provided in terms of these variables that may direct the outcomes.

The primary process of the intervention included clinical management. Secondly, I began the process of facilitation of patient self-management. The HIV/AIDS self-management education process, clinical management, and participant are further described because they are key processes for the model.

The HIV/AIDS self-management education process as described in Ch. 3 includes individual assessment, advice, participants' consent, facilitators' assistance, arrangement, individual action plan, and evaluation; all these direct the selection of appropriate educational materials and strategies. Evaluation of the process, outcome and impact of the strategies provides information that drives the assessment process. The HIV/AIDS self-management education process is not linear but is cyclic: assessment, consent, assistance, participant cooperation, follow-up,

reassessment, evaluation repeated during the educational relationship. The model requires documentation of the participant's progress through the assessment plan, intervention, evaluation, and follow-up. This documentation provides information for reviewing adherence to practice guidelines and information on the quality of care.

Clinical management process includes complex sub-processes such as physical and psychosocial assessment to medication and dosage, complication monitoring, and risk-reduction activities. Various practitioners can perform these activities, depending on their professional preparation and qualifications. The extent to which the activities occur will vary with the setting. These activities have been categorized as the activity, the test,, or the referral of the participant to the appropriate provider for completion of the activity.

The components of the HIV/AIDS self-management education process are organized around the behaviour change domains. In most circumstances, these behaviour change areas can be assessed through self-reported information obtained from the PLWHA.

The guidelines (see pp.228-231) for HIV/AIDS Self-Management Education provided guides for the organizational structure of the HIV/AIDS Self-management Education model, identification of the target population and appropriate resources, performance standards and timelines for review, definition of the educational team and assurance of continuing education, and a written curriculum.

7.4.6 Propositions of the Model

1. Consciousness-raising involves a critical and liberating dialogue in which people discover the power imbalances within a society that contribute to their oppression as well as the hidden distortions within themselves that cooperate with an oppressive society.
2. Knowledge produced in consciousness-raising is experiential and contextual, that is, grounded in a particular life context, in bodies, in families, in communities, in culture, and in time.
3. Motivation is enhanced by helping PLWHA to see how habit changes are in their interest and their broader goals.
4. Personal goals, rooted in value systems, provide further incentives for positive health habits.
5. The sooner the PLWHA adopts self-management behaviour the better their health-related quality of life will be.
6. Self-knowing enhances self-management which in turn promotes health and well-being.
7. Facilitation promotes the confidence of PLWHA in adopting health behaviour that will lead to improved health and life.
8. Networking among health care providers enhances health seeking behaviours of PLWHA.
9. The more the time spent on self-management education and support, the greater the chances of improved health and quality of life.

7.4.7 Expected outcomes of the Model

The expected outcomes were:

1. Positive and active engagement in life
2. Health-directed behaviour
3. Skill and technique acquisition
4. Constructive attitudes and approaches
5. Self-monitoring and insight
6. Health service navigation
7. Social integration and support
8. Emotional wellbeing.

Three categories of outcomes result from the HIV/AIDS Self-management Educational process, participant self-management, and clinical management. These outcomes can be categorized as learning, behavioural, and clinical or physiological. The HIV/AIDS Self-management Educational process contributes directly to the learning and behavioural outcomes through the interaction of the participant with the educator who uses teaching and counselling strategies. The clinical management process contributes directly to the clinical or physiological measurements of viral load and CD4 cell counts and body mass index. These outcomes can be measured quantitatively and are influenced by many variables (see Ch 6.) They exist on a continuum from immediate to intermediate to long term. Immediate outcomes are those that can be measured at the time of intervention; intermediate outcomes result over time and require more than a single measurement, are sensitive to change, and therefore cause statistical change. Long-term

outcomes will result from the impact of multiple variables over an extended time and are beyond the scope of this study.

The behavioural and physiological measurements have been categorized as intermediate outcomes. Behavioural outcomes are the unique and specific outcomes attributed to the HIV/AIDS Self-management Education process and the participants' self-management process. The physiological outcomes result from an interaction between the HIV/AIDS self-management education process, participant self-management, and clinical management. Both the immediate and intermediate outcomes contribute to the long-term outcome of the AIDS care system: improved health status of the individual or population with HIV/AIDS.

In addition to behavioural outcomes, immediate outcomes of knowledge and skill acquisition need to be assessed as well as outcomes of improved physiological indicators and health status. While it is useful to collect outcomes data in each of the eight behaviour domains, at least one outcome area was to be tracked for each individual participant. Data on programme outcome measures were collected and reported. A valid set of indicators for the self-management education programme can be determined by linking indicators to the elements of this model, identified by Nolte et al (2006), which were set as the expected outcomes for the programme.

7.4.8 Purposes and Uses of the Model

The model provides a practical way for users:

1. To identify the guidelines that will be used as the basis for the implementation of the self-management education process.

2. To identify the different components of the guidelines, for example the assessment, process, administrative, and the quality assurance guidelines.
3. To recognize and understand the process involved in self-management education.
4. To identify which behaviour change mediators to examine; for example, which factors HIV/AIDS education facilitators should prioritize to facilitate behaviour change.
5. To make use of participants' reports for evaluation of each step before moving to the next step; in this way, the model allows for built-in quality assurance.
6. To identify the range of outcomes to be evaluated, how they related to one another, and a variety of measurement and analysis issues.
7. To defend the effectiveness of interventions and describe best practices.

7.4.9 Essentials of the Model

1. Simplicity: the steps are easy to follow and are easily understood by users. "A commonality in all efforts to evaluate and test a model is the aspect of the model's simplicity and comprehensibility" (Theofanidis and Fountouki, 2008: 18).
2. The duration: depends on participants' readiness to change their lifestyles (for example, immediately, in the next three months, in the next year, longer), and is ongoing during the educational relationship.
3. The implementation process involves documentation of the participant's progress through the assessment, plan, intervention, evaluation and follow-up.
4. The model provides a pragmatic approach for users because of its built-in flexibility. Facilitators are able to consider the specific context, while following steps to ensure that the implementation process works best.

5. It is cost-effective, since it promotes proactive management of conditions. It is a clinic-based programme that does not require any special facilities, or equipment. Group meetings are tailored in terms of clinic days. The intervention can serve large numbers of people simultaneously under the guidance of one implementer and his staff (see, note 3, p 239) who provide valuable health promotion services at low cost.

7.4.10 The Concepts of the Model

A theory should be broken into parts which are examined individually, and in relation to each other, and consequently the theoretical structure as a whole should be examined for validity and approximation to the ‘real world’ (Theofanidis and Fountouki, 2008: 17).

7.4.10.1 Assessments of personal and environmental factors

The context in this study comprised the personal and environmental factors that influenced the development of the model. The context is comprised of the factors within the environment and the person in whom the proposed change is to occur after programme implementation. It provides “an understanding of the forces at work which give the physical environment a character and a feel” (Kitson, Harvey and McCormack, 1998: 152). There are personal and environmental factors that must be in place to initiate and sustain change. According to Glanz, Rimer and Lewis (2002), the types of influencing factors include: (1) *Predisposing factors*, which motivate behaviour; including knowledge, attitudes, cultural beliefs, readiness to change and socio-demographic variables. (2) *Enabling factors*, which enable persons to act on their predispositions; including available resources (income), and services. (3) *Reinforcing factors*, access and adherence to antiretroviral medications, supportive policies (access to nutritional and

social support), assistance (support group and emotional caregivers other than healthcare providers), which come into play after changed behaviour, has been initiated; they encourage persistence of behaviour by providing continuing incentives. These factors are directly linked with all the other concepts in the model and gave an assessment of how each of the concepts was understood. The guiding framework discussed in Ch 3 was the driving force which brought about the change, and led to the development of the conceptual model.

7.4.10.2 Vectors of explanatory variables

The vectors of explanatory variables included in the model are treatment duration, self-reported health-status, perceived levels of stigmatisation and the need to keep one's HIV status a secret self-management and education needs, preferred method of learning, readiness and willingness to learn, and perceived barriers to engagement in self-management education programme. All these variables may impact positively or negatively on engagement in self-management education programme.

7.4.10.3 Facilitation process

Facilitation is a technique by which one person makes things easier for others (Heron, 1989). It describes the support required to help people change their attitudes, habits, skills, ways of thinking, and working. It has received particular attention within nursing quality improvement and clinical practice development initiatives (Morrison, 1992, Burrows, 1996).

A self-management education intervention requires recognition of the persons involved. *Recognition* is the process in which a nurse, interacting with a patient, gathers patient-based evidence, interprets patterns related to patient experience, rather than pre-existing knowledge and

generalisations, and consciously labels the phenomenon-based or patient-specific patterns (Steis et al., 2009).

7.4.10.4 Self-concepts

Self is the sole motivational construct in self-management education programmes. The ‘self’ develops through interactions with others and involves awareness of being and functioning. A psychological form of the actualizing tendency related to this “self” is the “self-actualizing tendency”. It involves the actualization of that portion of experience symbolized in the self (Rogers, 1959). Connected to the development of the self concept and self actualization are “need for positive regard from others” and “the need for positive self-regard” (Maddi, 1996). *Self-interest* is seen as the motivation for action; people become involved when they see that it will benefit them. In other words, people are willing to change when they believe it is in their self-interest. Love of self is a crucial ingredient in the progress toward self-determination and emancipation (Henderson, 1997), while self-acceptance is a prerequisite to personality change. *Self-monitoring* can be defined as awareness of symptoms that is enhanced through periodic measurements, recordings and observations to provide information for improved self-management. *Self-tailoring* is using self-management skills and knowledge and applying these to self as appropriate. It distinguishes self-management education from more traditional health promotion and patient education programmes. Self-tailoring is done by the individual based on the principles for changing behaviours and self-management skills. Patients who self-tailor must have the principles for making behaviour changes, as well as decision-making and problem-solving skills.

Positive regard from others and positive self-regard enhances self evaluation and congruence between self and experience, with full psychological adjustment as a result (Rogers, 1959). When significant others in the person's world provide positive regard,, the person introjects the desired values, making them his or her own, and acquires "conditions' of worth" (Rogers, 1959). Change emerges organically from the interactive process and the individual ceases to stigmatise him/herself through the process of self-examination, exposure of dominating ideologies and the subsequent actions taken by participants themselves to move towards a new way of being (McCabe and Holmes, 2009).

Piaget (1971) distinguishes two types of self-regulatory mechanisms: one regulates structure and the other regulates function. An analysis of these two mechanisms leads to the identification of principles of self-regulation and assists in the critical evaluation of the nature of autonomy. Structural regulating mechanisms, such as homeorhesis [self-maintenance on new principles], promote a dynamic equilibrium, whereas functional self-regulatory mechanisms such as homeostasis [maintenance of a status quo], sustain a static equilibrium. Existing self-regulatory mechanisms may achieve stability by maintaining a static equilibrium. Structural self-regulating mechanisms achieve a dynamic equilibrium through evolution with the environment (Piaget, 1971).

7.4.10.5 Consciousness-raising (see further on P 236)

Consciousness may be defined as the quality or state of being aware, especially of something within oneself, but also of external objects, states or facts (Henderson, 1997). *Consciousness-raising* refers to the process of increasing the state or quality of being aware, particularly as it

applies to issues of personal and political freedom and it has generally been defined as an educational engagement in which people recognize and articulate the social, political, economic, and personal constraints on their freedom and become empowered to take action to remove those constraints. Fonow and Cook (1991) emphasize the importance of personal and political outcomes of consciousness-raising as “emotional catharsis, academic insight and intellectual product, and increasing politicization and activism”. This process occurs in a tripartite, overlapping experience of enlightenment, empowerment, and emancipation. Each of these exists in dynamic relation to the others.

Consciousness-raising allows the PLWHA to initiate policy change as they become knowledgeable and capable of utilizing the available health care resources in self-managing. The self-management education facilitator seeks to help PLWHA to recognize their inert power, and use this power responsibly- develop an internal locus of control and self-efficacy, and hence learn behaviours that contributed to overall health and health related quality of life. Consciousness-raising is an association with the transformative power of education. It is the process of developing self-knowledge and self-awareness (Cranton, 2006). This definition also parallels the central process of transformative learning – becoming aware of and then questioning one's construction of meaning. The concept of consciousness-raising is critical to understanding transformative learning, since it provides the importance of an elevated awareness that transcends, or goes beyond, what we perceive as normal consciousness. In some situations, consciousness-raising is provoked by exposure to new information, knowledge, insights, or values, especially if they are discrepant with currently held meaning schemes.

According to Ellis (1994), feedback serves as a general cover term for the information provided by listeners on the reception and comprehension of messages. This author emphasises that in consciousness-raising activities the learners are not expected to produce the target structure, only to understand it by formulating some kind of cognitive representation of how it works. Therefore, effective learning requires feedbacks that are analytical, suggestive, and to come at a time when learners are interested in it. To lead to improved skills learners have opportunities to express ideas and get feedback from their peers. But for feedback to be most helpful to learners, it must consist of more than the provision of correct answers. And then there must be time for learners to reflect on the feedback they receive, to make adjustments and to try again.

Self-management education facilitator, however, provide them with guidelines and, more important, provide them with activities which encourage them to think about their situations and to draw their own conclusions on what works. The general term for activities of this kind is consciousness-raising. Learners are encouraged to observe their own situation, to draw conclusions from what they observed and to organize their view of the situation in the light of the conclusions they have drawn. The aim of consciousness-raising tasks is to construct a conscious representation of the target feature, with production of that feature kept to a minimum. Walter (2004) argues that effective learning involves processes such as: (a) Making connections about what has been learnt in different contexts; (b) reflecting on one's own learning and learning strategies; (c) exploring how the learning contexts have played a part in making the learning effective; (d) setting further learning goals; and (e) engaging with others in learning.

Empowerment is a state of feeling more powerful than previously existed, of feeling one has the ability to affect others and change social institutions. Empowerment and emancipation depend on the relations of power in a particular context, and result from techniques employed by facilitators and participants during the educational process (McCabe and Holmes, 2009). The empowerment that results from awareness of the current set of truths and dominating power structures encourages people to undertake actions to improve their situation (Manias and Street, 2001).

7.4.11 Relationships of the Concepts in the Model

For change to take place, these personal and environmental factors must be considered. It is important for the self-management educator to determine the circumstances within and outside the participants during the implementation of self-management education. People learn who they are and gain collective power to determine the direction of their lives, because human beings cannot be separated from their social and historical contexts; reality is not static but a process. PLWHA undergo an evolution of self, and gain a new knowledge of selves. They may then use this knowledge to move towards a new way of being, and gain functional autonomy.

The interplay between awareness, measurements and observations can enhance self-management by improving how individuals self-monitor or pay attention to their health. Similarly, during self-management interventions, evolution of self is activated through self-reflection prompted by the facilitators. Self-reflection leading to love of self is a crucial ingredient in the progress towards self-management. Engaging in a self-management programme allows the participant to use reflexivity to discover dominating discourses and power structures with the assistance of the

facilitator. By coming to know self, and gaining an awareness of rules of conduct, one can redirect one's activities.

During a self-management intervention, participants examine their own (and others) behaviour and beliefs against a set of pre-established norms. The participants undergo the process of evolution of self, and gain a new understanding which they may use to move towards a new way of being. This movement is the change process which the facilitator should be attempting to capture during the intervention. In functional self-regulation, change is predicated as contingent upon the environment, whereas in structural self-regulation, change incorporates the environment as essential to the evolution of the structure. These self-regulatory mechanisms must be structural in nature to assure authority connoting self-governance.

Enlightenment is the experience of coming to see oneself and one's place in society in a radically new way. People often experience enlightenment, empowerment, and emancipation as overlapping circles of insight and action that are the result of raised consciousness. Emotions are critical elements in the process of consciousness-raising in PLWHA. The health care provider must relinquish his pastoral power (an accepted authoritative expertise) and assume the status of a facilitator to provide an enabling environment for people to go through a process of self-exploration, self-discovery and self-regulation, motivated by an impulse towards self-actualization.

7.4.12 Boundaries of the Model

Networking: This model depends on the existence and efficiency of networks among all sectors concerned in the intervention.

Existence of the structures and services: the model presupposes the required structures and services such as ARVs roll-out centres and laboratory facilities for CD4counts and viral load investigations.

District healthcare services: This model is intended for use within the semi-rural South African context, an area with primary health care facilities. It is intended for use in a country where 80% of the population is dependent on the Government for health care.

Readiness: There must be readiness for change among PLWHA prior to self-management education and support, to prevent resistance to change.

Adequate funding: Availability of funding to support the systems change processes is very important for the success of the model.

Experts in self-management education: Availability of self-management education facilitators with the appropriate credentials who could lead and facilitate the systems change processes.

Community health providers: Availability of community health care providers to implement the model. Community health care providers should be equipped with the necessary leadership knowledge and skills for managing the change.

7.4.13 Basic Assumptions of the Model

The model assumes that the primary goal of HIV/AIDS education is to support the priorities identified by the researcher for behaviour change in any of the eight domains. The basic assumptions of the study are that:

- Effective management of HIV/AIDS requires a complementary partnership between health care providers and PLWHA.
- Engagement in self-management education will empower PLWHA to take a proactive role in managing their illness and improving their quality of life.
- Empowerment of PLWHA through self-management education will improve health-related quality of life of PLWHA and lead to reduction in healthcare cost.
- The role of healthcare providers is to help PLWHA function independently and take responsibility for their care.

7.4.14 General Contributions of this Study

The construction of a model from the relationships among its constituent concepts has resulted in a model that supports assessment, implementation and evaluation of self-management education programmes. The model demonstrates in a practical way how the self-management education intervention can be best implemented, and it offers to a self-management educator the opportunity to learn and develop an appropriate design.

The model emphasises the combination of professional roles with that of facilitators to enable capacity building among PLWHA. In practical terms, the model described can identify individual needs, promote the design of appropriate strategies, and allow attention to personal and environment issues. It can also be used as a framework for the evaluation of self-management education interventions, examining factors outside the traditional range of most training evaluation efforts, and can provide a more complete picture of the success or otherwise of that intervention. It is clear from the literature and from this research that a range of factors

affect the implementation of self-management education programmes. It is hoped that the presented model can help in a practical way by providing a focus and a consistent measuring system for self-management educators. Self-management educators must learn to conceptualize facilitation as a process for health behaviour change, and negotiate goals with PLWHA. They must identify capacity building and alliance building approaches, as well as target audiences, and measure the impact of these initiatives on health.

My self-management education programme has had positive impacts on PLWHA attempting to manage their health and lives. It is not only about disease management, but about human development, that is, social, physical, emotional, intellectual, environmental, and spiritual well-being of PLWHA. My HIV/AIDS Self-Management Education model integrates the key processes of HIV/AIDS Self-Management Education, participant self-management, and clinical management activities to produce outcomes of HIV/AIDS Self-Management Education and care. These outcomes are collected at the individual level and aggregated for programme level outcomes. The outcomes of multiple programmes are aggregated to provide a large repository of data for analysis and benchmarking.

7.4.15. Unique Contributions of this Study

The model that emerges from this study provides: (a) A more collaborative and participatory decision-making framework, in which the needs, interests and concerns of people living with HIV/AIDS (PLWHA) can be mediated. This new situation in my intervention created new responsibilities for PLWHA and healthcare providers. The focus of the self-management education programme is to enable PLWHA to gain the motivation and skills needed to self-

manage their conditions; (b) conducive conditions for the integration and mutual enrichment of experiential learning, socially relevant research, and enhanced person development-oriented healthcare services delivery in semi-rural KwaZulu-Natal, South Africa. A focus on human development in terms of social, physical, emotional, intellectual, environmental and spiritual well-being of PLWHA and not only about disease management; (c) supports, assessment, implementation and evaluation of self-management education programmes. It examined factors outside the traditional range of most training efforts to provide a complete picture of the success or otherwise of self-management education intervention. It reflects PLWHAs' central role in care and treatment, and stresses the use of self-management support strategies, including assessment, goal setting, action planning, problem solving and follow-up; and (d) a practical way of how self-management can be implemented even in a resource limited primary health care centre. It described how identification of individual needs can be used to promote the design of appropriate self-management strategies and advise self-management facilitators to pay more attention to personal and environmental issues of their clients. It emphasises the combination of professional roles with that of facilitators to enable capacity building among PLWHA.

7.5 LIMITATIONS OF THE STUDY

7.5.1 Using a quasi-experimental design

The study was carried out using a quasi-experimental design in which PLWHA in an intervention group (Group A) were compared with those in a comparison group (Group B), with both groups on standard care and only Group A receiving self-management education. The comparison group was exposed to health education. A disadvantage of this design is that it precludes final conclusions about the effects of an intervention, i.e. whether the differences

between groups are due to the intervention or to other unknown factors. The division into Groups A and B was done randomly, but as a researcher dealing with people who returned home and interacted with families and with their communities, I had to acknowledge that I had no control over the input they received outside of the intervention. Although isolation of participants might have produced a different quality of data, it would have been undesirable, even had it been possible, to quarantine PLWHA who must eventually return to their communities and cope with the forces within them. The strength of this study was the enhanced knowledge and skills of participants in self-management and detailed collection of data using mixed methods.

7.5.2 Using a single site imposed by gate-keeping in selected sites

Using a single site for the intervention I tried to keep the two groups separate during the intervention to prevent diffusion of self-management information, demoralization, and rivalry. Different venues were used for the meetings and the groups had their meetings on different days of the week. This was to prevent comparison groups from gaining access to self-management education intended for the intervention group through sharing of information (see Ch 4.). As recommended by the University of KwaZulu-Natal I completed online courses on research ethics, human subject research ethics for clinical researchers (see Appendix 3). These courses equipped me with knowledge and skills in clinical research. I identified potential threats to the internal validity of the interventions and designed them so that these threats were minimized.

7.5.3 Participants who dropped out of the project

Low drop out rates occurred. The seven participants who dropped out of the project, either had died (n=2) or were acutely ill when contacted (n=5). The oversampling by ten percent

compensated for this loss and the groups were still comparable. The study benefited from a relatively large sample size and was clinic based providing a high level of quality assurance.

7.5.4 Using self-reported behaviour as a measure of programme impact

The use of self-reported behaviour as a measure of programme impact may be seen as a limitation of this study. Critics of self-reported behaviour often query the veracity of reports. Self-reported changes have however been used extensively to obtain evidence of changes in clinical practice (Felderman-Taylor and Vaverde, 2007). Schwarz and Oyserman (2001) suggesting how to avoid pitfalls and to design surveys that will obtain reasonably valid responses; identify five steps: understand the question, recall relevant behaviour, infer and estimate, map answers to questions, edit the answer for social desirability and self-presentation. The investigators adopted methodology consistent with Schwarz and Oyserman's recommendations. Acknowledging the potential limitations, we can assume that the cognitive load was not too burdensome, given the quantity and richness of responses.

7.6 RECOMMENDATIONS

The recommendations for different stakeholders will be discussed separately.

7.6.1 Recommendations for health care providers

Self-management education has demonstrated its effectiveness in improving outcomes and costs associated with HIV/AIDS. A careful situational analysis and community participation in the planning process should be done to ensure that projects address the self-management needs of PLWHA comprehensively; and bring about lasting improvements in HIV/AIDS prevention and care efforts. It is important to understand the ways in which PLWHA can help them. Through

asking potential recipients of health promotion for their input, PLWHA respondents became empowered to be co-planners of their care, with opportunities to identify their own learning preferences and needs (Mendias and Paar, 2007). Providers should note that the self-management needs of PLWHA are complex and may vary over the course of their illness and along with the availability of quality healthcare infrastructures and services. Providers should conduct situational analysis and encourage the participation of PLWHA in the planning process.

The present results are promising enough to support continued investment in self-management interventions and attempts to improve them. Other channels, perhaps television, magazines and internet could be added to the intervention, depending on the context in which the participants live. However, the face-to-face contacts with health professionals and the self-management education handbook (in the vernacular used in the area) are still recommended as additional effective communication channels.

7.6.2 Capacity building for PLWHA

This new paradigm of self-management has sparked debates regarding the expected level of individual responsibility and the expectations that individuals demonstrate the capacity to manage their health and wellbeing (Peerson and Saunders, 2009). PLWHA should not be viewed as passive recipients of programmes; rather, they must be valued as critical actors in the HIV/AIDS response. They should be empowered to provide assistance to each other in the absence of state sponsored efforts. They should be provided with an enabling environment in order to create incentives and enlist social support for their efforts.

7.6.3 Recommendations for further research

Given the diversity of self-management needs among PLWHA, future research, incorporating a greater number of field trials, case studies or both, will be helpful in scrutinizing the self-management needs of PLWHA in order to identify commonalities in their experiences and to share collective concerns. The elements in the model may be used to help clinicians to think about their implementation strategies and the model may also be used to generate hypotheses to be tested in systematic ways.

Researchers should conduct studies on cost-effectiveness of self-management education programmes. Both the direct and indirect costs of self-management education programmes should be examined, and compared with the cost of standard health education. Researchers should work to improve the quality of self-management education programme for PLWHA using a computerized data system. Further study is needed about implementation and effectiveness of online self-management education programmes (Noar, 2011).

7.6.4 Recommendations for the South African health system policy makers

There is need for integration of self-management education into the care of people living with HIV/AIDS in South Africa. Four major things need to happen before self-management can be fully integrated: provision of guidelines, preparation of the health system, preparation of patients, and an adequate financial commitment from the state. The South African health system should consider the followings for successful implementation of self-management education for PLWHA in rural settings:

- Effective training and information for community health care providers, including informal care givers, to provide evidence on the effectiveness of self-management programmes.
- Provision of a suite of self-management education interventions that are flexible and cater for PLWHA needs.
- A standardized quality assurance and monitoring system to enhance confidence that programmes delivered are achieving valuable outcomes for PLWHA.
- Delivery of programmes at the local level (rather than through large institutions) to encourage community ownership and enhance sustainability.
- Provision of support services at community level and standardized referral processes across health system to improve coordination and access to programmes.
- Raising awareness among community members and health care professionals and fostering their confidence in the quality of the self-management education programmes.
- Encouragement of new levels of cooperation through pooling of funds and strategic planning between federal and province governments.
- Establishing formal regional alliances and networks across the health care continuum.

There must in the future be many new challenges for policy makers, but it is to be hoped that they will recognise that using self-management interventions in clinical practice provides the continuing personalized guidance that enables PLWHA to exercise control over their condition.

7.6.5 Recommendations for self-management education facilitators

YouTube is the user-generated content social networking site that can be accessed at any time and from anywhere. It is a repository for user-generated content including personal video clips, TV clips and music videos uploaded to the internet by individual members of the public. Clifton and Mann (2011) found that the use of YouTube videos increased student engagement, critical awareness and facilitated deep learning. YouTube is established social software and has millions of users and is already being used as both an informal and formal learning tool by many. The increase in availability of online access at home, wireless access and smart devices supports the use of YouTube.

There is a need for self-management education facilitators and their clients to be internet and information literate in order to benefit from internet teaching and learning resources. This should occur under the guidance of facilitators, to avoid unregulated content which is often misleading, inaccurate or biased. However, I strongly urge self-management education facilitators to consider suitable internet sites for teaching and learning.

7.7 Conclusions

This chapter discussed the development, implementation and evaluation phases of the model. The emerging model was presented; general and unique contributions of the emerging model were highlighted. The chapter rounded off with the recommendations and the limitations of the study.

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18 FEBRUARY 2010

MR. F D OMISAKIN (209506889)
SCHOOL OF NURSING
HOWARD COLLEGE CAMPUS

Dear Mr. Omisakin

PROTOCOL REFERENCE NUMBER: HSS/0772/09D

PROJECT TITLE: "Development of HIV/AIDS self-management education conceptual framework for people living with HIV/AIDS in Semi-Rural KwaZulu-Natal, South Africa"

FULL APPROVAL NOTIFICATION – COMMITTEE REVIEWED PROTOCOL

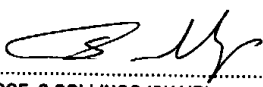
This letter serves to notify you that your application in connection with the above was reviewed by the Social Sciences & Humanities Research Ethics Committee in 2009, has now been granted full approval following your responses to queries previously addressed:

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study must be reviewed and approved through an amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol

Yours faithfully


.....
PROF. S COLLINGS (CHAIR)
HUMANITIES & SOCIAL SCIENCES ETHICS COMMITTEE

cc. Supervisor (Dr. BP Ncama)
cc. Ms. C Dhanraj
cc. Mr. S Reddy

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16 JULY 2010

MR. FD OMISAKIN (209506889)
SCHOOL OF NURSING

Dear Mr. Omisakin

PROTOCOL REFERENCE NUMBER: HSS/0772/09D
PROJECT TITLE: "Development of HIV/AIDS Self-Management Education Conceptual Framework for People Living with HIV/AIDS in Semi-Rural KwaZulu-Natal, South Africa"

FULL APPROVAL NOTIFICATION- AMENDMENT

This letter serves to notify you that your application for an amendment has been granted full approval. The documents reviewed and approved are:

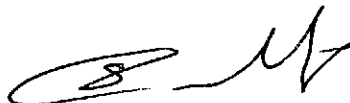
1. The new Settings: Danganya Clinic
2. The new Instrument: The SF-36

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol.

Yours faithfully



.....
**PROFESSOR STEVEN COLLINGS (CHAIR)
HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE**

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■ Howard College

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23 September 2011

Mr F D Omisakin (209506889)
School of Nursing

Dear Mr Omisakin

PROTOCOL REFERENCE NUMBER: HSS/0772/09D

NEW PROJECT TITLE: Developing, Testing and Refining of a model for implementation of HIV/AIDS Self-management education in a semi-rural area in KwaZulu-Natal, South Africa.

APPROVAL AND CHANGE OF DISSERTATION TITLE

I wish to confirm that ethical clearance has been granted full approval for the above mentioned project:

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number. **PLEASE NOTE:** Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol.

Yours faithfully

.....
PROFESSOR STEVEN COLLINGS (CHAIR)
HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

cc. Supervisor Busisiwe Ncama
cc. Mr Sugen Reddy

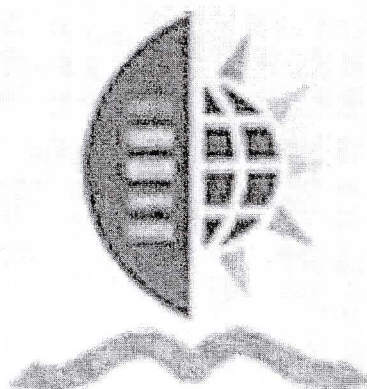


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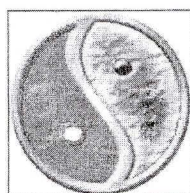
HEREBY ACKNOWLEDGES THAT

Mr Folorunso Omisakin

HAS COMPLETED A COURSE IN
RESEARCH POLICY V: RESEARCH ETHICS

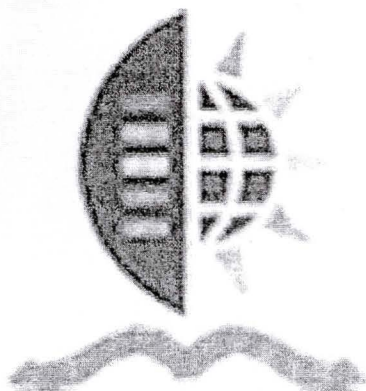
Completed On
15 - 9 - 2010

Valid Until
9 - 2013



THE FOLLOWING SUBJECTS WERE COMPLETED IN THIS
COURSE

- RESEARCH ETHICS POLICY
- CODE OF CONDUCT FOR RESEARCH



University of KwaZulu-Natal

HEREBY ACKNOWLEDGES THAT

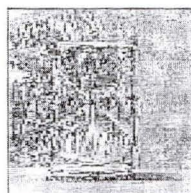
Mr Folorunso Omisakin

HAS COMPLETED A COURSE IN

Human Subject Research Ethics

Completed On
19 - 9 - 2010

Valid Until
9 - 2013



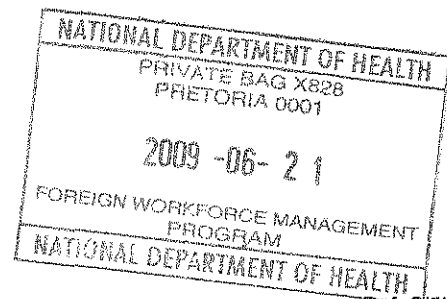
**THE FOLLOWING MODULES WERE COMPLETED IN THIS
COURSE**

Research Ethics in South Africa - An Overview
Guiding Principles of Ethical Research
Informed Consent
Research Vulnerabilities
Researcher Responsibilities



health

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Health
REPUBLIC OF SOUTH AFRICA



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Room 1125 Fedlife Building, Private Bag X828, PRETORIA, 0001

e-mail: voslos@health.gov.za

Folorunso Dipo OMISAKIN
University of KwaZulu-Natal
School of Nursing
Howard College Campus
Durban
4041

NATIONAL DEPARTMENT OF HEALTH ENDORSEMENT CERTIFICATE

PURPOSE OF APPLICATION: Postgraduate Studies

The following person may take up studies in South Africa subject to the conditions as contained in this certificate:

| | |
|--------------------------|-------------------------|
| APPLICANT NAME | Folorunso Dipo OMISAKIN |
| PASSPORT / PERMIT NUMBER | A00196851 |
| COUNTRY OF ORIGIN | Nigeria |
| DATE OF BIRTH | 17 March 1963 |
| RESIDENTIAL STATUS IN SA | Student |
| OCCUPATION | Professional Nurse |

The following conditions apply to the approval for support:

| | |
|---|--|
| INSTITUTION / DEPARTMENT | Education |
| PROVINCE | KwaZulu-Natal |
| HEALTH FACILITY | University of KwaZulu-Natal |
| RANK / POSITION | Student (PhD Nursing Degree) |
| REGISTRATION CATEGORY | Student Nurse |
| PROFESSIONAL COUNCIL | South African Nursing Council |
| APPLICABLE SECTION OF IMMIGRATION ACT 2002, AS AMENDED 2004 | Study Permit - Section 13 |
| DURATION OF PERMIT | Until 31 December 2010 |
| OTHER CONDITIONS | May pursue postgraduate studies May not seek or be offered employment subsequent to completing studies Must apply to the FWMP for endorsement prior to beginning further studies |

DURATION AND VALIDITY OF THIS CERTIFICATE:

Notwithstanding the conditions for support as listed above, this certificate is valid for six (6) months from the date of issuance. No amendments to this document are allowed in any way whatsoever and the document is issued without any alterations.

P ZULU

ACTING DIRECTOR: WORKFORCE MANAGEMENT

DATE: 21/06/2009

Applicant Signature: _____

Date: _____

DANGANYA CLINIC

Danganya, Department of Health, KwaZulu-Natal province, South Africa

LETTER OF APPROVAL OF PERMISSION TO CONDUCT RESEARCH

Dear Mr. Omisakin FD,

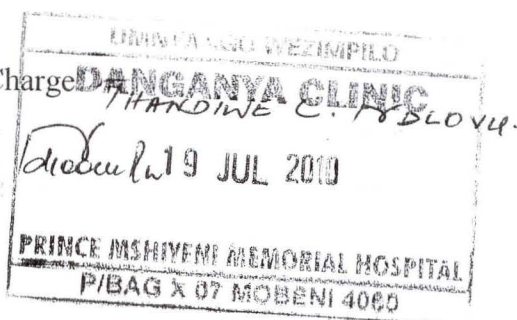
I am pleased to inform you that you have been given permission to conduct your research titled: "Development of HIV/AIDS Self-management Education Conceptual framework for People Living with HIV/AIDS in Semi-Rural Kwazulu-Natal, South Africa" in the above named clinic. You are allowed to use the clinic facilities provided that:

1. You will abide by the ethical principles as stated in your letter, and
2. Your research will not disrupt the routine activities of the clinic.

Please do not hesitate to contact me if you have any problem in the conduct of your study.

Accept my blessings.

Sister-in-Charge



26-10-2011

Dear Sir/Madam

A LETTER FROM THE STATISTICIAN

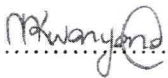
Re: Folorunso Dipo Omisakin (student number: 209506889)

Thank you for the opportunity to write this letter for the mentioned PhD nursing candidate.

This is to certify that I gave statistical advice and assisted Mr. Omisakin with data analysis in his project entitled "Developing, testing and refining of a model for implementation of HIV/AIDS self-management education in a semi-rural area in KwaZulu-Natal, South Africa.

Having checked for normality in the data using One-Sample Kolmogorov-Sminov Test, Non-parametric tests were used for the analysis of data where the scores were not normally distributed. These tests were appropriate for the type of data and the data analysis was correct.

Yours Sincerely,

.....


Ntombifikile Nkwanyana (Mrs.)

(UKZN- College of Health Sciences Biostatistician).

English Studies
Memorial Tower Building
Howard College Campus
University of KwaZulu-Natal
Durban 4041

To Whom It May Concern

Mr Omisaskin Folorunso's Ph D thesis was edited by me. My interventions were purely linguistic: I have no skills or experience in his field.



Margaret Lenta, Senior Research Associate and Emeritus Professor

Re: Application for permission to use Stanford questionnaire

From: Kate R Lorig <lorig@stanford.edu>

To: Folorunso Omisakin <209506889@ukzn.ac.za>

Date: Monday - April 27, 2009 10:14 PM

Subject: Re: Application for permission to use Stanford questionnaire

Attachments: Mime.822

all of our questionnaires for free to anyone to use so you may certainly use them. Let us know what you find. Kate

----- Original Message -----

From: "Folorunso Omisakin" <209506889@ukzn.ac.za>

To: self-management@stanford.edu

Sent: Monday, April 27, 2009 3:17:05 AM GMT -08:00 US/Canada Pacific

Subject: Application for permission to use Stanford questionnaire

Dear Sir/Ma,

I hereby apply for permission to use some of the questions from your questionnaire code book.

I am a PhD Nursing student in the School of Nursing, University of KwaZulu-Natal, Howard Campus, Durban 4041, South Africa. My thesis is on "Effectiveness of HIV/AIDS Self-management Education for People living with HIV/AIDS". I am prepared to share raw data and research outcomes with the Stanford research team and will also acknowledge the source of the Stanford tool in my work. I agree to provide a project summary and results at the completion of the PhD work. I look forward to your reply.

Regards,

Omisakin Folorunso Dipo

Please find our Email Disclaimer here-->: <http://www.ukzn.ac.za/disclaimer>

RE: Application for permission to use UCSF HIV/AIDS SymptomManagement Manual.

From: "Holzemer, Bill" <bill.holzemer@nursing.ucsf.edu>
To: "Folorunso Omisakin" <209506889@ukzn.ac.za>
Date: Tuesday - April 28, 2009 1:34 AM
Subject: RE: Application for permission to use UCSF HIV/AIDS SymptomManagement Manual.
Attachments: Mime.822

You are most welcome to use the manual. Bill

William L. Holzemer, RN, PhD, FAAN
Professor and Associate Dean, International Programs
Lillian & Dudley Aldous Endowed Chair in Nursing Science
School of Nursing, N531C
University of California, San Francisco
2 Koret Way
San Francisco, CA 94143-0608 USA
415 476 2763 work
415 476 6042 fax
bill.holzemer@nursing.ucsf.edu

From: Folorunso Omisakin [mailto:209506889@ukzn.ac.za]
Sent: Monday, April 27, 2009 9:43 AM
To: Holzemer, Bill
Subject: Application for permission to use UCSF HIV/AIDS Symptom Management Manual.

Dear Sir/Ma,

I hereby apply for permission to UCSF HIV/AIDS Symptom Management Manual:Strategies for PLWHA. I am a PhD Nursing student in the School of Nursing, University of KwaZulu-Natal, Howard Campus, Durban 4041, South Africa. My thesis is on "Effectiveness of HIV/AIDS Self-management Education for People living with HIV/AIDS". I am prepared to share raw data and research outcomes with your research team and will also acknowledge the source of the tool in my work. I agree to provide a project summary and results at the completion of the PhD work. I look forward to your reply.

Regards,
Omisakin Folorunso Dipo

Please find our Email Disclaimer here-->: <http://www.ukzn.ac.za/disclaimer>

RE: instrument for assessing self-care leaning needs of PLWHA.

From: "Mendias, Nonie" <nmendias@utmb.edu>
To: "Folorunso Omisakin" <209506889@ukzn.ac.za>
CC: "Paar, David" <dpaar@UTMB.EDU>
Date: Friday - March 20, 2009 9:20 PM
Subject: RE: instrument for assessing self-care leaning needs of PLWHA.
Attachments: Scan001.PDF; Mime.822

Good afternoon. Thank you for your noted about yourself and your planned study.

I am attaching a PDF file of the instrument I constructed and that my colleague, Dr. David Paar, and I used in our study referenced below. This questionnaire was specific to our population and study site, so has some details you might wish to change (such as county, etc.). However, you are welcome to use or adapt this to fit your needs for your dissertation study. Should you use it, we would ask that you: 1) credit us and our university; and 2) let us know how your study turned out (an abstract would be great!).

Best wishes to you in your doctoral program and your research area.

Elnora (Nonie) P. Mendias, PhD, RN, FNP-BC
Associate Professor
Jesse and Alicia Dunn Professor of Nursing
Distinguished Teaching Professor
The University of Texas Medical Branch School of Nursing
301 University Boulevard
Galveston, Texas 77555-1029
(O) 409-772-8258 (P) 409-643-3479 (Fax) 409-772-3770
nmendias@utmb.edu

From: Folorunso Omisakin [mailto:209506889@ukzn.ac.za]
Sent: Wednesday, March 18, 2009 3:18 AM
To: Mendias, Nonie
Subject: RE: instrument for assessing self-care leaning needs of PLWHA.

I am a PhD Nursing student in the School of Nursing, University of Kwazulu-Natal, Howard campus, Durban 4041, South Africa. I have just written a research proposal on "Effectiveness of HIV/AIDS Self-Management Education for PLWHA". While reviewing literature I found your article and the instrument very useful. I hereby seek for your permission for the release and usage of the instrument. I shall be grateful if you can send me the instrument and any related materials. This will facilitate my PhD thesis proposal. Thank you in anticipation and best professional regards. my cell no: +27735836337.

Yours Sincerely,
Omisakin Folorunso Dipo.

>>> "Mendias, Nonie" <nmendias@utmb.edu> 3/17/2009 2:14 PM >>>

Good morning. Could you please send me further information about why you are requesting the instrument? Thank you.

Elnora (Nonie) P. Mendias, PhD, RN, FNP-BC
Associate Professor
Jesse and Alicia Dunn Professor of Nursing

Distinguished Teaching Professor
The University of Texas Medical Branch School of Nursing
301 University Boulevard
Galveston, Texas 77555-1029
(O) 409-772-8258 (P) 409-643-3479 (Fax) 409-772-3770
nmendias@utmb.edu

From: Folorunso Omisakin [mailto:209506889@ukzn.ac.za]
Sent: Sunday, March 15, 2009 6:07 AM
To: Mendias, Nonie
Subject: instrument for assessing self-care leaning needs of PLWHA.

Re:Me dias and Paar .(2007).Perception of health and self-care learning needs of outpatients with HIV/AIDS,Journal of community health nursing,24(1),49-64. kindly send me a copy of the instrument used in the above study.

Regards,
Omisakin F.D.

Please find our Email Disclaimer here-->: <http://www.ukzn.ac.za/disclaimer>

Please find our Email Disclaimer here-->: <http://www.ukzn.ac.za/disclaimer>

LICENSE AGREEMENT

Between

FLINDERS UNIVERSITY
("Flinders")

And

Omisakin Folorunso Dipo
("the student")

For licensing the use the tools comprising the Finders Model for research and evaluation purposes

BACKGROUND

1. Flinders through its Flinders Human Behaviour and Health Research Unit ("the Unit") has developed the **"Flinders Model"**, a set of generic tools and processes enabling clinicians and clients to undertake a structured process that allows assessment of self-management behaviours, collaborative identification of problems and goal setting leading to the development of individualised care plans. These care plans are important cornerstones in enhancing self-management in people with chronic medical conditions.
2. The material comprising the Flinders Model has been developed by the Unit during projects funded by the South Australian Department of Human Services (the HealthPlus Coordinated Care trial) and the Commonwealth Department of Health and Ageing (Sharing Health Care Initiative).
3. The tools comprising the Flinders Model and general information concerning the licensing and use of the Flinders Model are described in the attachment to this agreement (Appendix 1).
4. The student wishes to use the Partners in Health Scale (PIH) in a PhD research project to be undertaken in the School of Nursing, University of KwaZulu-Natal, Howard Campus, Durban 4041, South Africa. The thesis topic is "Effectiveness of HIV/AIDS Self-management Education for People living with HIV/AIDS".

TERMS:

- 1 Flinders agrees to grant a license to the student for use in the PhD project. The license is for a period of three years from the signing of this agreement by both parties. Any renewal of the license will be subject to renegotiation.
- 2 The student may seek permission to adapt the tool to a style suited to its purposes. The student agrees that intellectual property in the adapted tool will be owned by Flinders University.
- 3 The student agrees to ensure that proper acknowledgement is given to Flinders and the authors of the Flinders Model tools in the redeveloped materials.
- 4 The student agrees that the source of the Flinders CCSM tools will be acknowledged in the PhD thesis and all published papers.

- 5 There is no license fee for the use of the tool/s for research or evaluation purposes. The student agrees to register the PhD project with FHBHRU.
- 6 The student agrees to share raw data and research outcomes with FHBHRU. The student agrees to provide to FHBHRU a project summary and the results annually and at the completion of the project
- 7 Individuals using the tools for clinical purposes must hold a Certificate of Competence. Notwithstanding this individuals may use the Partners in Health scale without requiring training.
- 8 Flinders undertakes to the student that it has developed and owns the Flinders Model, and the tools comprising it, and therefore has the right to grant this license.
- 9 The student agrees that Flinders' responsibilities under this agreement are limited to providing the tools and processes comprising the PIH and that Flinders will not be responsible for meeting the student's requirements for any ongoing educational or technical support.
- 10 The student agrees that Flinders will not be liable for any damages, including, without limitation, special, indirect or consequential damages, or any damages, whatsoever resulting from the student's access to or use of the tool/s and agrees to indemnify Flinders against any loss as a result of action taken against Flinders which arises from the student's use of the tools.
- 11 In the event of a dispute about a matter arising out of this Agreement, the matter will be referred to the nominee of the student and the Deputy Vice-Chancellor (Research) of the University for resolution. If they are unable to resolve the matter, the matter will be referred for final determination to an external arbitrator appointed by mutual agreement, or failing that, to an arbitrator nominated by the President of the Law Society of South Australia.
- 12 This Agreement represents the entirety of the agreement between the parties. No other terms, written, verbal or implied, shall be construed as being incorporated herein.

Signed

For and on behalf of

Flinders University

Name **Ion Wallace**

Faculty General Manager

Position **Faculty of Health Sciences**

Date **4/6/09**

Student

Name

Date **11-05-2009**

PhD Supervisor (University of KwaZulu-Natal, Howard Campus)

Name

Date **11-05-2009**

**UNIVERSITY OF KWAZULU-NATAL
CONSENT TO BE A RESEARCH PARTICIPANT
IMVUME YOKUBAMBA IQHAZA**

**Title: DEVELOPMENT OF HIV/AIDS SELF-MANAGEMENT EDUCATION
CONCEPTUAL FRAMEWORK FOR PEOPLE LIVING WITH HIV/AIDS IN SEMI-
RURAL KWAZULU-NATAL, SOUTH AFRICA**

You have been asked to be a part of a research study. This form gives information on the study in order to help you decide if you want to participate. Take as much time as you like to read over this information carefully. Please ask any question you may have on the study. It is okay if you decide not to participate. If you decide to participate, you may stop participating in the study at any time.

Purpose and Background

Increase in HIV/AIDS-related illness and deaths put an additional burden on constrained services in South Africa and particularly Kwazulu-Natal, a PhD student in the Schools of Nursing at the University of Kwazulu-Natal (UKZN) is currently conducting a research project to develop a comprehensive self-management education Conceptual framework, focusing on the totality of life experience of individuals with HIV/AIDS.

The findings from the study will be used to inform policy makers, community organizations and universities in hopes to develop interventions that will target the appropriate population for HIV/AIDS self-management education.

Study contacts.

The investigators in charge can be reached at the contact information below.

UKZN School of Nursing

University of KwaZulu- Natal

Durban 4041

Office number: 0312602499

031 260 2499

E-mail: ncamab@uzkn.ac.za

Uyacelwa ukuba ubambe iqhaza kulolucwaningo. Lelifomu likunika ulwazi mayelana nalolucwaningo lokukusiza ucabange ngokubamba iqhaza. Ngicela uthathe isikhathi sakho esanele sokufunda lolulwazi. Uvumelekile ukubuza noma yimuphi umbuzo mayelana nalolucwaningo. Uma uvumile ukubamba iqhaza, ungayeka noma inini uma ufuna ukuyeka ukubamba iqhaza kulolucwaningo.

A. Inhloso

Ukuxoxa mayelana ngezinga eliphezulu lokukhula kwesifo segciwane lesandulela ngculazi eNingizimu neAfrika kakhulukazi kwaZulu-Natal, isikole sobuhlelengikazi esiseNyuvesi yakwaZulu-Natal senza ucwaningo lolwazi kanye nokuqonda ngesifo sesandulela ngculazi nengculazi kanye nesifo esibizwa ngokuthi iperipheral neuropathy.

Umpfumela walolucwaningo uyobe sewusetshenziswa ukwazisa izinhlangano zomphakathi kanye namanyuvesi ukuze kubhekwe izindlela ezinobuqotho zokubhekana nezidingo zolwazi ngesandulela ngculazi kanye nengculazi

B. Ongaxhumana nabo ngalolucwaningo

Abacwaningi batholakala kulezizinamba ezingezansi. Uma undinga ulwazi ngesiZulu, ungaxhumana ne UKZN School of Nursing (Dr Busi Ncama) futhi nemininigwane yabo iyatholakala ngezansi.

Procedures

If you agree to participate in the study, the following will take place:

You will be asked to answer questions about your self-management education needs, how confident you are in doing certain activities, and how much your illness and /or its treatment interfere with your life and taught self-management strategies in respect of HIV/AIDS for approximately 120 to 150 minutes twice in a week for seven weeks. This interview will be one-on-one and in group; will take place in a mutually agreeable place.

Costs

There are no costs associated with participation in this study.

Risks and discomforts

Your participation in this research may cause a loss of privacy. Everything will be done to assure that this does not occur.

You will be asked questions about your personal life in addition to your health and sexual behavior that may make you feel uncomfortable. You do not have to answer any questions that you do not want to answer. You can also stop participating in the study at any time.

If you feel upset about any of the questions that you were asked to answer, the supervisor of the investigator, Dr Busi Ncama, will be happy to meet with you at your convenience to discuss your concerns and answer any of your questions.

You may become tired during the interview. If you do become tired, you will be able to rest and answer the questions at your own pace.

Benefits

There may be no direct benefit for your participation in this study though you may be encouraged to learn more about HIV/AIDS and. Your contribution of providing valuable information will hopefully be used to create interventions that will be able to teach you, your friends and people of your age about HIV/AIDS.

Alternatives

You are free to participate in this study or not. It is okay to not participate in this study and there are no negative feelings or problems if you decide not to participate in the project.

Confidentiality

The researchers will keep information about you as confidential as possible. You will not need to provide us with your name. Only the investigators will have access to the questionnaires. After the study has been completed, the data will be stored in a locked file. The results may be published in a journal or used for teaching purposes. Your name or other identifiers will not be used in any publication or teaching material.

Request for More Information

You may have more questions about the study which you are free to ask at any time. The investigator has provided her phone numbers so that you can contact him with any questions or concerns about the study at

any time. You will be informed about any significant new findings during the course of this study that may influence your continued participation.

If during the study or later you wish to discuss your rights as a research subject, your participation and/or concerns about this study, or if you feel under any pressure to enroll in this study, you are asked to contact a representative of the Biomedical Research Ethics Committee, University of KwaZulu-Natal, Durban, South Africa

Umgomo

Uma uvuma ukubamba iqhaza, nakhu okulandelayo okuzokwenzeka:

Uzobuzwa imibuzo emayelana nawe, ngolwazi lwesandulela ngculazi nengculazi, ngendlela oyibona ngayo isandulela ngculazi nengculazi, nangesimo sakho sezocansi. Uzocelwa ukuba inkulamo yenu iqoshwe phansi uma uthanda unganqaba ukuba lokho kwenziwe.

Ama-interviews azothatha isikhathi esingangemizuzu engamashumi amathathu azokwenziwa endaweni lapho sivumelane khona sobabili. Kuleyo interview uzobuzwa imibuzo mayelana nesandulela ngculazi.

Inkokhelo

Ayikho ingxenye yemali emayelana nokubamba kwakho iqhaza kulolucwaningo.

Ubungozi

Ukubamba kwakho iqhaza kungaveza izimfihlo. Konke okuzokwenziwa kuzoqiniseka ukuthi lokhu ngeke kwenzeke.

Uzobuzwa ngempilo yakho yezemfihlo nangendlela yokuziphatha ngokwezocansi lokho okungakuphatha kabi kanye nangesifo seperipheral neuropathy. Unelungelo lokungayiphenduli imibuzo uma uthanda ukungayiphenduli. Unelungelo ukuyeka noma inini.

Uma ufikelwa ukudinwa ngenxa yombuzo obuzwe wona, Umcwaningi omkhulu, Dr Busi Ncama, uyokuthokozelela ukuxoxisa nawe kanti futhi aphenhulelwe yonke imibuzo onayo

Kuma-interviews uma uzwa ukukhathala, ungaphumula noma uphendule imibuzo ngendlela oyidingayo.

Umhlomulo

Awukho umhlomulo ozowuthola ngokubamba kwakho iqhaza kulolucwaningo kodwa uzothola ulwazi mayelana nesandulela ngculazi nengculazi. Indima oyidlalile ngokusinika ulwazi kuyosiza ekwenzeni ama-interventions azokwazi ukuthi ikufundise wena, nabangane bakho kanye nabalingane bakho ngokweminyaka mayelana nesandulela ngculazi nengculazi kanye nangedlela yokwazi ukuvikela isandulela ngculazi nengculazi.

Okunye

Kuyilungelo lakho ukubamba iqhaza. Kuyilungelo lakho ukungavumi ukubamba iqhaza kulolucwaningo kanti futhi ngeke uhlangabezane nezinkinga uma ukhetha ukungabambi iqhaza kulolucwaningo.

Imfihlo

Osocwaningo bazocina ulwazi olutholakale kulolucwaningo. Akudingekile ukuthi nisinike amagama enu. Kuma-interviews kuzosetshenziswa amagama okungawona kanti ama-tapes

kanye nama-transcribed interviews azokhiyelwa futhi agcinw e endaweni lapho kungafinyeleli muntu khona.

Kuphela umcwaningi ozofinyelela lapho kugcinwe khona lolulwazi. Emva kwalolucwaningo lonke ulwazi luzogcinwa kumafayela. Imiphumela kanye nengxenye yamatapes alolucwaningo azoshicilelwa noma asetshenziswe ukufundisa. Amagama enu ngeke asetshenziswe uma kushicilelwa noma kufundiswa.

Isicelo solwazi

Uvumelekile ukubuza imibuzo mayelana nalolucwaningo . Izinombolo zomcwaningi ziyatholakala, ungamthinta noma inini uma unombuzo noma kukhona ongakutholi kahle mayelana nalolucwaningo noma inini. Uzokwaziswa ngemiphumela yalolucwaningo lusaqhubeka lokho okuzokwenza ukuthi uqhubeke nokubamba iqhaza kulolucwaningo. Unelungelo lokuxoxa mayelana neqhaza olibambile noma okukuphathe kabi ngalolucwaningo noma uke waba ngaphansi kwengcidezi yokubamba iqhaza, uyacelwa uthintane ne Research Biomedical Research Ethics Committee, University of KwaZulu-Natal, Durban, South Africa. Tel. 031 260 3587.

Reimbursement

You will be given a R30 coupon after you complete the interview and the questionnaire to thank you for your participation in the research study.

Questions

This study has been explained to me. If I have further questions about this study, I would first talk to the investigator. I can also contact a member of the Research Ethics Committee at the University of Kwa-Zulu Natal at Faculty of Biomedical Research.

Inkokhelo

Uyonikezwa I voucher ka R30 lokukubonga uma usuqedile ukubamba iqhaza kulolucwaningo.

Imibuzo

Lolucwaningo seluchaziwe kimina ngomunye wabamele ucwaningo noma omunye umsizi. Uma ngineminye imibuzo ngizokhuluma nabacwaningi noma abasizi babo, futhi ngingaxhumana nesisebenzi seResearch Ethics Committee e Nyuvesi yakwaZulu-Natal.

Imvume

Nginikiwe icopy yemvume yaleli-form.

University of KwaZulu-Natal, Durban, South Africa. University
Tel. 031 260 3587.

Consent

I have been given a copy of this consent form to keep

CONSENT TO PARTICIPATE IN RESEARCH PROJECT

I..... (your full name) hereby confirm
that I understand the contents of this document and the nature of the research project, and I consent
to participating in the research project.

I understand that PARTICIPATION IS VOLUNTARY and I am at liberty to withdraw from the
project at any time, should I so desire.

**ILUNGELO LOKUBAMBA IQHAZA KUCWANINGO –
DEVELOPMENT OF HIV/AIDS SELF-MANAGEMENT EDUCATION
CONCEPTUAL FRAMEWORK FOR PEOPLE LIVING WITH HIV/AIDS IN SEMI-
RURAL KWAZULU-NATAL, SOUTH**

Ngingu..... (Igama lakho eligcwele),
Ngithanda ukuvuma ukuthi ngiyaqonda ngaleli-document kanti futhi ngiyavuma ukubamba iqhaza
kulolucwaningo.

**Ngiyaqonda ukuthi ukubamba iqhaza kusuka othandweni lami kanti futhi ngingayeka
noma inini uma ngithanda**

.....
ISIGINISHA YOBAMB' IQHAZA

.....
USUKU

INSTRUMENT 1

HIV/AIDS Self-Management Education Needs Survey

People living with HIV/AIDS must receive education on how to manage and live with their illness over a long period of time. The purpose of this survey is to evaluate self-management education needs, barriers to education, and preferred methods of education acceptable to PLWHA. The responses to this survey will be completely anonymous, so you are not asked to put your name on it or identify yourself in any way. Please use a pencil or black ball point pen to indicate your responses. If you have any comment or concerns, just write it at the margin. Thank you very much for your participation.

Gender

Male

☐

Female

☐

Year Age

18-25

☐

26-35

☐

36-45

☐

46-55

☐

56-65

☐

66 and over

☐

Education

(Primary school)

1 2 3 4 5 6

(High school)

7 8 9 10 11 12

(College/university)

13 14 15 16

(Graduate school)

17 18 19 20 21 22 23

Have you ever been diagnosed with AIDS?

Yes

☐

No

☐

If yes, year AIDS was diagnosed _____

Place of residence _____

How do you rate your current health? Excellent ☐ Good ☐ Fair ☐ Poor ☐

HIV/AIDS medications currently prescribe daily? _____

How difficult do you think it is to live with your illness? Not at all difficult

somewhat difficult

Difficult

☐

very difficult

☐

How difficult do you think it is currently to take your medication correctly? Not at all difficult

Somewhat difficult

☐

Difficult

☐

very difficult

☐☐

Are you using alternative/complementary therapies? Yes ☐ No ☐

Self-Management Education Needs

Please rate your interest in knowing more about the following:

| Overall health and well being | <i>Very much</i> | <i>Much</i> | <i>some</i> | <i>A little</i> | <i>Not at all</i> |
|---|------------------|-------------|-------------|-----------------|-------------------|
| Recommended health screening for adults | | | | | |
| Recommended immunizations (shots) for adults | | | | | |
| Recommended skin test for Tuberculosis | | | | | |
| Women's health concerns | | | | | |
| Men's health concerns | | | | | |
| Healthy aging | | | | | |
| Nutrition | | | | | |
| Food groups and their importance | | | | | |
| Relationship between nutrition and HIV | | | | | |
| Reasons PLWHA become undernourished | | | | | |
| Practice creating meals to help PLWHA | | | | | |
| HIV/AIDS Management | | | | | |
| Understanding HIV/AIDS | | | | | |
| Understanding viral load and CD4 cell counts | | | | | |
| Understanding HIV transmission | | | | | |
| Understanding HIV/AIDS medications and how they work | | | | | |
| Managing HIV/AIDS medications (how to take them to best effect) | | | | | |
| Managing side effects from HIV/AIDS medications | | | | | |
| How to come to terms with your HIV status | | | | | |
| Dealing with stigma | | | | | |
| Increasing awareness of self importance | | | | | |
| How to live positively being positive | | | | | |
| Recognizing emergencies | | | | | |
| Coping with fatigue | | | | | |
| Coping with stress | | | | | |
| Coping with loss | | | | | |

| | | | | | |
|---|--|--|--|--|--|
| Coping with uncertainty | | | | | |
| How to talk to others about HIV/AIDS | | | | | |
| How to disclose your HIV status to others | | | | | |
| Exercise for health and well being | | | | | |
| Sex and HIV/AIDS | | | | | |
| Using community resources | | | | | |
| Seeking social support | | | | | |
| Managing work and home life with HIV/AIDS | | | | | |
| Legal issues for persons with HIV/AIDS | | | | | |

What one thing would be most helpful in meeting your current self-management needs?

Please rate how much the following would affect your participation Self-Management Education

| Barriers or Obstacles | <i>Very much</i> | <i>much</i> | <i>some</i> | <i>A little</i> | <i>Not at all</i> |
|-----------------------------------|------------------|-------------|-------------|-----------------|-------------------|
| Distance from clinic | | | | | |
| Transportation to and from clinic | | | | | |
| Stigma attached to the clinic | | | | | |
| Costs of travel or supplies | | | | | |
| Hours classes are offered | | | | | |
| Confidentiality | | | | | |
| Don't feel well enough | | | | | |
| Other health limitations | | | | | |
| Poor vision | | | | | |
| Family obligation | | | | | |
| Work obligation | | | | | |

Please indicate how well the following methods might help you learn more about what you want to learn:

| Methods of learning | <i>Very much</i> | <i>much</i> | <i>some</i> | <i>A little</i> | <i>Not at all</i> |
|---|------------------|-------------|-------------|-----------------|-------------------|
| Pamphlets and handouts available at the clinic. | | | | | |
| Clinic bulletin board (current health information, changed every 2-3months) | | | | | |
| Individual classes on appointment days. | | | | | |
| Individual classes on schedule days | | | | | |
| In-clinic group classes on appointment days | | | | | |
| In-clinic group classes on scheduled days | | | | | |
| In-clinic videos | | | | | |
| Group classes at UKZN (but not in the clinic) | | | | | |
| A video library (could be borrowed for use at home) | | | | | |
| Mailed newsletter | | | | | |
| Mailing in question with response by mail | | | | | |
| Individual telephone calls by appointment | | | | | |
| Computer resources: Electronic newsletter | | | | | |
| Computer resources: Emails | | | | | |
| Computer resources: Chat rooms | | | | | |
| Computer resources: On-line resources | | | | | |
| In-community group classes | | | | | |
| Home visits | | | | | |
| Others | | | | | |

SF-36 QUESTIONNAIRE

Name: _____

Ref. Dr: _____

Date: _____

ID#: _____

Age: _____

Gender: M / F

Please answer the 36 questions of the **Health Survey** completely, honestly, and without interruptions.

GENERAL HEALTH:

In general, would you say your health is:

- ☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

Compared to one year ago, how would you rate your health in general now?

- ☐ Much better now than one year ago
☐ Somewhat better now than one year ago
☐ About the same
☐ Somewhat worse now than one year ago
☐ Much worse than one year ago

LIMITATIONS OF ACTIVITIES:

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.

- ☐ Yes, Limited a lot ☐ Yes, Limited a Little ☐ No, Not Limited at all

Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

- ☐ Yes, Limited a Lot ☐ Yes, Limited a Little ☐ No, Not Limited at all

Lifting or carrying groceries

- ☐ Yes, Limited a Lot ☐ Yes, Limited a Little ☐ No, Not Limited at all

Climbing several flights of stairs

- ☐ Yes, Limited a Lot ☐ Yes, Limited a Little ☐ No, Not Limited at all

Climbing one flight of stairs

- ☐ Yes, Limited a Lot ☐ Yes, Limited a Little ☐ No, Not Limited at all

Bending, kneeling, or stooping

- ☐ Yes, Limited a Lot ☐ Yes, Limited a Little ☐ No, Not Limited at all

Walking more than a mile

- ☐ Yes, Limited a Lot ☐ Yes, Limited a Little ☐ No, Not Limited at all

Walking several blocks

- ☐ Yes, Limited a Lot ☐ Yes, Limited a Little ☐ No, Not Limited at all

Walking one block

- ☐ Yes, Limited a Lot ☐ Yes, Limited a Little ☐ No, Not Limited at all

Bathing or dressing yourself☐ Yes, Limited a Lot☐ Yes, Limited a Little☐ No, Not Limited at all**PHYSICAL HEALTH PROBLEMS:**

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

Cut down the amount of time you spent on work or other activities☐ Yes☐ No**Accomplished less than you would like**☐ Yes☐ No**Were limited in the kind of work or other activities**☐ Yes☐ No**Had difficulty performing the work or other activities (for example, it took extra effort)**☐ Yes☐ No**EMOTIONAL HEALTH PROBLEMS:**

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

Cut down the amount of time you spent on work or other activities☐ Yes☐ No**Accomplished less than you would like**☐ Yes☐ No**Didn't do work or other activities as carefully as usual**☐ Yes☐ No**SOCIAL ACTIVITIES:**

Emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

☐ Not at all☐ Slightly☐ Moderately☐ Severe☐ Very Severe**PAIN:**

How much bodily pain have you had during the past 4 weeks?

☐ None☐ Very Mild☐ Mild☐ Moderate☐ Severe☐ Very Severe

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all☐ A little bit☐ Moderately☐ Quite a bit☐ Extremely

ENERGY AND EMOTIONS:

These questions are about how you feel and how things have been with you during the last 4 weeks. For each question, please give the answer that comes closest to the way you have been feeling.

Did you feel full of pep?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good Bit of the Time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

Have you been a very nervous person?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good Bit of the Time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

Have you felt so down in the dumps that nothing could cheer you up?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good Bit of the Time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

Have you felt calm and peaceful?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good Bit of the Time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

Did you have a lot of energy?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good Bit of the Time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

Have you felt downhearted and blue?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good Bit of the Time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

Did you feel worn out?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good Bit of the Time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

Have you been a happy person?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good Bit of the Time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

Did you feel tired?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good Bit of the Time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

SOCIAL ACTIVITIES:

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little bit of the time
- ☐ None of the Time

GENERAL HEALTH:

How true or false is each of the following statements for you?

I seem to get sick a little easier than other people

- ☐ Definitely true ☐ Mostly true ☐ Don't know ☐ Mostly false ☐ Definitely false

I am as healthy as anybody I know

- ☐ Definitely true ☐ Mostly true ☐ Don't know ☐ Mostly false ☐ Definitely false

I expect my health to get worse

- ☐ Definitely true ☐ Mostly true ☐ Don't know ☐ Mostly false ☐ Definitely false

My health is excellent

- ☐ Definitely true ☐ Mostly true ☐ Don't know ☐ Mostly false ☐ Definitely false

How to Score the Rand SF-36 Questionnaire

STEP 1: SCORING QUESTIONS:

| QUESTION NUMBER | ORIGINAL RESPONSE | RECORDED VALUE |
|---------------------------------|-------------------|----------------|
| 1, 2, 20, 22, 34, 36 | 1 | 100 |
| | 2 | 75 |
| | 3 | 50 |
| | 4 | 25 |
| | 5 | 0 |
| 3, 4, 5, 6, 7, 8, 9, 10, 11, 12 | 1 | 0 |
| | 2 | 50 |
| | 3 | 100 |
| 13, 14, 15, 16, 17, 18, 19 | 1 | 0 |
| | 2 | 100 |
| 21, 23, 26, 27, 30 | 1 | 100 |
| | 2 | 80 |
| | 3 | 60 |
| | 4 | 40 |
| | 5 | 20 |
| | 6 | 0 |
| 24, 25, 28, 29, 31 | 1 | 0 |
| | 2 | 20 |
| | 3 | 40 |
| | 4 | 60 |
| | 5 | 80 |
| | 6 | 100 |
| 32, 33, 35 | 1 | 0 |
| | 2 | 25 |
| | 3 | 50 |
| | 4 | 75 |
| | 5 | 100 |

STEP 2: AVERAGING ITEMS TO FORM 8 SCALES:

| SCALE | NUMBER OF ITEMS | AFTER RECORDING AS PER TABLE 1, AVERAGE THE FOLLOWING ITEMS |
|--|-----------------|---|
| Physical functioning | 10 | 3, 4, 5, 6, 7, 8, 9, 10, 11, 12 |
| Role limitations due to physical health | 4 | 13, 14, 15, 16 |
| Role limitations due to emotional problems | 3 | 17, 18, 19 |
| Energy/ fatigue | 4 | 23, 27, 29, 31 |
| Emotional well being | 5 | 24, 25, 26, 28, 30 |
| Social functioning | 2 | 20, 32 |
| Pain | 2 | 21, 22 |
| General health | 5 | 1, 33, 34, 35, 36 |

STEP 3: FIGURING SCORES:

RAND recommends the following straightforward approach to scoring the RAND 36-Item Health Survey.

All questions are scored on a scale from 0 to 100, with 100 representing the highest level of functioning possible. Aggregate scores are compiled as a percentage of the total points possible, using the RAND scoring table (STEP I chart).

The scores from those questions that address each specific area of functional health status (STEP II chart) are then averaged together, for a final score within each of the 8 dimensions measured. (eg pain, physical functioning etc.)

For example, to measure the patients energy/fatigue level, add the scores from questions 23, 27, 29, and 31. If a patient circled 4 on 23, 3 on 27, 3 on 29 and left 31 blank, use table 1 to score them.

An answer of 4 to Q23 is scored as 40, 3 to Q27 is scored as 60, and 3 to Q29 is scored as 40. Q31 is omitted. The score for this block is $40+60+40=140$. Now we divide by the 3 answered questions to get a total of 46.7. Since a score of 100 represents high energy with no fatigue, the lower score of 46.7% suggests the patient is experiencing a loss of energy and is experiencing some fatigue.

All 8 categories are scored in the same way. Using this questionnaire at the beginning and during the course of care, we can track the progress of the 8 parameters mentioned in the STEP II chart. Pretty nifty, eh?

INSTRUMENT 3

INTERVIEW QUESTIONS

1. In general, what did you think was most helpful about the program?
2. If you could only keep two of the things in the program, which two things would you keep?
3. If you had to throw two things of the program, what would you throw out?
4. What would you do differently if you were to design the program?
5. What would you like to be added to this program in future?
6. Are there things that you do now to improve your health that you didn't used to do before the program?
7. Are there changes in your health and functional ability since you've attended the program?
8. What did you think about the self-management education handbook?
9. What did you think about the participants in your group?
10. What did you think about the facilitators of the program?



23 March 2010



TO WHOM IT MAY CONCERN

Letter of Introduction for Omisakin Folorunso Dipo

Mr. Omisakin Folorunso Dipo is one of the second year postgraduate students in the School of Nursing, registered for PhD in Nursing. His PhD research project is titled "Development of HIV/AIDS self-management education conceptual framework for people living with HIV/AIDS in semi-rural Kwazulu-Natal, South Africa" His research falls into one of the major research streams in our school "HIV and AIDS".

I hereby wish to confirm that I am Mr. Omisakin's supervisor. He has progressed remarkably fast with his research project. Mr. Omisakin is a hard working, diligent and mature student. Kindly use your good office to assist him in the conduct of his research. Thank you so much for your usual cooperation.

Thanking You

Yours faithfully

B. P. Ncama. (Ass. Prof.)

School of Nursing, Howard College Campus

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■ Howard College

■ Medical School

■ Pietermaritzburg

■ Westville

Omisakin Folorunso Dipo

School of Nursing, UKZN,

Durban 4041, South Africa.

Cell: +27735836337,

Email: 209506889@ukzn.ac.za

22-02-2010

The Nursing Officer-inCharge,
Danganya Clinic,
Danganya, KZN,
South Africa.

Dear Madam,

APPLICATION FOR PERMISSION TO CONDUCT RESEARCH AT DANGANYA CLINIC

I hereby apply for permission to conduct research in your noble clinic. I am a PhD Nursing student at the School of Nursing, University of KwaZulu-Natal, Howard Campus, Durban 4041, and South Africa. I have just received my PhD proposal ethics approval.

My main fields of study are medical-surgical nursing, critical care and health promotion. During my studies, I have found that my interests are focused particularly in the area of patient care and health promotion, recently with emphasis on care of people living with HIV/AIDS. My M.Sc. Nursing thesis was on care of PLWHA out of which I have published two articles in the Nigerian Journal of Medicine. I decided to come to South Africa to broaden my horizons while enhancing my career profile.

It has always been a strong motivation for me to promote, extend life expectancy and improved health status of the population to contribute to the reduction of diseases as well as their determinants. I feel comfortable both working with a team environment and on individual tasks. I have learnt to work towards, and achieve my aims with great commitment and perseverance. A brief description of the study, ethics approval from UKZN, Support letter from the Department of Health and Consent form for the participants are hereby attached. I look forward to your reply.

Yours sincerely,

Omisakin FD.

SUMMARY OF THE PROJECT

Title of Project: Development of HIV/AIDS Self-management Education Conceptual framework for People Living with HIV/AIDS in Semi-Rural Kwazulu-Natal, South Africa.

Project description: HIV/AIDS Self-Management Education Program (HASMEP) is a workshop engaging People Living with HIV/AIDS (PLWHA) given two and a half hours, twice a week, for seven weeks, in hospital settings (ARV roll-out centers) in rural KwaZulu-Natal, South Africa. The workshop will be facilitated by two trained leaders, who are non-health professionals living with HIV/AIDS and the investigator. The package comprises of: (a) information exchange about HIV/AIDS (b) skills development, and (c) social support enlistment and (d) program evaluation related to the physical and psychosocial well-being of People Living with HIV/AIDS (PLWHA).

Purpose: The purpose of this study is to demonstrate the effectiveness of self-management education on health and well being of PLWHA in African context.

Aims: HASMEP aimed at helping PLWHA to develop self-care behaviors which include: lifestyle (diet and exercise); managing therapy; using services effectively; and being able to understand their symptoms and problems and respond appropriately to them.

How the problem will be addressed: An advertisement (notice) will be placed at the center to assist in recruitment of 80 People Living with HIV/AIDS (over 18 years of age, taking antiretroviral medications, with CD4 count range of 200-349) who express verbal interest in participating will be assessed by the program officer on presentation for consultation and will be given the participant's information sheet and statement of consent form and randomly grouped into intervention and comparison groups. Focus Group Discussion will be conducted to establish the self-management education needs of PLWHA. The findings of the FGD will inform the content of the self-management education. The intervention group participants will meet twice weekly for seven weeks in interactive fourteen sessions and complete a structured curriculum that teaches self-management skills and information, Symptom assessment and management, medication use, physical exercise, relaxation, communication of health problems with providers, and nutrition will be taught. Self-management skills development in; (1).problem solving, (2)

decision making, (3) forming patient-provider partnerships (4) resource utilization and (5) self-tailoring. Self-management tasks include; medical management, developing new roles and coping with emotions. Evaluation of the program will be done at twenty-four week.

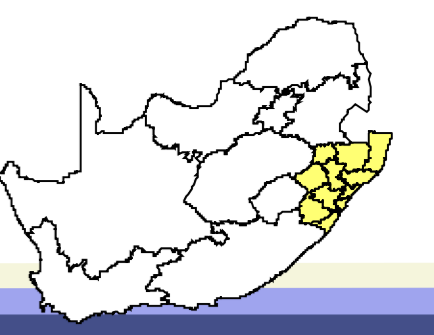
Contact person: Prof. BP Ncama, School of Nursing, University of KwaZulu-Natal, Howard Campus, Durban 4041, South Africa. Phone: +27(0)312602270 or cell: +27833785433. Facsimile: +27(0)312601543. Email:ncamab@ukzn.ac.za

Definition of success for the program: A repeated measures analysis of variance (ANOVA) will be performed to determine any difference between the two groups. The intervention group will significantly improve in self-management abilities. The viral load will decrease and CD4 counts will increase significantly in intervention group. The intervention group will display effective self-managers skills such as ; being knowledgeable about their HIV/AIDS; develop effective communication skills; actively partner with providers in decision-making; practice action-planning and problem solving; self-monitor symptoms and follow treatment directions; seek expert medical care and advice; use family , peer and community support resources, maintain emotional and psychological balance; practice health enhancing behaviors; and generally enjoys improved quality of life. The study will also raise awareness in PLWHAs' abilities and resources to mobilize for action.

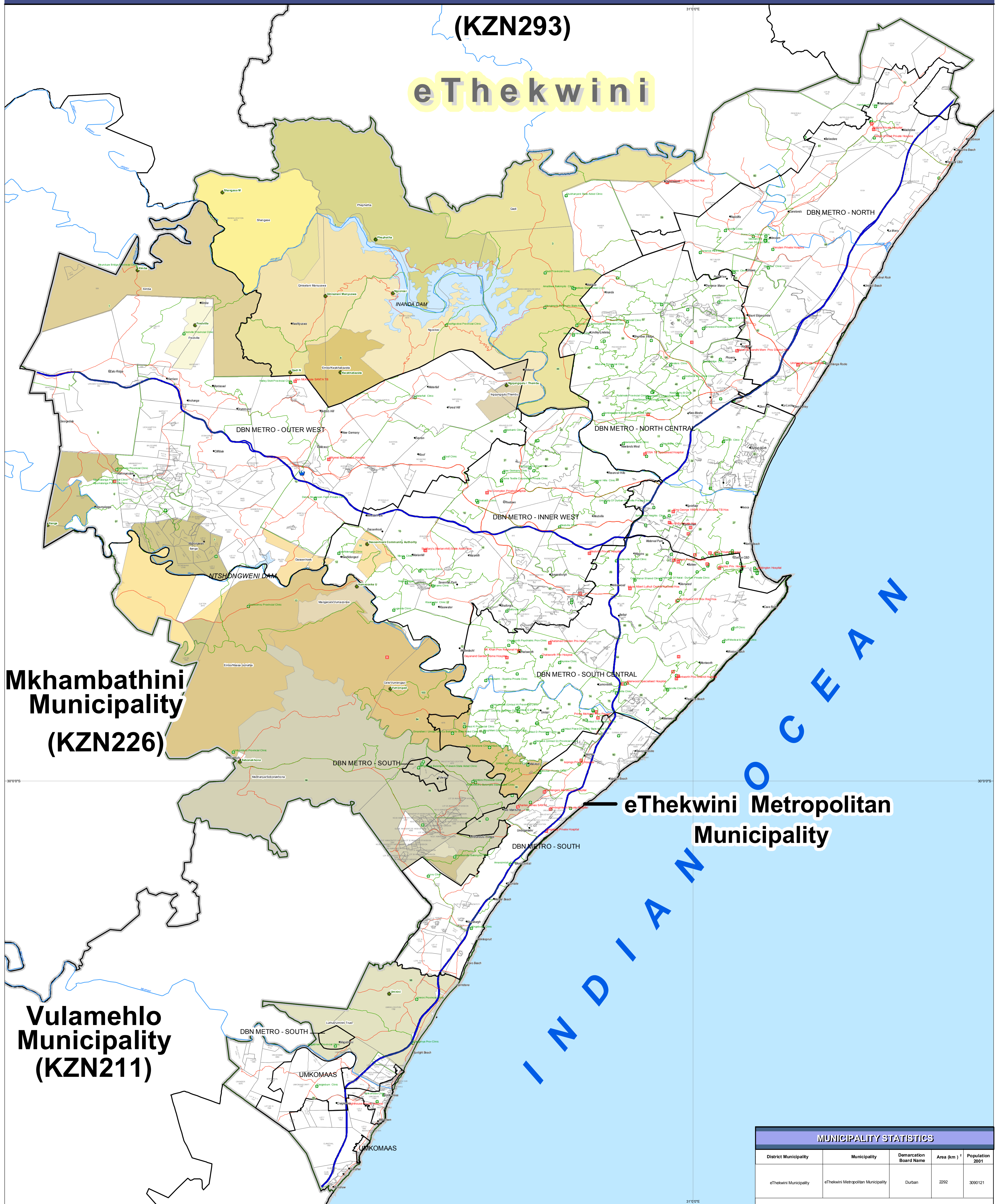


DEPARTMENT OF LOCAL GOVERNMENT AND TRADITIONAL AFFAIRS

KwaZulu-Natal Provincial Government



eThekweni Municipality (Durban)



Mkhambathini Municipality (KZN226)

Vulamehlo Municipality (KZN211)

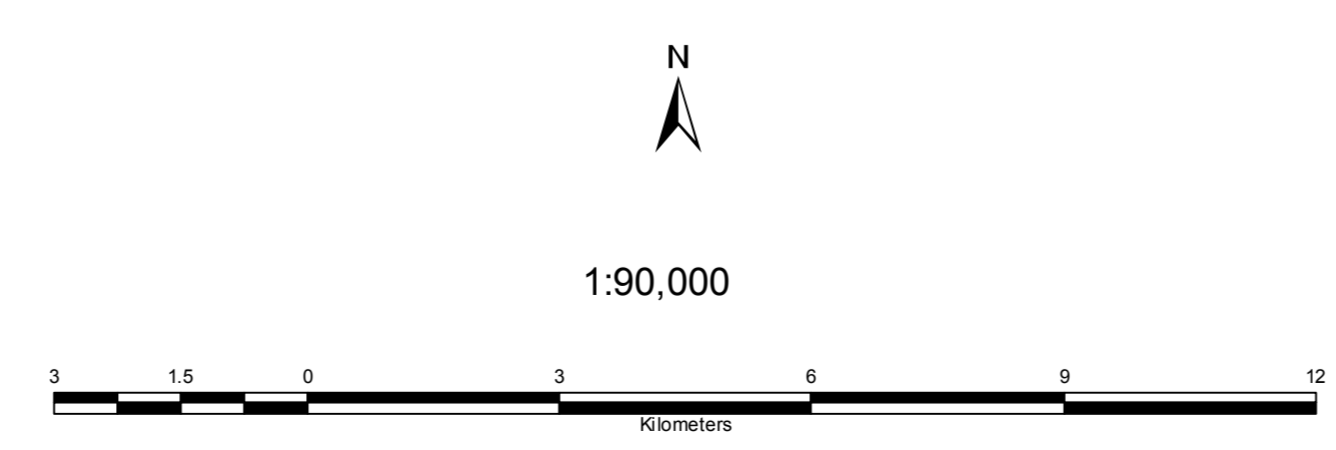
eThekweni Metropolitan Municipality

| MUNICIPALITY STATISTICS | | | | |
|-------------------------|-------------------------------------|------------------------|-------------------------|-----------------|
| District Municipality | Municipality | Demarcation Board Name | Area (km ²) | Population 2011 |
| eThekweni Municipality | eThekweni Metropolitan Municipality | Durban | 2292 | 3090121 |

Date Compiled: March 2009
Reference: eThekweni ETH
Tel: (031) 204 1711
Fax: (031) 204 1980
Website: <http://devplan.kzntl.gov.za>

Dir: Development Information Services (GIS)
KwaZulu-Natal

Disclaimer:
The Department Local Government and Traditional Affairs (DLGTA) is in no way responsible for the accuracy or completeness of data here presented. Therefore, in no event will DLGTA be liable for damages, including loss of profits or consequential damages arising out of the use of information.



Co-ordinate System : WGS84 Geographic

Legend

Placenames

- Ex- Transitional Local Council
- Main Place Names
- Secondary Place Names
- Tourism
- Places of Interest

Clincs & Other

- Hospitals
- National Road Labels
- National Roads
- Provincial Roads
- Major Rivers

KZN Wards

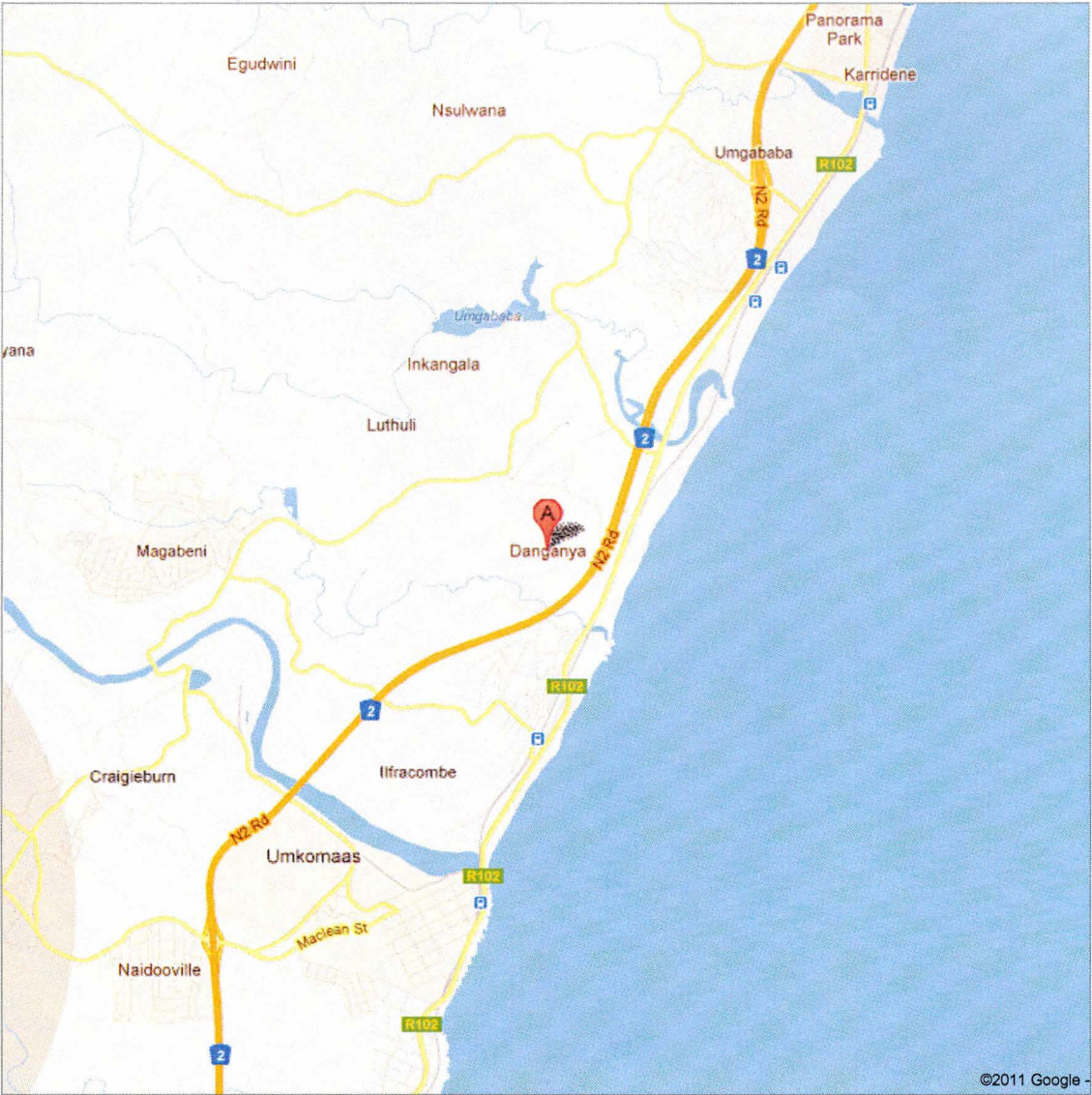
- Local Municipal Boundary
- District Municipal Boundary
- Major Dams
- District Management Areas
- Traditional Communities

MPCC

- TAC's
- Farm Parents

Data Sources:

- Place Names / Tribal Authorities: Department of Local Government and Traditional Affairs
- Roads: Department of Transport
- Demarcation Boundaries: Municipal Demarcation Board
- Municipal Statistics: Statistics South Africa
- Water Bodies: Department of Water Affairs and Forestry



PEER GROUP LEADER'S MANUAL

HIV/AIDS SELF-MANAGEMENT EDUCATION PROGRAM (HASMEP) IMPLEMENTATION PACKAGE

PROGRAM DESCRIPTIONS

HASMEP is a health promotion package comprising of three central components: (a) information exchange, (b) skills development, and (c) social support enlistment, related to the physical, and psychosocial well-being of PLWHA. **Information exchange.** The aim of the baseline and follow-up information components will be to increase participants' level of knowledge about HIV/AIDS and HIV/AIDS-related health problems. **Skills development.** PLWHA usually need guidance on how to cultivate self-regulatory and coping skills in order to translate information into action. Thus the aim of the skills training component is to equip PLWHA with successful strategies for self-management. Self-management skills training includes: (1) self-monitoring, (2) goal setting, and (3) enlistment of self-incentives. The purpose of self-monitoring will be to self-diagnose the determinants of health problems, self-evaluate progress towards goals, and enhance self-management efficacy. At follow-up visits, notes in the diary will be discussed with the investigator, and supportive feedback will be given to the participant. Goal setting-at baseline and follow-up visits, participants will be asked to set proximal sub-goals that will be instrumental in achieving larger future goals. It is theorized that proximal sub goals provided incentives and guides for action, and sub goal attainments bolster confidence and produce self-satisfaction that sustain one's efforts at personal change along the way (Bandura, 1997). Enlistment of self-incentives-at the baseline and follow-up visits, participants will be asked to create self-incentive for attaining their sub-goals. The rationale is that individuals achieve greater self-directed change if they reward their successful efforts than if they provide no incentives for themselves. **Enlisting social support**-at the initial counseling session, participants will be asked to name a supportive partner or friend. During follow-up visits, the researcher will encourage the participant to ask the named person to provide assistance.

There is great emphasis on three process skills, action planning, and disease related problem solving, and decision making. I follow a scripted manual each time the program is in session. I have scripted every minute of the course for content as well as the interactions with the workshop participants. It is the process in which a program is taught that makes it effective. Classes will be highly participative, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active fulfilling lives. HASMEP is dynamic and exciting; the investigator will not only teach but try making it as fun and stimulating as possible. This allows the participants to grow and develop, and enjoy the privilege of being able to share in some of the rich experience of being a participant. HASMEP will be run over fourteen sessions lasting about three hours each, twice a week for six weeks, in a selected hospital. The program will be developed with and for PLWHA. Workshops will be facilitated by two technical staffs, one or both of whom are non-health professionals living with HIV/AIDS.

The elements of HASMEP curriculum include:

1. Health literacy and HIV/AIDS-related knowledge.
2. Goal setting and problem-solving strategies.
3. Understanding the relationship between laboratory results and physical health.
4. Strategies for symptom management.
5. Communicating effectively with one's health care provider.
6. Seeking and utilizing health care services.
7. Managing psychosocial problems and building networks of social support.
8. Nutrition, exercise and relaxation techniques.
9. Strategies to increase medication adherence and militate against side effects of medications.

The mission of HASMEP is to improve the quality of care, ultimately, the quality of life for PLWHA. The incorporation of HASMEP into care activities could empower PLWHA to take a more proactive role in managing their illness and improving their quality of life.

Does HASMEP replace existing programs and treatments?

The HASMEP will not conflict with existing programs or treatment. It is designed to enhance the regular treatment and disease-specific education. The program will (a) explicitly involve PLWHA as active participants in their health care; (b) facilitate development of skills and knowledge necessary to collaborate with their health care providers and implement treatments effectively and (c) enable PLWHA to develop confidence to put their knowledge and skills into practice.

How will the program be developed?

The content of the program will be developed from the initial assessment of self-management educational needs of PLWHA, and focus group discussion in which the potential participants discussed which content areas were the most important for them, as well as consultation with National and International experts who will assist in developing key messages and being sure that the content is accurate, and evidenced based with self-efficacy.

How will the program be evaluated?

Evaluation of the program will be done comparing the pre- and post- intervention health-related quality of life, CD4 counts, and viral load of the intervention and comparison groups after twenty-four weeks. In-depth group interviews will also be conducted for a subset of the intervention group to explore their post- engagement experiences.

What will be the expected results?

The intervention group will significantly improve in health-related quality of life. The viral load will decrease and CD4 cell counts will increase significantly in the intervention group. The intervention group will display effective self-managers skills such as; being knowledgeable about their HIV/AIDS; develop effective communication skills; actively partner with providers in decision-making; practice action-planning and problem solving; self-monitor symptoms and follow treatment directions; seek expert medical care and advice; use family, peer and community support resources, and generally enjoys improved quality of life.

Why program might be implemented?

Program implementation will be based on the desire to offer evidence based self-management education to PLWHA. Evidenced based intervention is defined as one that when evaluated improved behaviours, and health status.

What about cost savings?

There is evidence that HASMEP will result in reduction in health care expenditures. There is evidence to support the notion that HASMEP WILL save enough money in health care expenditures. This statement is made with a moderate degree of confidence based on previous studies.

How do we convince health professionals to trust the program?

The very easiest way to convince health professionals is to let them sit in one or two session of the program. Many health professionals like evidence so giving them the abstracts of the key program studies is useful. Health professionals usually do not want read long articles but the researcher will make these available if they want to see them. The researcher will also have a trusted professional talk about the program to his colleagues. The researcher will also make it very easy for health professionals to access the program.

What is needed for implementation HASMEP?

The investigator must put into consideration the followings that will be needed before implementation.

- Program coordinator (researcher).
- Technical staffs (2)
- Participants
- Systematic participant recruiting (marketing) effort
- Professional backup.
- Research setting (community site).
- Program materials.
- Protection of human subjects (participants)

- Data management and storage.
- Quality assurance/fidelity strategies.

Program coordinator. The program coordinator is responsible for the program. Recruits staffs, arrange for workshop site, maintains program fidelity and will conduct program evaluation.

Technical staff. Acts as research assistants and takes care of the technical aspects of the program. Implementation of HASMEP requires two technical staffs for twelve week workshop. The technical staffs will be non-professionals living with HIV/AIDS. They are volunteers that will receive a small stipend (R600 for participating in a fourteen week program). The technical staff will be compensated for their time and for participating in the study. To recruit technical staff the researcher will: look around in the neighborhood of the research setting; talk with people in ongoing support groups; post a notice with the community volunteer centre; post the opportunity on website; post a notice in the newsletters of voluntary health organizations; ask health professionals to ask their favorite clients and post notices in neighborhood newsletters and health clubs.

Participants. Eighty (80) PLWHA will constitute the participants. Finding participants, the researcher will put together a publicity kit containing a simple fact about the program along with; public service announcement (print, radio, and TV), flyer, letter to potential participants, website link, and a reminder in the electronic medical record to health professionals to refer people to the program or better a link where they can download information and hand it to their patient.

Professional backup. This program deals with PLWHA who have multiple health problems. Thus, it is not surprising that sometimes questions or situations arise that require help from health professionals. The investigator will have health professionals who are to answer specific medical questions, and will be available in case of emergency.

Research Setting. According to Campbell et al (2007) the findings of trials of complex interventions are more generalizable if they are performed in the setting in which they are most likely to be implemented. In this study, health settings that are involved in HAART roll-out will be used since they are (1) part of the public health service to the needs of PLWHA, (2) most likely to have an interest in addressing the issues of Self-Management Education Needs of PLWHA, and (3) they allow for monitoring outcomes in terms of CD4counts and HAART

uptake, which non-HAART settings will not do. Since the health care of the population in all African countries are mainly provided by the governments, the public health services is the relevant sites for this research.

Protection of human subjects (participants). The researcher will: obtain ethics approval from the UKZN ethics committee. Obtain permission to conduct the study from the appropriate provincial and district health authorities. Provide participants with information about the background of the study and informed that participation is voluntary and that they may withdraw from participating at any time. Obtain informed consent from participants.

Data management and storage. A computer that has a special login code known to the investigator only will be used. Papers used to transcribe data will be kept under lock and key. Tapes used to record interviews will also be kept under lock and key. Data will be disposed after a period of three years.

Program fidelity. Fidelity refers to how closely staff members follow the program as provided by the investigator. The researcher monitor and follow-up on drop outs, monitor the effectiveness of recruiting and implementation strategies, and conduct program evaluation at the end of twenty-four weeks.

Program materials include:

- A comfortable room where trainees can sit in a circle or open square hopefully with tables in front of them. The room is accessible as are the toilets, bathrooms, and the chairs are comfortable.
- One additional breakout room is needed with easel and chart pads, during teaching.
- A daily roster sheet-to keep track of is there each day.
- Reusable name tags for each participants and staffs and black felt tip pen.
- A complete set of prepared charts plus duplicates of charts for posting throughout training.
- An audio/ CD player (boom box) for use for playing relaxation.
- A computer with printer.
- A tape recorder.

- Overheads or power points slides for power point presentations (found on the CD-rom).
- Projector, extra extension cord/lead.
- Flip chart or whiteboard, markers and eraser or blackboard and chalk.
- Pencil and or pen and writing pad for each participant.
- For demonstration: ARVs, hygiene article (soap to display hand washing) and condoms.
- Box of tissues.
- Food: provision needs to be made for food including lunch, snacks and water.
- Book: Self-Management Handbook for People living with HIV/AIDS.
- Program manual.
- Calendar diary.
- Program evaluation forms.
- Certificates of completion.

Community site (research setting). The program site must meet several minimal criteria: it must be safe, have insurance, handicap accessible (this includes not requiring the use of stairs), be able to accommodate up to 40 people in a circle or u, have parking if this is a consideration, be near public transportation if this is a consideration, have well lighted exteriors if the program is after dark, be opened to having anyone from the community attend, and have a room that provides privacy and provides enough space for the (staffs, participants, flip charts, white board and still moving around).

How will the researcher assure participants have all needed materials?

Materials for the workshops are an important part of the program. This will be financially supported through the purchase of training materials by the researcher or a sponsoring organization. The program will use the books and CDs as incentives to the participants.

Special considerations for working with different cultures.

Cultural competence is a developmental process. The researcher will:

1. Approach cultural issues from a humble position without making judgments.
2. Be careful about cultural stereotypes and advice from cultural experts, but rather listen to more than one expert and most importantly to the experts in the community.
3. Ask people that know if he does not understand something and avoid assumptions.

4. Connect the diet recommendations with the traditional diet to add credibility to the presentation.
5. Be ready to share information about him and be a good listener.
6. Plan for sustainability, the best work is that which enable the community to continue the program.

Costs.

- Program coordinator (full-time)
- Technical staffs (may be volunteer or may receive stipend)
- Training (food, materials, recruiting, and manuals).
- Publicity.
- Participant's registration support.

Guidelines for Implementation of HIV/AIDS Self-Management Education

1. *The HIV/AIDS Self-Management Education should be need-based, goal-directed and outcome-focused.*
2. *The HIV/AIDS Self-Management Education should have documentation of its organizational structure, mission statement, and goals and should be recognize as an integral component of HIV/AIDS care.*
3. *The HIV/AIDS Self-Management Education entity should determine the self-management educational needs of PLWHA and identify resources necessary to meet these needs. Demographic variables, such as ethnic background, age, formal educational level, literacy, and barriers to participation in an educational programme should also be considered to maximize the effectiveness of HIV/AIDS Self-Management Education.*
4. *An individual assessment and education plan should be developed collaboratively by the participants and health professionals to direct the selection of appropriate educational interventions and self-management support strategies. This assessment of an education plan, the intervention and the outcomes should be documented in the education record.*
5. *Written curriculum reflecting current evidence and practice guidelines, with criteria for evaluating outcomes, should serve as the framework for the HIV/AIDS Self-Management Education entity. Assessed needs of PLWHA should determine the curriculum content. Practical*

problem-solving skills, collaborative care, psychosocial issues, behaviour change, and strategies to sustain self-management efforts should be emphasized.

- 6. A facilitator should be designated to oversee the planning, implementation, and evaluation of HIV/AIDS Self-Management Education. The facilitator should have academic or experiential preparation in chronic disease care and education and programme management.*
- 7. HIV/AIDS Self-Management Education should be provided by members of the team responsible for designing the curriculum and assisting in the delivery. The team should include the facilitator, the technical staff, and PLWHA.*
- 8. The HIV/AIDS Self-Management Education entity should appoint an advisory group to promote quality. This group should include representatives from the health professions, PLWHA, the community, and other stakeholders.*
- 9. A follow-up plan for ongoing self management education and support should be developed collaboratively by the participant and the team members. The patient's outcomes and goals and the plan for ongoing self-management education should be communicated by the referring provider.*
- 10. The HIV/AIDS Self-Management Education entity will measure attainment of patient-defined goals and patient outcomes at regular intervals, using appropriate measurement techniques to evaluate the effectiveness of the educational intervention.*
- 11. The HIV/AIDS Self-Management Education entity should measure the effectiveness of the self-management education programme and determine opportunities for improvement, using a written continuous quality improvement plan that describes and documents a systematic review of the entities' process and outcome data.*

Principles and methods of training

Some key points to be considered before starting training session:

- Prepare well for training day keeping in mind the audience.
- Have a round of introduction of the participants and try to memorize their names.
- Provide a training overview and objectives.
- Establish ground rules (such as no cell phone, no side conversations and respect for other opinions).

- Think of enough drinking water, refreshers on the tables/lunch.
- Have small breaks.
- Have ice breakers, energizers and wrap up sessions.

Researcher obtains and holds learner's attention by:

- Relating the topic of the session to the learner's interest.
- Introducing the session in such a way that the learners will not only see and become interested in this relationship, but will want to learn more about it.
- Beginning with a good story to which the learners can relate.
- Having done these things, maintain the learner's attention by doing all that is possible to facilitate their understanding and absorption of the material.
- Ensure that the learner's learning is an active process in which the teacher and learners are equal partners in terms of participation.

General principles

1. Participation is voluntary: Researcher respects the individual rights of PLWHA to choose whether they would like to participate in the program. PLWHA have the right to continue or discontinue services as needed.
2. Part of the continuum of care: All HIV/AIDS care services need to be linked together to ensure PLWHA have optimal access to essential care.
3. Service provision is based on need: HASMEP attempt to support PLWHA and meet their expressed needs. The program will conduct needs assessment with PLWHA to determine their self-management educational needs and provide self-management education to meet the identified needs.
4. Promotion of self-reliance: The researcher will work with PLWHA to support them in identifying ways to remain independent, continue working, to live with dignity and respect.
5. Client-centered therapy: Provide services to PLWHA within the context of their ability. This includes assessing and helping to address the needs of PLWHA.

6. PLWHA with these services as needed.

Methods

- Discussion
- Presentation
- Role play
- Group work
- Group visualization
- Exercise
- Energizers

HIV/AIDS SELF MANAGEMENT EDUCATION PROGRAMME

| Time | DAY 1 | DAY 2 | DAY 3 | DAY 4 |
|-------------|---|---|---|---|
| 09:00 | Welcome, introductions, expectations, objectives, programme, & ground rules. | INCREASING KNOWLEDGE ABOUT HIV/AIDS <ul style="list-style-type: none"> ▪ Definitions of HIV and AIDS ▪ Impact of HIV on the immune system ▪ Relationship between CD4 cells and HIV ▪ Opportunistic infections ▪ Stages of HIV/AIDS. | HIGHLY ACTIVE ANTIRETROVIRAL THERAPY <ul style="list-style-type: none"> ▪ Definition and description of HAART. ▪ Management of medication adherence problems. ▪ Keeping immune system as strong as possible in addition to HAART. | SELF-MANAGEMENT OF ANXIETY, DEPRESSION, FORGETFULNESS AND INSOMNIA |
| 09:30 | Tea Break | | | |
| 10:00 | INCREASING EMOTIONAL CAPACITY <ul style="list-style-type: none"> • Helping participants to come to terms with their HIV status. • Dealing with stigma. • Increasing awareness of self importance. | POSITIVE LIVING AND SELF-MANAGEMENT <ul style="list-style-type: none"> ▪ Positive living. ▪ Self-management. ▪ Components of positive living and self-management. ▪ Importance of exercise to PLWHA. | NUTRITION, RELATIONSHIP BETWEEN NUTRITION AND HIV/AIDS. <ul style="list-style-type: none"> ▪ Food and water safety and sanitation for PLWHA. ▪ Food groups and their importance. ▪ Relationship between nutrition and HIV. ▪ Importance of good nutrition for PLWHA. ▪ Reasons PLWHA become undernourished. ▪ Practice creating meals to help PLWHA. | SELF-MANAGEMENT OF CONSTIPATION, DIARRHEA, AND NAUSEA. |
| 11:00 | Lunch Break | | | |
| | | | | |

HIV/AIDS SELF MANAGEMENT EDUCATION PROGRAMME(CONTD)

| Time | DAY 5 | DAY 6 | DAY 7 | |
|-------------|--|---|--|--|
| 09:00 | SELF-MANAGEMENT OF SHORTNESS OF BREATH, DIZZINESS, LOSS OF STRENGTH (FATIGUE) AND FEVER. | SELF-MANAGEMENT OF SKIN ABSCESSSES, BLISTERS, AND RASHES. | SEEKING SOCIAL SUPPORT <ul style="list-style-type: none"> ▪ Continuing friendships. ▪ Graduation ceremony. | |
| 09:30 | Tea Break | | | |
| 10:00 | SELF-MANAGEMENT OF COUGH, NIGHT SWEATS, PAINS AND SWELLINGS. | WEIGHT LOSS (UNPLANNED), ORALTRUSH, GENITAL ITCHING, BURNING AND DISCHARGE. | | |
| 11:00 | Lunch Break | | | |
| | | | | |

SESSION 1: Introductions, expectations and course objectives. Time: 30minutes

Objective: to make the participants feel valued by the team, to alleviate their fear make them feel relaxed, to know the nature of the program and what is expected of them.

Methodology: short presentation.

Materials: name tag, information booklet, writing materials.

Activities:

The investigator will greet everyone warmly and praise them for attending the program. Explain the nature of HASMEP and introduce the members of the team. The team wants to care for you and we will have to work together. So we need your cooperation. The nature of this course is to give you information and skills to live positively with HIV/AIDS and build new supportive friendships. The investigator will explain to the participants that, as a member of the team you are expected to:

- Accept responsibility for your health care.
- Trust the skills of other team members.
- Share information that pertains to your health.
- Come to appointments on time.
- Develop a relationship with the other team members.

The technical staff will give everyone a name tag. Ask them to write their names and pin it onto themselves. Play the rhythm clap game. This will help everyone to get to know each other's name and helps to break the ice. The information booklet specifically designed for PLWHA and learning materials will be given to the participants of the intervention group at the commencement of the program.

SESSION 2: INCREASING EMOTIONAL CAPACITY Time: 90minutes

- **Helping the participants to come to terms with their HIV status.**
- **Dealing with stigma.**
- **Increasing awareness of self importance.**

Objective: to help participants to come to terms with the fact that they have HIV.

Methodology: short presentation, role play and discussion.

Materials: flip chart, colored markers, drawing sheet, paper, and whiteboard.

Activities:

Ask the participants, who are you?

Give everyone a piece of paper and ask them to draw a picture. This picture should depict:

- Who you were before you knew you had the virus.

- Who you are now that you know you have the virus.
- Who you wish you could be.

Encourage them to use whatever they feel comfortable with to express themselves. Once everyone has had a chance to draw. Ask them to tell the group about their pictures. Allow the braver participants to start first, but make sure that everyone gets a turn.

Be especially sensitive to the shy people, or those who seem to be struggling. Once everyone has had a turn. Explain that everyone who has HIV can sometimes feel controlled by the virus. They sometimes feels like the virus owns them, makes decisions about their future. Explain that in this program we believe that PLWHA are able to be in control of their illness. Instead of feeling like the virus owns them, we rather want to believe that we own the virus and can make many more decisions about how healthy we want to be, what we want for our future and how much we will allow the virus to affect our lives. This training will help us understand the virus so that we can be more in control and stay healthy longer.

Allow the participant to stretch, or play a quick ice-breaker to give them a rest.

Note

This exercise helps participants to come to terms with the fact that they have HIV. It helps them understand the emotional and physical impact that HIV has had on them. It gives them an opportunity to express their feelings about what has happened to them. It is also useful for the facilitator to get an idea of what stage of acceptance each participant is in, that is, who has accepted their illness, and who is still in denial. This is an exercise in which participants will begin to share their stories. There may be some teachable moments or opportunities for participants to support one another.

Dealing with stigma

What is stigma?

Activities:

Explain that stigma is when people treat you differently once they know you have HIV. Stigma can make you feel very unhappy and stressed. Stigma can come from others or from us. Ask the group why they think that people stigmatize others with HIV. Write the answers on the whiteboard. Explain that stigma is mostly due to fear that if they keep HIV-infected people away they will stay safe. Explain that stigma can also come from within us. We can accept the stigma from others and believe things about ourselves that are not true:

- We stop accepting ourselves;
- We believe that we have done something bad;
- We believe that we deserve stigma; or
- We pretend that there is nothing wrong with us because we are so frightened.

This is so bad for our immune system, as we:

- Lose hope;
- Don't forgive ourselves;
- Don't try to learn about HIV;
- Don't get help; and/or
- Don't fight for our lives.

So we give up and get sicker faster!

Ask the participants what they can do to overcome their own stigma and the stigma of others.

Self-management strategies to overcome stigma includes:

- Learn as much about HIV/AIDS as possible.
- Teach others about HIV/AIDS.
- Accept yourself and believe that you deserve love and care.
- Understand that stigma from others comes from their own fears.
- Decide to choose life, and make a decision to fight it.
- Gain the skills needed to disclose your status.

Making me important

Activities:

Ask the participant to suggest ways in which they can make themselves and their needs important. Write these on the whiteboard.

Self-management strategies to make you important in the family include:

- Make sure that you get enough nutritious food.
- Do not allow everyone else to get the best food.
- Teach other household members to also do chores.
- Rest enough-this helps your immune system to stay strong.
- Do not carry all of the financial and parenting stress.
- Find ways to include other family members in handling the finances and parenting stress.
- Make time to talk to a counselor or friend if you have a problem.
- Make time to come to your clinic appointments as well as activities (such as support group) that will help you understand your illness and stay strong.
- Don't allow family members or friends to share your medicines-they should get their own medicine! You need all of your medicines to stay healthy.
- Take the time to find out what you need the most in each stage of your illness.

Wrapping up the session for the facilitator:

- Plan a fun game which will help participants remember each other's names.
- Praise the participants for completing their first visit.

- Collect the name tags and pictures that they drew.
- Give a date and time for next training.
- Ask participants to remember to be on time.
- Close with a song and / or prayer.
- Encourage participants to stay for snacks, and to use the time to get to know someone new.

SESSION 3: INCREASING KNOWLEDGE ABOUT HIV/AIDS Time: 60minutes

Definitions of HIV and AIDS.

Impact of HIV on immune system.

Relationship between CD4cells and HIV.

Opportunistic infections.

Stages of HIV/AIDS.

Objectives: participants will be able to;

Acknowledge adequate information about HIV/AIDS.

Self-monitor symptoms and relate laboratory results to their health.

Describe self-management strategies to keep their immune systems strong at every stage of their illness.

Methodology: Brainstorming, Short presentations and Discussion.

Materials: flip chart, colored markers, LCD and Computer, and Handout

Preparation: on flip chart paper, prepare the HIV and immune system graph.

Definitions of HIV and AIDS

Activities:

Explain that we can only fight an enemy if we know a lot about it. Use examples of war or crime. We can only know how to stop crime if we know where the gangsters stay, what their strategy is and when they are planning their activities. Explain that the HIV is the enemy. We start to fight the enemy through knowing as much as we can about how it works, what gives it strength, and what weakens it. Very quickly! Ask the participants to shout out one thing they know about HIV. Give each person a turn. Write the answers on the side of a whiteboard. Thereafter ask them to all shout out one thing they wish they could know about HIV. Again, do not comment on the answers; rather write them on the other side of the whiteboard. After the exercise, explain that you will be covering all the answers to their questions over the course of the sessions.

Note.

The aim of the exercise is to allow participants to tell the investigator what they know (or think they know) about HIV, and what they wish they know. This is not an opportunity to correct information or to give information. It is a useful tool for the facilitator to gauge the levels of

knowledge and to pick up some of the myths and misconceptions about HIV/AIDS. It is also a means of finding out what participants are most interested in and what their needs are.

What are HIV and AIDS?

HIV (human immunodeficiency virus) is a germ that enters the human body, where it breeds rapidly and multiplies.

What is immune system?

Every healthy person has a strong body defense against diseases. This defense system is called the immune system. White blood cells an important role in defending the body against all kinds of diseases. A CD4 cell is a type of white blood cell and is the main part of the immune system responsible for fighting invading infectious germs.

What does HIV do to the immune system?

When a person is infected with HIV, the virus will start to attack the immune system. HIV attacks mostly the CD4 cells. This is why the number of CD4 cells is a good way of checking how well your defense is working.

What happens to CD4s?

- CD4 cells decrease in number as HIV progresses.
- People with good immune system have CD4 counts between 450 and 1500.
- When the number of CD4 has decreased below 450, the person may start to have opportunistic infections.
- When the CD4 has decreased below 200, the person is at risk for very serious opportunistic infections.

What are opportunistic infections?

- All people, whether they have HIV or not, carry germs within them. These include bacteria, viruses, fungi, and other germs that our immune systems keep under control.
- If our immune system is weakened it can no longer suppress these germs and they can make us sick. We are also more vulnerable to catching new germs that our immune system would normally not let into our bodies at all.
- These are known as opportunistic infections. Opportunistic infections can include many different types of diseases that are commonly known such as TB, candidiasis, pneumonia, and others that are less commonly known such as Cryptococcus, meningitis, and toxoplasmosis.
- After the presentation, facilitate a Q and A on HIV and its impact on the immune system.

WHO clinical staging of HIV/AIDS

Explain that there are four stages of HIV/AIDS, generally related to the number of CD4 cells one has in the body. The lower the CD4 count, the more frequently the person will become ill. When the CD4 drops to below 200, this stage is referred to as the AIDS stage. Explain that there are different things one can do to stay healthy in each stage of illness. Reinforce the fact that it is not HIV that kills a person but opportunistic infections. Remind participants that most opportunistic infections are treatable! Explain that one way to fight opportunistic infections is to get help as soon as you start to feel it. Remind participants that we can prevent many of the opportunistic infections before they start by using cotrimxazole every day. This is called prophylaxis. Explain that in the next sessions we will show what to do for specific opportunistic infections. Ask participants whether they have any questions or comments.

Wrapping up the session

Thank everyone for their input.
Encourage them to be on time at the next session.
Close with a song and/or prayer.

Clinical stage 1

Asymptomatic
Persistent generalized lymphadenopathy

Clinical stage 2

Moderate unexplained weight loss (under 10% of presumed or measured body weight).
Recurrent respiratory tract infections.
Herpes zoster
Angular cheilitis.
Recurrent oral ulceration.
Popular pruritic eruptions.
Seborrhoeic dermatitis.
Fungal nail infections.

Clinical stage 3

Unexplained severe weight loss (over 10% of presumed or measured body weight).
Unexplained chronic diarrhea for longer than one month.
Unexplained persistent fever (intermittent or constant for longer than one month).
Persistent oral candidiasis.
Oral leukoplakia.
Pulmonary tuberculosis.
Severe bacterial infections.
Acute necrotizing ulcerative stomatitis, gingivitis, or periodontitis.
Unexplained anemia.

ts

Clinical stage 4

HIV wasting syndrome.
Pneumocystis pneumonia.
Recurrent severe bacterial pneumonia.
Chronic herpes simplex infection (orolabial, genital, or anorectal of more than one month's duration or visceral at any site).
Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs).
Extra pulmonary tuberculosis.
Kaposi sarcoma.
Cytomegalovirus infection (retinitis or infection of other organs).
Central nervous system toxoplasmosis.
HIV encephalopathy.
Extra pulmonary cryptococcosis including meningitis.
Disseminated non-tuberculous mycobacteria infection.
Progressive multifocal leucoencephalopathy.
Chronic cryptosporidiosis.
Chronic isosporiasis.
Disseminated mycosis (extra pulmonary histoplasmosis, coccidiomycosis).
Recurrent septicaemia (including non-typhoidal salmonella).
Lymphoma (cerebral B cell non-Hdskins).
Invasive cervical carcinoma.
Atypical disseminated leishmaniasis.
Symptomatic HIV-associated neuropathy or HIV-associated cardiomyopathy.

SESSION 4: POSITIVE LIVING AND SELF-MANAGEMENT Time: 60minutes

-Definition of positive living.

What is self-management?

Components of positive living and self-management.

Importance of exercise to PLWHA.

Objectives: participants will be able to:

Live well with HIV/AIDS and use self-management strategies at every stage of the disease.

Plan for future, list hope and desires.

Methodology: Brainstorming, short presentation and roleplay.

Materials: whiteboard, flip chart papers, colored markers, LCD and computer, and Handout.

Preparation: have blank white sheet of paper ready for distribution for the lifeline plan activity.

Activities:

-Introduce the session by asking participants what their understanding of positive living is. Write responses on the whiteboard. Then summarize, stating that good care for PLWHA starts with them. It starts with a sense of hope, self-respect, and a belief that

there are things you can do to improve your health and well-being. When these things are in place, then you will be able to think about future and plan for it. Ask participants if positive living is only for PLWHA. Tell participants that, in fact, all people need positive living in order to live well but that it is even more important for those who have life-limiting diseases such as HIV/AIDS. The more you do to support your immune system, the better you will feel. Point to the immune system graph and remind participants why it is so important to live positively.

- Give the presentation and emphasize self-management skills among PLWHA.

- After the presentation, invite a guest lecturer to speak. The speaker should be someone living with HIV/AIDS who would like to present on strategies of positive living, and provide advice on what they can do to support positive living and self-management skills.

- Facilitate a Q and A with participants and PLWHA speaker.

Show participants the slide on future planning. Ask them to prepare a 'life-line' and future plan. A life-line is simply a line of their life to date where they mark important events in their life (both happy and sad). The future plan is listed along a dotted line which represents the future. On this line participants should brainstorm the top three things they want to achieve and mark when they want to achieve it on the line of the future. They should then write down the main steps they feel they need to complete to achieve these future goals. These will not be shared but kept by participants to continue to work on until they have completed their future plan. Close this part of the session by summarizing the definitions of positive living and self-management.

What is positive living?

Positive living is when you reach a point where you accept your diagnosis and begin to feel hope. It is when you respect and love yourself, and want to care for yourself and others. This is including wanting to plan for the future to ensure that you and your loved ones are as best cared for as possible.

What is self-management?

Self-management is being able to manage your own emotions and be resilient in a range of complex and demanding situations. Self-management is underpinned by a high level of self-awareness; knowing your own triggers points in certain situations helps you to manage your reactions appropriately. Self-management is critical to any interaction with people, especially at times of conflict or disagreement, pressure and other frustrations. It requires you to be tenacious focused on the achievement of both short-term and long-term goals, irrespective of the obstacles or resistance that stand in the way. *Self-management refers to your ability, in a complementary partnership with your health care providers to manage the symptoms, treatment, lifestyle behavior changes, and many physical psychosocial challenges that you face each day.* Self-management is the product of positive living. It consists of having the knowledge, motivation and skills to keep you as healthy as possible. This includes knowing how to eat well, being committed to staying adherent to HAART, going to clinic appointment on time, and collaboration with health care providers among others.

What can positive living and self-management include?

- Accepting the HIV diagnosis and disclosing to those you love.
- Feeling hope.
- Learning as much as possible about HIV, what it does to the body, and how to protect you from and manage infections.
- Developing a daily schedule to promote a sense of security and stability.
- Eating enough nutritious foods and drinking enough water.
- Trying to maintain good hygiene and keep food and water clean to prevent infections.
- Getting regular, moderate exercise.
- Resting and relaxing.
- Knowing how to take medicines correctly.
- Planning for future. Preparing a will, saving money, deciding where children will live after your death.
- Spending time with friends and family.
- Having fun.
- Joining a PLWHA support group.
- Counseling and caring for others including other PLWHA.
- Practicing safer sex.
- Getting a life insurance.

Importance of exercise to PLWHA

Objective: participants will be able to demonstrate different types of exercise for PLWHA.

Methodology: Brainstorming, short presentation, sorting game, and discussion.

Materials: flip chart paper, paper cards, Handout.

Preparation: write the names of different types of common exercises on paper cards (one per card). For example, walking, singing, dancing, gardening, or playing football.

Activities: Pass out cards to participants with names of exercise written on them. Ask participants to stand in a circle. Call out the different types of exercise and select participants to demonstrate to the rest of the group. Summarize the types of exercise and the importance with participants. Allow them to practice for some time.

Note

Exercise improves wellbeing: regular exercise makes a person feel more alert, helps to relieve stress, improves sleep, and stimulates the appetite. Exercise is the only way to strengthen and build muscles. The body uses muscles to store energy and protein that the immune system can draw upon when required. Exercise is therefore especially important for maintaining the health of PLWHA. It may be that everyday activities such as cleaning, working in the field, and collecting firewood and water provide enough exercise. If a person's work does not involve much exercise program should be found that can be part of his or her daily life. Exercise should not be tiring or stressful; gentle muscle-building exercise is recommended. Walking, Running,

swimming, and dancing are all suitable. For people who are bedridden, the following exercises can be done in bed to increase circulation and improve joint and muscle health.

Limb/joint exercise: learn to exercise your joints, neck, shoulder, elbow, wrist, fingers, hands, hip, knee, ankles, and feet, and toes. Position changes also help for some joint exercise. Deep breathing and coughing exercises can also help prevent respiratory complication due to lack of movement.

SESSION 5: HIGHLY ACTIVE ANTIRETROVIRAL THERAPY (HAART) Time: 45minutes

Definition and description of HAART.

Self-management of medication adherence problems.

Keeping immune system as strong as possible in addition to HAART.

Objective: participants will be able to recognize HAART and adhere to their drug regimen.

Methodology: Brainstorming, short presentation and discussion

Materials: Flip chart paper, LCD and computer, HAART samples, Handout

Preparation: Collect some samples of HAART.

Activities:

Ask participants, what is HAART?

HAART (highly active antiretroviral therapy) is a form of treatment for HIV. It can also be called ARV (antiretroviral) therapy. To stop HIV from multiplying, you will need to take three kinds of medicine which stop the virus at different places in the CD4 cell. You need to take these three types of medicine every day. Some of the pills will need to be taken twice a day. HAART does not cure HIV. It stops HIV from growing while you take the treatment. If you stop taking the treatment, HIV multiplies again. So HAART is only helpful if you take it everyday for the rest of your life. You have to take it at exactly the same time everyday.

When can I go on HAART?

When you are in stage 3 or 4 or when your CD4 count is less than 200, you qualify for HAART.

What will HAART do for me?

HAART will stop the HIV from multiplying. It will reduce your viral load. So your immune system will have a chance to get better. When your immune system is back to normal, you will still have to take HAART.

Are there any problems with HAART?

All medicines can give you side-effects. HAART can sometimes make you feel unwell, especially when you start taking the pills. The side-effects don't usually last a long time, but you will need to see a doctor if you have side-effects. There are a few very serious side-effects. Ask

your doctor to tell you everything about the side-effects and what to do about them before you start on treatment. Your doctor should monitor your blood and your CD4 count regularly to make sure the pills are working.

Where can I get HAART?

From some government sites: ask your local health department. From a private doctor: make sure your doctor knows all about HAART. Try to choose a doctor who belongs to the HIV clinician society. These doctors should know a lot about HAART. From some privately funded clinics: never buy HAART from friends, relatives or people who do not have the qualifications to give this treatment. HAART can be very dangerous if it is not used properly.

What is medication adherence?

Medication adherence, or compliance, broadly means the extent to which the patient follows medical instructions in taking their medications.

Why is it important?

Poor adherence can lead to virological failure, the evolution drug resistance and subsequent immunological and clinical failure.

Self-management strategies to improve medication adherence

Many patients experience difficulty following medication recommendations, here are some strategies to improve medication adherence.

- Integrate your regimen into your daily routine.
- Keep a checklist of doses taken.
- Use a daily planner.
- Plan ahead for weekends and vacations.
- Keep your medication with you when travelling.
- Plan ahead for privacy.
- Keep a diary.
- Use a support network of friends or family.

Ten things that can be done in addition to HAART to keep the immune system as strong as possible for as long as possible.

- Positive living and self-management.
- Nutrition, hydration, and exercise.
- Hygiene and infection prevention.
- HIV/STD prevention.
- TB screening and treatment: ensure you are screened for active TB once a year, and if you have active TB complete your treatment.
- Cotrimoxazole prophylaxis.
- Regular health check-up.
- Symptom care and treatment of opportunistic infections.
- Medicine adherence.

-Counseling.

Wrapping up the session

- Praise the group for their achievements
- Give a date and time for next training.
- Close with a prayer.

SESSION 6: NUTRITION AND HIV/AIDS Time: 60minutes

- Food groups and their importance.**
- Relationship between nutrition and HIV.**
- Reasons PLWHA become undernourished.**
- Practice creating meals to help PLWHA.**

Objectives: participants will be able to: identify nutritious foods in the locality and prepare them to meet their nutritional needs; have adequate knowledge of the relationship between nutrition and HIV/AIDS.

Methodology: Brainstorming, short presentation, small group work, and sorting game.

Materials: Flip chart, colored markers, sample of locally available affordable foods.

Preparation: survey the local market and, with the help from technical staffs, buy locally available and affordable foods within each of the food groups. This includes energy giving food (staples, sugar, oils/fats); protein (animal and vegetable) and fruits and vegetables. Prepare four sets of signs to place on the table where the food is. One should say “go”, one “grow” and one “glow” and “water”.

Note

Prior to facilitating the session, the investigator will find out more about the dietary habits in the community, varieties of local food, hindrances that prevent healthy eating, and local or national food guides if available. Modification of the charts may be necessary to suit the local situation.

Activities:

Start presentation with the basics of food and nutrition. Ask the participants why do we eat? Why is good nutrition essential for all humans? Show the presentation slides, which list all the things good nutrition does for the body. Ask participants what constitutes a nutritious diet? Ask if it is OK to only eat the same thing all the time? Ask them what food they think may be bad for the body? Ask participants to explain the different food groups and what type of food fit within the different groups. Write down the answers on the whiteboard. Show the power point slide with explanations on the food groups and what they do. Ask participants if it is important to drink fluids such as water. Also ask how much water a person should consume in a day (2litres). Show the slide that reviews why hydration is important. Explain that participants will now be responsible for showing that they understand the three foods groups and hydration by dividing up the locally procure foods correctly. Divide participants into groups and tell them that they have

10minutes to divide the foods into each food group and place a sign in front of each. When each group is done, ask them to present their work offer corrections politely. After each group has presented, have everyone return to their desks.

Relationship between nutrition and HIV

Activities:

Explain that food can help prevent some of the damage done by HIV and that it can be used to fight the virus. Explain that HIV uses a lot of energy to replicate (make more virus). It steals this energy from the fat and muscles in our body. That is why PLWHA lose so much weight. We need our fat and muscles to help us stay strong and fit. So PLWHA need to eat more food than other people in order stay healthy. Eating powerful foods can keep us healthy. What should we eat? We should eat foods that give us a lot of energy and build our bodies. We should eat foods that contain vitamins and minerals that can fight the virus and protect the immune system. When infected with the HIV, the immune system works harder to fight infection. This uses up the body's energy and food. Infection and fever also uses up the body's food. People who are infected with HIV have to eat more.

HIV/AIDS makes you eat less. How?

PLWHA often do not eat enough because:

- They have no appetite and the food does not taste the same;
- Sore mouth, nausea and vomiting make it difficult to eat;
- Tiredness, isolation and depression reduce the appetite and the willingness to make an effort to prepare food and eat regularly;
- There is not enough money to buy food.

HIV/AIDS reduces the absorption of food. How?

Food, once eaten, is broken down by digestion into nutrients. These nutrients pass through the gut walls into the blood stream and are transported to the organs and tissues in the body where they are needed. HIV damages the gut wall and food is not absorbed properly. When a person has diarrhea, the food passes through the gut so quickly that it is not properly digested and fewer nutrients are absorbed. Reduced food intake and absorption lead to weight loss and malnutrition.

HIV/AIDS affects weight. How?

When a person does not eat enough food, or the food eaten is poorly absorbed, the body gets energy from the fat and muscles in the body. Then the person loses weight. If a person loses weight he or she needs to take action to increase weight to the normal level.

SESSION 7: FOOD, WATER SAFETY AND HYGIENE

Time: 20minutes

Food safety and hygiene practices include:

Sanitary disposal of faeces:

- Use a latrine and keep it clean and free from flies.
- Keep surroundings clean.
- Wash in hot water with soap; clothes, bedding, and surfaces that might have been contaminated with faeces.
- Wash hands after defecation.

Personal hygiene:

- Always wash hands with clean water and soap during and after preparation of food or eating, and after visiting the toilet. Dry hands on a clean cloth or towel or shake dry.
- Cover all wounds to prevent contamination of food during preparation and handling.
- Use safe, clean water from protected sources such as treated piped water supplies, boreholes, and protected wells. If the water is not from a protected source it should be boiled for 10 minutes before drinking or use. Care must be taken during collection and storage. Use clean containers and prevent contamination.

Hygiene in the kitchen:

- Keep all food preparation surfaces clean. Use clean dishes and utensils to store, prepare, serve and eat food.
- Wash vegetables and fruit with clean water.
- Cover food to prevent flies and dust from contaminating it.
- Keep rubbish in a covered bin (and empty it regularly) so it will not cause offensive smells and attract flies, which can contaminate food with germs.
- Germs multiply more quickly in warm food. Storing food in a refrigerator or cool place slows this growth. Cooking on high heat can also kill most germs. Food should be eaten as soon as it is cooked.
- Cover and store food in containers away from insects, rodents, and other animals. Store fresh food in a cool place or refrigerator where available.
- Cook food thoroughly, but do not overcook vegetables.
- Serve food immediately after cooking to avoid germs multiplying. Do not leave the food standing at room temperature before eating.
- Do not store raw and cooked foods together; use containers to avoid contact in between.
- Avoid storing leftovers unless they can be kept in a refrigerator or a cool place. Do not store them for more than one or two days and always reheat them at a high temperature to kill germs before eating.

Food hygiene for animal products:

- Cook meat and fish well; meat should have no red juices.
- Wash utensils surfaces touched by animal products with hot water and soap before preparing other foods.
- Keep meat and fish separate from other foods.

-Eggs should be hard-boiled. Do not eat soft-boiled eggs, raw eggs, cracked eggs or any food containing raw eggs.

-However careful one is, food-borne infections may still occur. When this happens, go and see your health care provider without delay in order to avoid life threatening dehydration.

UCSF HIV/AIDS SYMPTOM MANAGEMENT MANUAL: STRATEGIES FOR PEOPLE LIVING WITH HIV/AIDS will be used for sessions 8 to 13.

SESSION 14: SEEKING SOCIAL SUPPORT Time: 90minutes

Continuing friendships

Ask the group if anyone would like to share how it felt to meet new people. How has hearing the experiences of others changed the way they felt about themselves and their illness? Explain that we are designed to interact with other people. We cannot live in isolation. The most damaging aspect of HIV disease is that it isolates us through stigma, lack of information and fear. Explain that in order to gain support, skills, love and positive input, we need to choose friendships that will build us up and help us to stay strong and focused. One of the ways to do this is to continue friendship with those we have met. Another way is to become involved with a spiritual support group, like a church. However; it is always good in this context to disclose your status with a few spiritually strong people so that you are not isolated and will receive prayer and advice when needed. Explain that as we play a part in helping others, we in turn will receive help when we need it. Ask the group to spend some time sharing addresses, phone numbers and contact details with people they have met. This is good time to suggest the formation of support group or other activities. Allow the group to come up with their own suggestions. If possible, help them to choose a coordinator or group leader who can organize times or activities. Help the group to access any existing support group in the area. Ask the group whether there are any outstanding questions or issues that need to be addressed. Spend sometime wrapping up questions or comments.

Wrapping up the session

Praise the group for their achievements.

Encourage the group to stay involved with each other and take their health seriously.

Close with a graduation ceremony. Congratulate everyone for their participation in the program.

Ask them to come for their certificates in six weeks.

Obtain contact details of the participants.

UNIVERSITY OF KWAZULU-NATAL

***SELF-MANAGEMENT HANDBOOK FOR
PEOPLE LIVING WITH HIV/AIDS***



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SCHOOL OF NURSING.

2010

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The authors gratefully acknowledge the assistance of persons and organizations whose materials helped in the preparation of this handbook.

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Dr. Mendias E P and Dr. Paar D P both of the University Of Texas Medical Branch School Of Nursing also granted permission to use or adapt their instrument for Self-Management needs assessment.

This handbook might not have been developed without information from the following sources:

Symptom Management Strategies: A manual for people living with HIV/AIDS, San Francisco, California: University of California, San Francisco Regents, School of Nursing, 2004.

Counseling and Testing for HIV course handbook for participants. JHPIEGO An Affiliate of John Hopkins University, 2004.

HIV Patient's Handbook. AIDS Clinical Center (ACC) of International Medical Center of Japan, 2005.

Reproductive Choices and Family Planning for people living with HIV. World Health Organization, Geneva, World Health Organization, 2006.

Primary Health Care Standard Treatment Guidelines and Essential Medicines list, Essential Drug Programme. The National Department of Health, Pretoria, South Africa, 2008.

We appreciate your contributions and thank you all.

INTRODUCTION

This handbook was developed in response to self-management needs assessment of people living with HIV/AIDS in semi-rural KwaZulu-Natal, South Africa. The book will serve as a resource for PLWHA, primary care providers, HIV/AIDS counselors, nurses, trainers, program managers and technical advisors who organize or facilitate training events and advocacy workshops on HIV/AIDS self-management. It is designed to provide facilitators with the background information, materials, instructions and tips necessary to effectively facilitate self-management education among PLWHA. There are also materials to conduct a workshop to help PLWHA increase their skills in facilitating self-management activities. This handbook was developed based on information collected from PLWHA in semi-rural KwaZulu-Natal province South Africa and a thorough review of the literature on self-management education.

The focus on this handbook is on holistic care, support, treatment and self-management of PLWHA. It provides PLWHA with information about HIV/AIDS and support for dealing with being HIV-positive, including systematic, sustained enhancement of skills to enable them take active, leading role in their care. The handbook will also help PLWHA to engage in self-management behaviours and maintain such behaviours over time in order to maximize their health. It will help with the scale-up of HIV prevention, care and antiretroviral therapy (ART) in resource-limited semi-rural African settings.

The need for a guide on self-management by PLWHA prompted the investigator to embark on developing this Handbook and fill the gap. The handbook was developed following an extensive review of existing guides, ongoing services, and in consultation with stakeholders within and outside the country. The handbook is designed to suit the specific needs of PLWHA in the South African context, and serves as a guide for PLWHA in self-

management endeavors. We are pleased to make this handbook available to all those PLWHA engaged in HIV/AIDS self-management program. We would like to thank all those people who participated in the process of developing the handbook.

This handbook was designed to be a flexible resource that can serve training needs for a variety of audiences and settings. It is not a structured curriculum, but rather a collection of activities and materials that can be used individually or in combination. The handbook is designed to promote the greater involvement of PLWHA (GIPA) in treatment and self-care management.

This handbook is developed to fill the gap in healthcare and self-management of People Living with HIV/AIDS. Fulfilling needed information for follow-up including self-management education for People Living with HIV/AIDS. This will further help in the control and prevention of spread of HIV/AIDS in our communities.

TABLE OF CONTENTS

Unit One

GENERAL INFORMATION



General Knowledge about HIV/AIDS



How HIV Becomes AIDS



How HIV is spread



HIV cannot be spread in these ways:



Healthy Living



The Viral Load and the Progression of HIV Diseases



What is Viral Load (HIV-RNA level)?



The Viral Load and the Progression of HIV Diseases



What is a CD4+ lymphocyte?



Predict the likelihood of developing AIDS from the CD4+ count



Anti-HIV Therapy



Before starting anti-HIV treatment



Adherence to anti-HIV therapy regimen is critical if you want to make the therapy successful



Anti-HIV drugs approved in South Africa



Watch out for changes in your body



Care for oral conditions



Things to watch out



**Routine medical examinations:
keeping track of the state of your own health**



Medical expense and Social resources



Normal values for a routine test



Keep your records

UNIT TWO

ANTIRETROVIRAL THERAPY



Nucleotide Reverse Transcriptase Inhibitors (NRTI)



Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI)



Protease Inhibitors (PI)



Data Sheet

UNIT THREE

SYMPTOM MANAGEMENT



General Symptom Management Strategies



Anxiety



Constipation



Cough



Depression



Diarrhea



Dizziness



Fever



Constipation



Forgetfulness



Loss of Strength (Fatigue)



Nausea



Night Sweats



Pain in Arms, Hands, Legs, Feet (Neuropathy)



Shortness of Breath



Skin Abscesses (Boils)



Skin Blisters, (Painful) (Herpes Zoster)



Skin Rash (Dermatitis)



Skin Rash (Dermatitis) Cont'd



Swelling of Arms, Hands, Legs, Feet



Trouble Sleeping (Insomnia)



Weight Loss (Unplanned)



Weight Loss (Unplanned) Cont'd



White Spots in Mouth (Oral Thrush)



Vaginal Itching, Burning, and Discharge



Glossary / Thesaurus

UNIT FOUR



REPRODUCTIVE CHOICES AND FAMILY PLANNING

- You can have a healthy sexual life.
- Questions to ASSESS situation and needs.
- Do you know your partner's HIV status?
- ADVISE: Saver sex and living with HIV.
- ADVISE: Not in a sexual relationship.
- ADVISE: You can use almost any family planning method.
- ADVISE: Possible protection strategies.
- Know the facts about condoms.
- AGREE: Comparing methods.
- ASSIST, ARRANGE: Making a choice and a plan that works.
- ADVISE: Thinking about pregnancy: what you need to know.
- Risk of infecting the baby.
- AGREE: A good idea for you now? What to consider.
- ASSIST, ARRANGE: Having a baby.
- The male condom
 - how to use a male condom.
 - what to remember.
- The female condom.
 - how to use a female condom.
 - what to remember.
- The Pill
 - who can and cannot use the pill.
 - using the pill
- Long-acting injectable
 - who cannot use a long-acting injectable.

- using the injectable.
- Emergency contraception (EC).
 - emergency contraception pills (ECPs)
- Fertility awareness-based methods.
- Referral methods.
- For returning family planning users: help using your method.
- Family planning after childbirth.
- Tips for talking with your partner.
- Making reasonably sure a woman is not pregnant.

GENERAL INFORMATION

General Knowledge about HIV/AIDS

HIV is the virus that causes people to develop a condition called AIDS. HIV stands for: Human Immunodeficiency Virus. AIDS stands for: Acquired Immune Deficiency Syndrome. A virus is a very small organism (seen only with a powerful microscope) that can make people sick. HIV is different from other viruses, because it does not go away. Once a person is infected with HIV, s/he will always have HIV. Anyone who is infected with HIV can pass the HIV virus on to another person, even if the HIV-infected person looks and feels well and does not have AIDS.

When a person is infected with HIV, the virus attacks her/his immune system. The immune system in the body fights off infections. HIV will damage the immune system of an HIV-infected person until it cannot protect the body from infections that usually do not cause problems for people. When an HIV-infected person's immune system gets very weak and s/he begins developing infections, the person has AIDS.

How HIV Becomes AIDS

Being infected with HIV (also called being HIV-infected or HIV positive) is not the same as having AIDS. The table below shows the stages that a person who has been infected with HIV goes through.

| | |
|---------------------|--|
| Infection with HIV | <p>After getting infected with HIV, some people have symptoms such as fever, muscle and joint pains, or swollen lymph nodes for 1 to 2 weeks. Some people have no symptoms at all. After a person is infected with HIV, there is a period of time when s/he will not test positive for HIV but can infect other people. This is called window period, and it can last from several weeks to 3months.</p> <p>After the window period, the immune system of an HIV-infected person will begin to fight HIV by making antibodies. When this happens, an infected person will test positive for HIV.</p> |
| Asymptomatic (No | Many people who have HIV do not get sick for many years. Some people live without symptom of HIV for 10 years or |

| | |
|-------------------------------|--|
| symptoms) | <p>more.</p> <p>There are drugs that can help an HIV positive person stay healthy for a longer period of time. These drugs are called antiretroviral therapy. They slow down the damage that HIV does to immune system.</p> |
| Symptomatic (Has symptoms) | <p>At this stage, an HIV-infected person begins to have symptoms such as chest infections, fever, and diarrhea. These can often be treated.</p> |
| AIDS | <p>When the immune system of an HIV-infected person gets very weak, s/he begins to develop opportunistic infections. The infections are called opportunistic because they take advantage of the weakness in the immune system.</p> <p>AIDS is a group of opportunistic infections that includes cancers infections caused by viruses, bacteria, and fungi. Common AIDS-related opportunistic infections includes:</p> <ul style="list-style-type: none"> -PCP (Pneumocystis Carinii Pneumonia), a lung infection. -KS (Kaposki's Sarcoma), a skin cancer. -CMV (cytomegalovirus), an infection that usually affects the eyes. -TB (Mycobacterium tuberculosis), an infection that usually the lungs. <p>There are also other health problems related to AIDS, such as serious weight loss or brain tumors.</p> <p>A doctor will say that an HIV positive person has AIDS when the person develops one or more AIDS-related opportunistic infections and when the person's immune system is seriously damaged.</p> <p>AIDS is different in every HIV-infected person. Some people die soon after being diagnosed with AIDS, while others live fairly normal lives for many years.</p> |

| | |
|--|--|
| | |
|--|--|

How HIV is spread

Large amounts of HIV can be found in the following body fluids in an HIV-infected person: Blood; Semen (male sexual fluid); vaginal fluids (in women); and Breast milk. Other body fluids such as saliva (spit) or tears contain HIV in small amounts, but there are no known cases of people getting HIV through those fluids.

A person gets HIV when infected body fluids enter the blood. The main ways that HIV is passed or transmitted are:

By having sex with an infected person;

By using needles or syringes that have been used by an HIV-infected person; and

By an HIV-infected woman passing HIV to her baby while she is pregnant, during childbirth, or through breast milks.

HIV cannot be spread in these ways:

Hugging, touching or shaking hands; Being bitten by an insect; Sharing toilets, latrines or showers; Coughing or sneezing; Sharing dishes and eating utensils; Swimming in public pools; Using public phones; and Sharing food or drinks.

Healthy Living

Being infected with HIV does not mean that a person's life is over. PLWHA can use antiretroviral therapy and other special treatments to help them stay healthy.

There are also some simple actions that HIV positive people can take to better care for themselves physically and emotionally. These include the following:

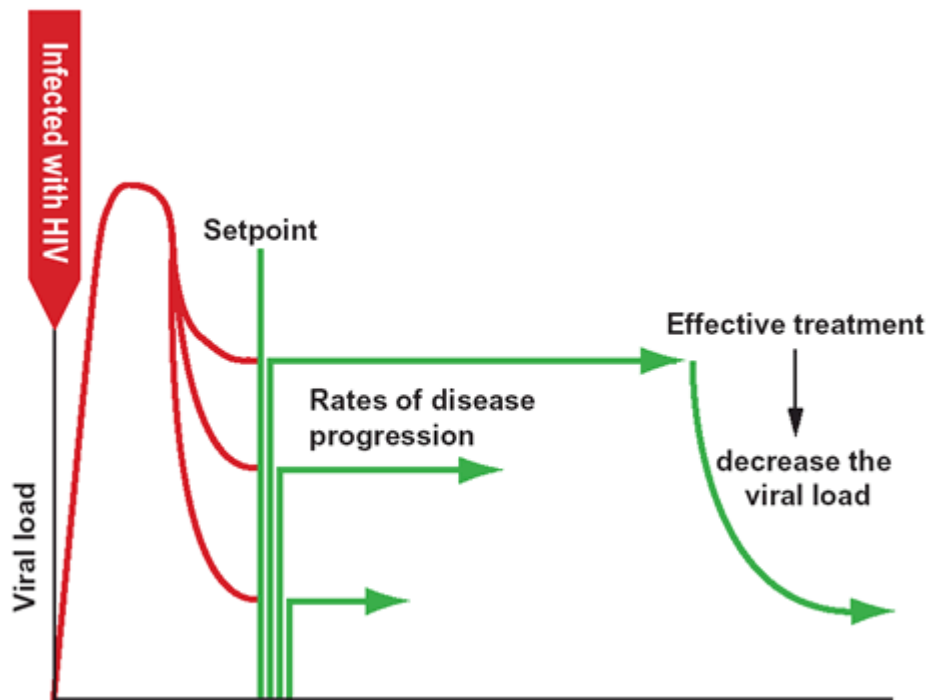
- getting regular medical checkups that include diagnosis and treatment of sexually transmitted and other infections.
- eating a healthy diet; exercising regularly; avoiding infections and illnesses.
- practicing safer sex to avoid getting and spreading HIV and other sexually transmitted infections.
- avoiding tobacco and drugs that people use recreationally (for fun) such as alcohol, marijuana or ganja and heroin.
- managing stress through exercise, support groups, meditation, spiritual practices, or other means.



The Viral Load and the Progression of HIV Diseases

- The viral load will begin to decrease naturally at about one month after getting infected with the virus.

- After six months, the viral load will reach a point beyond which no further decrease occurs. This point is called the setpoint.
- The higher the viral load at the setpoint, the more quickly the disease progresses.
- The treatment regimen is planned according to the viral load at the setpoint.

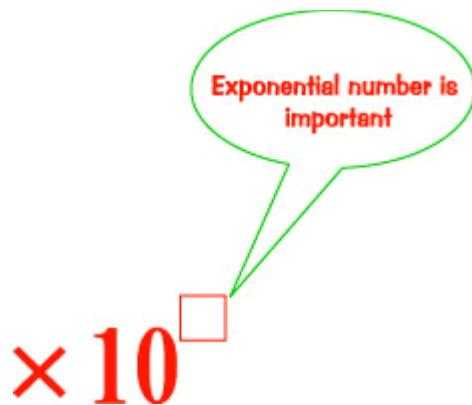


What is Viral Load (HIV-RNA level)?

What is Viral Load (HIV-RNA level)?

- The term "viral load" refers to the number of viruses in 1 ml of blood plasma.
- Generally, the lower the viral load, the better.

- Viral load can be an index for starting medication, and for evaluation of the drug effectiveness.
- For those under HIV treatment, the target viral load should be UD*.
- The viral load can fluctuate a bit, so make sure to compare the data from previous tests.



How to interpret the test result

| | |
|--------------------|---|
| Undetectable (UD*) | 400 copies/ml or less 50 copies/ml or less |
| 2.0×10^4 | 20,000 copies/ml |
| 5.4×10^5 | 540,000 copies/ml |

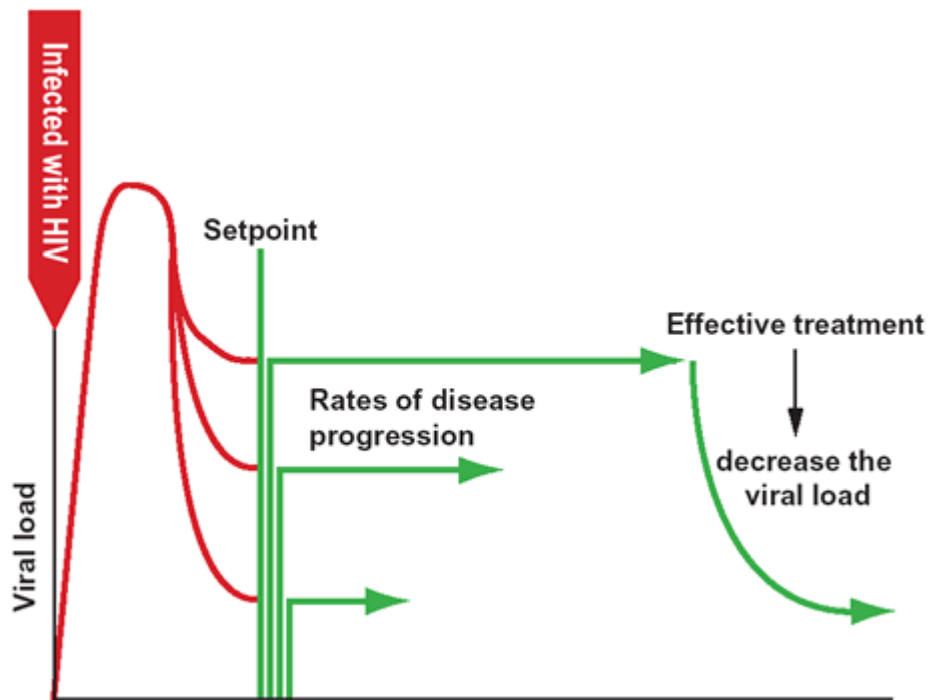
*Undetectable (UD) refers to the level at which the viral load is too low to measure in a viral load test.



The Viral Load and the Progression of HIV Diseases

- The viral load will begin to decrease naturally at about one month after getting infected with the virus.

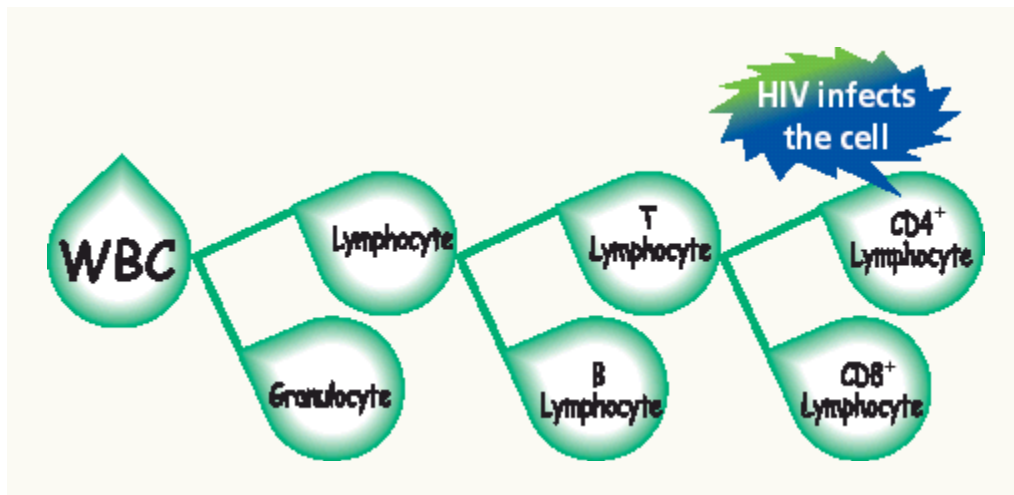
- After six months, the viral load will reach a point beyond which no further decrease occurs. This point is called the setpoint.
- The higher the viral load at the setpoint, the more quickly the disease progresses.
- The treatment regimen is planned according to the viral load at the setpoint.



What is a CD4+ lymphocyte?

- The number of CD4+ lymphocytes indicates what condition the immune system is in.
- A CD4+ lymphocyte is a type of white blood cells and acts as the "commanding officer" that controls the immune functions to attack germs and viruses.

- About 700 to 1,500 CD4+ cells are found in 1 μ l of blood in a healthy person.
- The higher the CD4+ cell count, the better it would be.
- HIV viruses replicate themselves within the infected CD4+ lymphocytes. They destroy the infected cells and as the result the number of CD4+ lymphocytes decreases.



•

Calculating the CD4+ cell count

$$\text{Number of WBC} \times \text{Lymphocyte\% (Ly \%)} \times \text{CD4+ lymphocyte\% (CD4\%)} = \text{Number of CD4+ Cells}$$

Example

$$6000 \times 0.24 \text{ (24\%)} \times 0.15 \text{ (15\%)} = 216$$

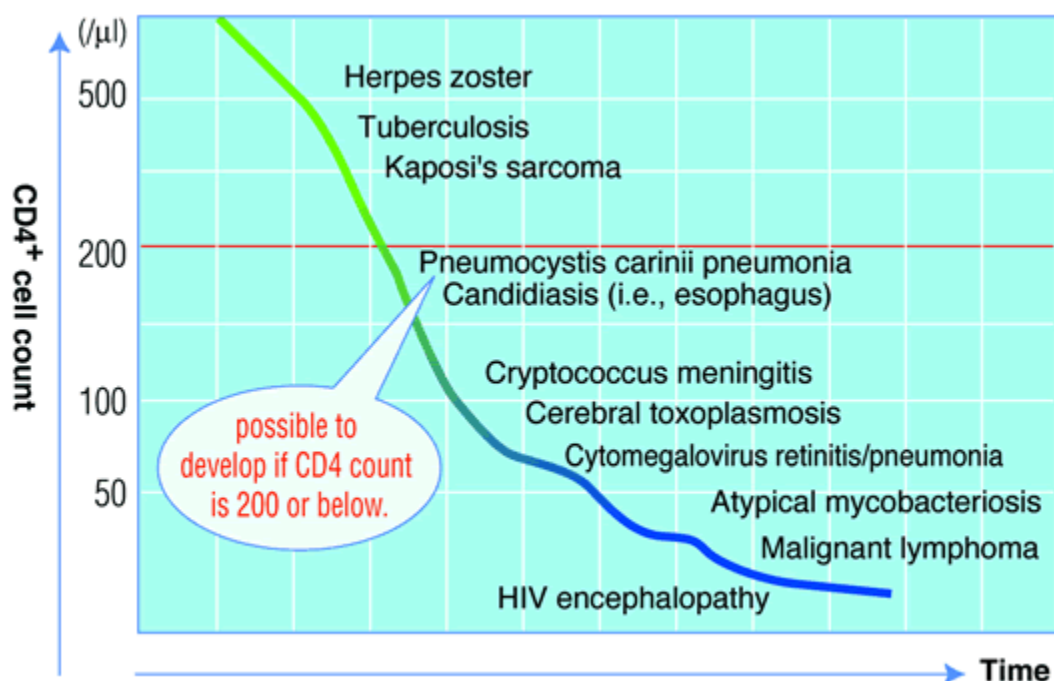
•

□– To compensate for the randomness in the cell counts, always look at the general trend of the data points taken from multiple tests.



Predict the likelihood of developing AIDS from the CD4+ count

- It is possible to predict what kinds of opportunistic diseases are likely to develop from the number of CD4+ lymphocytes found in blood.
- As the CD4+ cell count goes below 200/ μL of blood, various types of diseases could develop in the patient.



-
- Please take both of antibody and antigen tests early if you have developed any of them. Also, make sure to record the test results in the infection checklist.
- Take precautionary measures to reduce the risk of opportunistic diseases. For example, if your CD4 count is 200 or below, take the sulfamethoxazol/trimethoprim mixture (Baktar) to prevent *Pneumocystis pneumonia*.

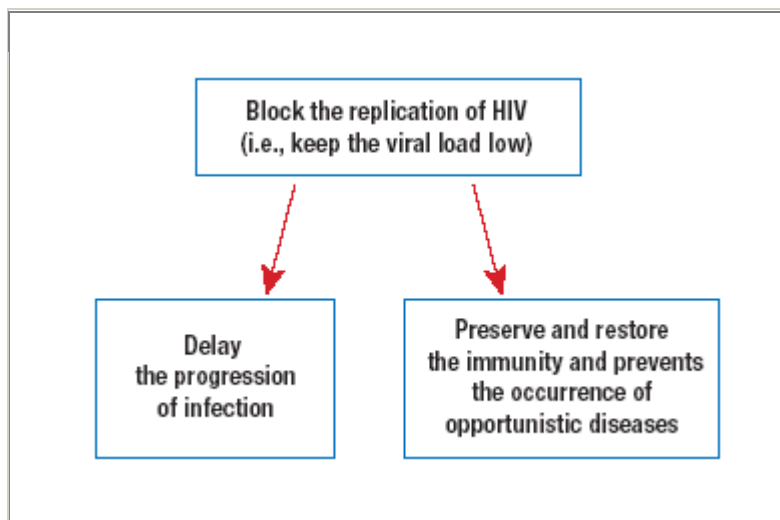
* *Pneumocystis carinii* has changed its name to *Pneumocystis pneumonia*.



Anti-HIV Therapy

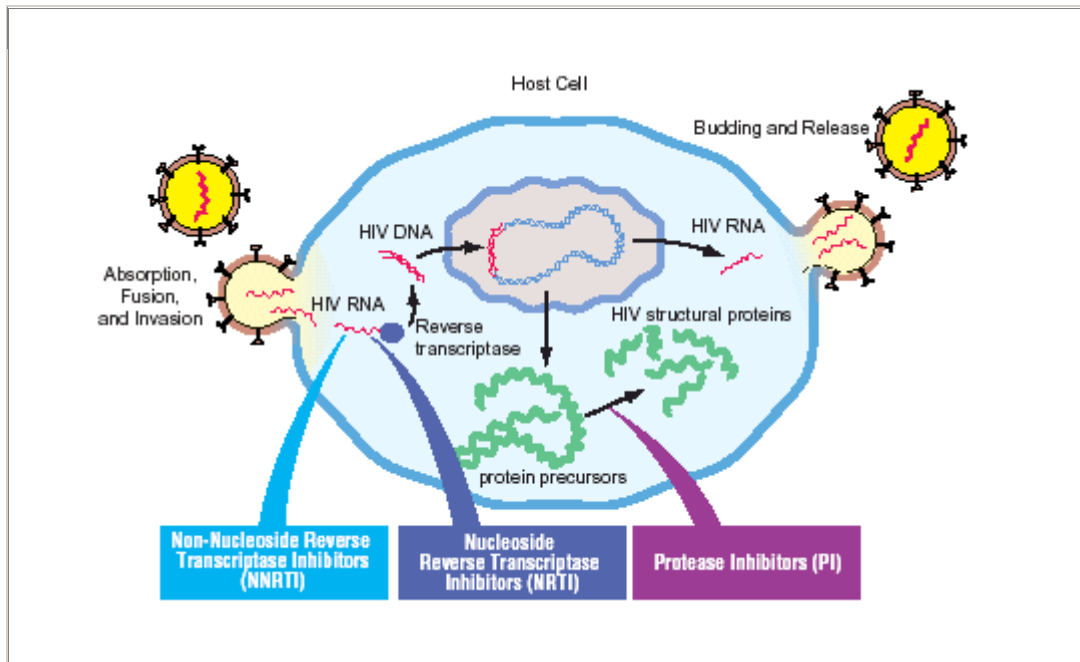
Anti-HIV therapy

- Objective



- Effects of Anti-HIV Drugs

To sufficiently prevent the viral replications, different types of drugs are used to act on different points of the replication cycle.



2. Prevention and Therapy of Opportunistic Diseases

- The risk of developing opportunistic diseases is prevented mainly by monitoring the number of CD4+ lymphocytes.

**Start/stop criteria for
primary prevention and preventive treatments**

| | Start criteria | Stop criteria |
|---|---|---|
| <i>Pneumocystis pneumonia</i> | CD4 count < 200/ μ l or oral candidiasis 1. One Baktar tablet daily 2. Inhaler administration of 300mg of pentamidine every 4 weeks (Note: Preventive treatment often fails) 3. Infusion of pentamidine (4mg) every 4 weeks 4. 100 mg of Dapsone daily | CD4 count is >200/ μ l for more than 3 months (if HAART is successful) |
| <i>Toxoplasmic encephalitis</i> | CD4 count < 100/ μ l and toxoplasma antibody (IgG) positive Two Baktar tablets daily | CD4 count is >200/ μ l for more than 3 months (if HAART is successful) |
| <i>Disseminated atypical mycobacteriosis</i> | CD4 count < 50/ μ l 1. 1200mg of azithromycin weekly 2. 800mg of clarithromycin daily (1000mg of clarithromycin daily in the US guideline) | CD4 count is >100/ μ l for more than 3 to 6 months (if HAART is successful) |

-
- For a patient with CD4 count <50/ μ l, CMV retinitis prevention will be considered.
- After the occurrence of opportunistic diseases, reoccurrence (secondary) preventions will be carried out.



Before starting anti-HIV treatment

It is important to consult your doctor and fully understand what anti-HIV treatment entails. You will need to consider carefully if the treatment plan would fit your current lifestyle. Ultimately it is up to you to decide if you have the willpower to adhere to the medication regimen. Relevant information is available to help you reach the decision.

The current criteria for starting the standard treatment regimen are as follows:

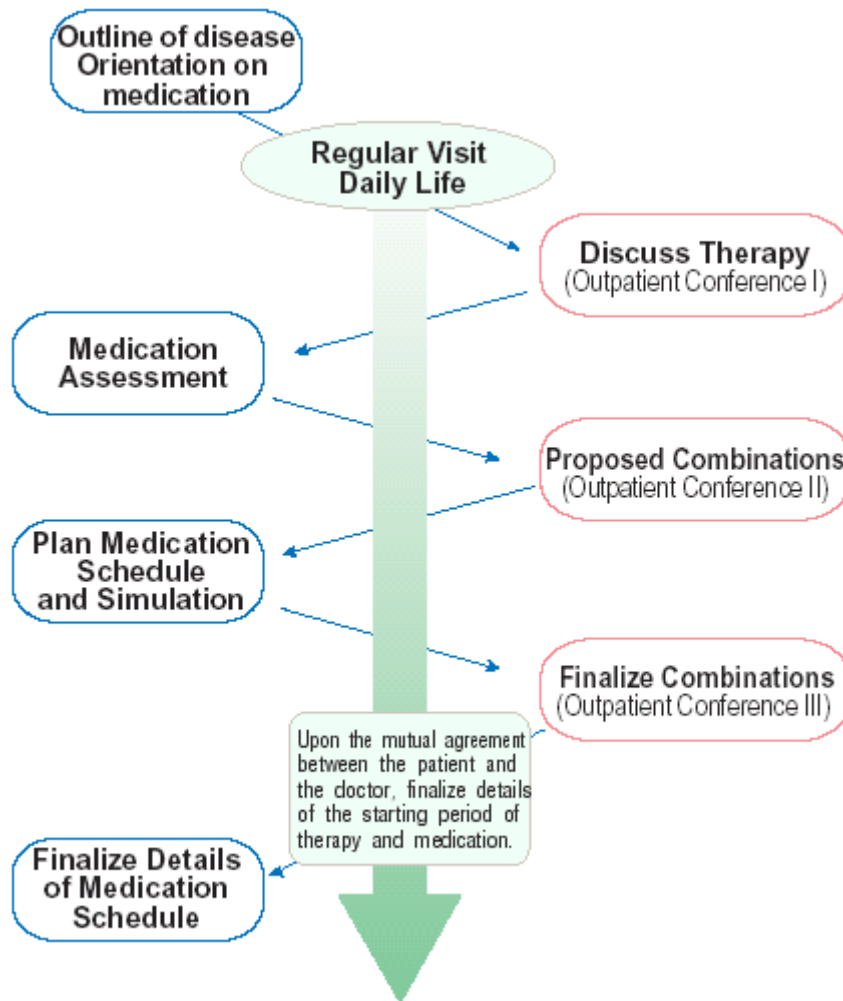
| | | |
|---|---|---------------------------------|
| ● If you have severe conditions of AIDS and AIDS related conditions | → | Start the treatment |
| ● If the number of CD4+ lymphocytes is 200/ μ l or below | → | Start the treatment |
| ● If the number of CD4+ lymphocytes is 350~200/ μ l and the speed of a decreasing number of CD4+ lymphocytes is 100/ μ l per annum or, If the number of viruses is 50,000-100,000 copies/ml or above. | → | Consider the start of treatment |
| The criteria for starting the treatment is based on two laboratory test data. (Source: HIV Infection "Guidelines on Therapy", Eighth Edition, published by Research Group for Therapy of HIV Infection) | | |

In addition to the above criteria, the following factors are taken into consideration to ensure successful treatment:

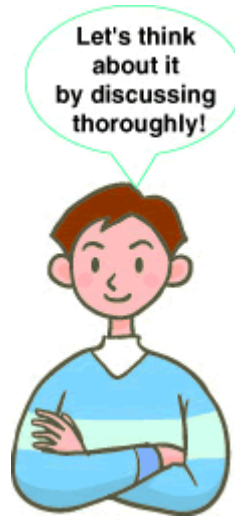
| |
|--|
| Understanding of the disease and treatment |
| Regular check-up |
| Management of complications |
| Daily life cycle |
| Support from friends and family members |
| Financial conditions |

- It might also be beneficial to seek a second opinion.

Pre-medication counselling process



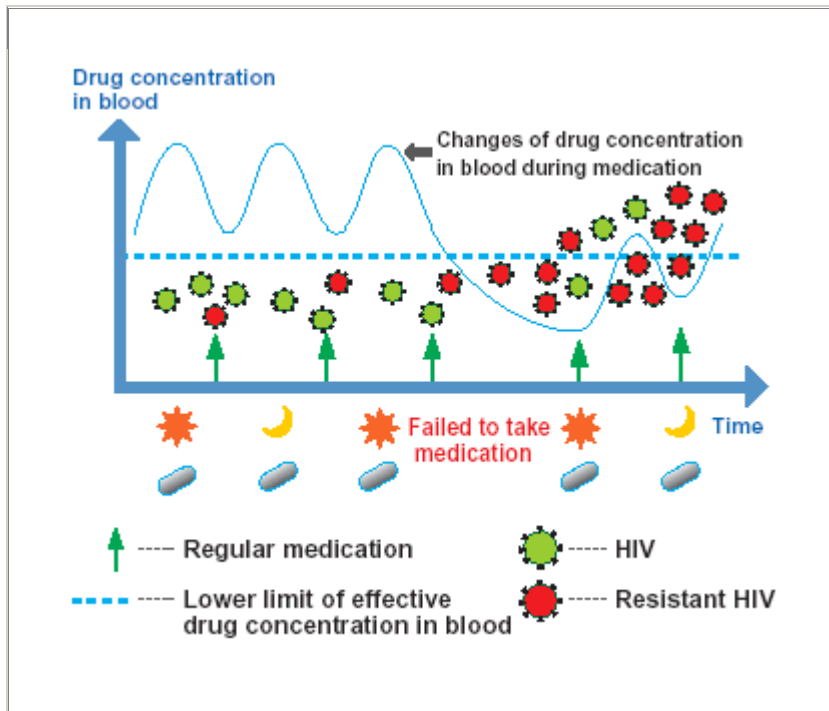
- If you develop side effects or have any concerns after starting the treatment, contact your doctor immediately. Do not stop or reduce the amount of drugs without consulting a medical professional.
- ALWAYS have the medical emergency number available with you.



Adherence to anti-HIV therapy regimen is critical if you want to make the therapy successful

What is a resistant virus?

- If you reduce or stop medication by your self-judgment, the drug concentration in blood will decrease and suppression of viral replication will be incomplete which may incur the danger of developing viruses that do not react to drugs, known as drug-resistant viruses.



What is cross-resistance?

- As a result of the emergence of drug-resistant viruses, other drugs which are structurally and/or functionally similar to the ones being used, will no longer work as cross-resistance develops.
- If the therapy does not show any results, a drug-resistance test is carried out. The test result, along with viral loads, the number of CD4+ lymphocytes and the medication regimen are all taken into consideration and you should discuss with your doctor on whether the therapy should be altered.



Anti-HIV drugs approved in South Africa

- The following drugs are available for use in anti-HIV therapies in South Africa:

| Names for drug | Product names | |
|--|-----------------------|------------|
| Nucleoside Reverse Transcriptase Inhibitors (NRTI) | | |
| zidovudine | Retrovir | AZT (ZDV) |
| didanosine | Videx | ddI |
| | Videx EC | ddI-EC |
| zalcitabine | Hivid | ddC |
| stavudine (sanilvudine) | Zerit | d4T |
| lamivudine | Epivir | 3TC |
| zidovudine/lamivudine | Combivir | AZT/3TC |
| abacavir | Ziagen | ABC |
| tenofovir disoproxil fumarate | Viread | TDF |
| lamivudine/abacavir | Epzicom | 3TC/ABC |
| emtricitabine/tenofovir | Truvada | FTC/TDF |
| emtricitabine | Emtriva | FTC |
| Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI) | | |
| nevirapine | Viramune | NVP |
| efavirenz | Sustiva (Stocklin) | EFV |
| delavirdine | Rescriptor | DLV |
| Protease Inhibitors (PI) | | |
| indinavir | Crixivan | IDV |
| saquinavir | Invirase | SQV (-HGC) |
| | Fortovase | SQV-SGC |
| ritonavir | Norvir Soft Capsules | RTV |
| | Norvir Liquid | |
| nelfinavir | Viracept | NFV |
| amprenavir | Agenerase (Prozei) | APV |
| lopinavir • ritonavir | Kaletra Soft Capsules | LPV • RTV |
| | Kaletra Liquid | |
| atazanavir | Reyataz | ATV |
| fosamprenavir | Lexiva | FPV |



Watch out for changes in your body

See your doctor immediately when you notice any changes in your body.

- As your immune system is destroyed, you might find certain conditions develop in your body. Some of these conditions include:

Fever, diarrhoea, constipation, headache, nausea, shortness of breath, inflammation of lymph nodes, sore mouth, white coating on tongue, red skin, skin rash or pain, tiredness, pain or itchiness on genitals, impaired vision, etc.

Ask your doctor immediately when you have any symptoms, and don't forget to record any changes of the condition in the patient datasheet as well.



Oral candidiasis



Fever



Shortness of breath



Herpes zoster (shingles)



Care for oral conditions

Please also talk to your doctor when you would like to see a dentist or notice any changes in your mouth.

Oral ailments

Cavities, gum bleeding, oral candidiasis, stomatitis, red

spots, dry mouth, white tongue, etc.

How to take care of your mouth

- **Brush your teeth**

Brush your teeth in short strokes with a small toothbrush. Pay particular attention to the gumline. Use an interdental brush or a floss to clean between the teeth as well.

- **Clean your tongue and mucous membranes**

You can clean the mucus membranes of your tongue, upper palate and inside the cheeks. Use a very soft brush or sponge brush to rub these areas gently.

- **Rinse your mouth**

Rinse your mouth when you can. □first brush your teeth, like going outside. Cavities and periodontitis have higher chances of developing if your mouth is dry. Use moisturising gel or alcohol-free mouth rinse as necessary.



Tell your doctor that you are HIV positive.

There are painkillers and antibiotics not compatible with anti-HIV drugs.

Obtain the list of contraindications for anti-HIV drugs.



Things to watch out

Daily routines

- Establish a pattern in your daily life cycle.
- Food: There is no special food to improve the immune function. It is most important to eat balanced meals that include many different food types. With that in mind we encourage you to evaluate your eating habits.
- Wash organic vegetables thoroughly because they tend to carry parasites.
- Drinking water: Try to drink only boiled water to avoid cryptosporidiosis and other infectious diseases.



Pets

You could contract various pathogens from your pets. Please see your doctor for advice if you have a pet.

Examples: *Cryptococcus* from pigeons and their faeces;

Toxoplasma from cats



Prevent secondary infections

Since HIV is found in blood, semen, and the vaginal fluid, beware of other people coming in direct contact with any of them.

- Do not share a razor blade or a toothbrush with others.
- Laundry can be done in the usual manner. If the clothes contain lots of blood, soak them in diluted hydrochloric bleach (i.e., Chlorox) for half an hour or so, and then wash them as normal.
- Do not donate blood.
- Used needles and syringes should be brought to the hospital in a needle disposal box.
- Avoid using alcohol or other mind-altering drugs when you have sex since they can damage your self-control.



- Please talk to your doctor or health care questions about pregnancy and delivery.



Routine medical examinations: keeping track of the state of your own health

Main purposes of routine check-ups

- Know the status of your immune function.
- Catch hidden problems early before they become serious.

You need to be checked regularly even if no apparent symptoms of AIDS have yet developed. Impaired immune function seldom manifests itself in the form of physical symptoms you can easily find and often needs the examinations to be detected. If you miss them, your immune function could be insufficient even if you are not aware of it.

Take your medications at the right times, and take preventative measures against opportunistic infections.

Other examinations you should take:

Eyegrounds examination:

As the immune functions are destroyed, the risk of developing cytomegalovirus retinitis increases. If your CD4 count is <200 , have your eyes checked regularly for early detection of the disease.

Gynecological tests (females only):

See a gynecologist on a regular basis to detect cervical cancer and other diseases.

Vaccinations work well against some infectious diseases.



Medical expense and Social resources

Anti-HIV treatment and hospitalization can be expensive. The followings are two social welfare supports that are available for HIV patients.

- **Physical Disability Certificate**
People with the acquired immuno-deficiency syndrome (AIDS) who are considered to have disabilities of their immune functions, are entitled to receive the Physical Disability Certificate. Please check with your medical institution if it applies to you or not.

Benefits you could receive:

- Part of the medical care payment exempted.
- Service by the local health care providers

- Benefit for high-cost medical care



There are other support systems available for you. See your health care provider for details.

HOW TO APPLY FOR THE DISABILITY GRANT?

You can apply for the disability grant by filling in an application form at your nearest **District Welfare office** or counter service point of a District Office. You do not need to pay anything to make the application.

You will be interviewed, have your fingerprints taken, and given information on whether you qualify for the grant. You will need to have certain documents and provide some information,

You will also have to undergo a medical examination. The degree of your disability will be assessed either by a doctor appointed by the state. You should bring along any previous medical records and reports both when you

make the application and when the assessment is done. The doctor will complete a medical report and will forward the report to the Department. The report is valid for three months from the date you are assessed.

When you make the application, you should say how you would like the money to be paid. The money can be paid out in cash on specific days at a Pay Point, or you can get the money paid electronically into your bank account. Remember that normal bank charges apply to any money going in and out of your bank account. You can decide to change the payment method at any time by filling in a form at a Welfare office, but the change will only happen a month later.

It will take about thirty working days for your application to be processed and checked, once the medical report is received, and either approved or refused. If your application is refused you will get a letter explaining why it has been refused and how you can appeal.

If it is approved you will start getting payments within 3 months. The payments will be backdated to the day you applied for the grant. You can find out what has happened to your application and when you can expect payment by telephoning the South African Social Security Agency's toll-free number on 0800 601 011.

The disability grant will be cancelled if you die, if you are admitted to a state institution, or if your income or assets improve so much that you no longer qualify in terms of the means test, or, in the case of a temporary disability grant, when the period of the temporary disability had lapsed. You must inform the Department if any changes in your circumstances.



Normal values for a routine test

Normal values for routine tests

| Item | Unit | Normal range | Purpose of test |
|-------------------|---------------------|----------------------------|------------------|
| Leucocyte count | (/ μ l) | 3500-9000 | Immune functions |
| Lymphocyte | (%) | 20-50 | |
| CD4 | (%) | 30.5-53.7 | |
| CD8 | (%) | 17.4-43.0 | |
| CD4/CD8 | | 0.5-2.3 | |
| CD4 count | (/ μ l) | 700-1500 | |
| CD8 count | (/ μ l) | 700 or more | |
| Viral load | (copy/ml) | 0 | Viral load |
| Hemoglobin | (g/dl) | Male 14-17 Female 12-16 | Anemia |
| MCV | (fl) | 80-100 | |
| Platelet | (10^4 / μ l) | 12-40 | Coagulation |
| AST(GOT) | (IU/l) | 0-35 | Liver function |
| ALT(GPT) | (IU/l) | 0-30 | |
| Triglyceride | (mg/dl) | 38-149 | Lipid metabolism |
| Total cholesterol | (mg/dl) | 140-219 | |



Keep your records

- Record the results of your examinations in a datasheet to keep track of the status of your immune functions.
- The datasheet is useful if you go to multiple medical institutions, because you can keep your data in one place and see how your condition changes.

- Keep the records of anemia, liver functions and lipid metabolism as well.

Data Sheet

No. _____

| Items \ Date | / / | / / | / / |
|--------------------------------|-----|-----|-----|
| Weight (kg) | | | |
| Leucocyte count (/μl) | | | |
| Lymphocyte (%) | | | |
| CD4 (%) | | | |
| CD8 (%) | | | |
| CD4/CD8 | | | |
| CD4 count (/μl) | | | |
| CD8 count (/μl) | | | |
| Viral load(copies/ml) | | | |
| Hemoglobin(g/dl) | | | |
| MCV (fl) | | | |
| Platelet (10 ⁴ /μl) | | | |
| AST(GOT) (IU/l) | | | |
| ALT(GPT) (IU/l) | | | |
| | | | |


UNIT TWO


ANTIRETROVIRAL THERAPY



Nucleotide Reverse Transcriptase Inhibitors (NRTI)



AZT(ZDV) | [3TC](#) | [ABC](#) | [AZT/3TC](#) | [3TC/ABC](#) | [d4T](#) | [ddI](#) | [ddC](#) | [TDF](#) | [FTC](#) | [FTC/TDF](#)

| | |
|--------------------|--|
| Name of drug | AZT(ZDV) |
| Generic name | Zidovudine |
| Trade name | Retrovir |
| Dosage from design | White, hard capsule |
| Symbol | GSYJU |
| Active ingredient | 1 capsule contains 100mg of AZT |
| Storage | Room temperature. Avoid exposure to light. |
| |  |
| Dosage | <p>Take 1 or 2 capsules 2 to 6 times daily. (Take 2 capsules 2 times daily.)</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. |

| | |
|-------------------|--|
| Main side effects |  <ul style="list-style-type: none"> Anemia (25%) Decrease in leukocytes (18%), Decrease in granulocytes (8%) Nausea (12%) Headache (6%) Abdominal pain (6%) Loss of appetite (6%) Thrombocytopenia (5%) Lactic acidosis (Frequency unknown) <ul style="list-style-type: none"> The frequency of side effects occurrence is based on domestic results, at the time of approval for the usage of drugs, and the results obtained by the usage of drugs. |
| Cautions | <ul style="list-style-type: none"> Some drugs cannot be used in combination with AZT or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |


[AZT\(ZDV\)](#) | [3TC](#) | [ABC](#) | [AZT/3TC](#) | [3TC/ABC](#) | [d4T](#) | [ddI](#) | [ddC](#) | [TDF](#) | [FTC](#) | [FTC/TDF](#)


| | |
|--------------------|---|
| Name of drug | 3TC |
| Generic name | Lamivudine |
| Trade name | Epivir |
| Dosage from design | 150mg: White lozenge, film coated tablet 300mg: Gray lozenge, film coated tablet |
| Symbol | GXCJ7 / GXEJ7 |
| Active ingredient | 1 tablet contains 150 mg or 300mg of 3TC |
| Storage | Room temperature |

| | |
|-------------------|---|
| | <div>   </div> <div> 150mg 300mg </div> <div> ZZZZ </div> |
| Dosage | <p>150mg tablet: Take 1 tablet 2 times daily.</p> <p>300mg tablet: Take 1 tablet once daily.</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Diarrhea (6%) • Anemia (5%) • Hyperlipemia (5%) • Nausea (4%) • Hepatic dysfunction (4%) • Lactic acidosis (0.3%) • The frequency of side effects occurrence is based on domestic results, at the time of approval for the usage of drugs, and the results obtained by the usage of drugs. |
| Cautions | <ul style="list-style-type: none"> • This drug can also be used to treat chronic hepatitis B. However, cases of worsening hepatitis B have been reported when patients stopped taking 3TC after six months of treatment. Always check for infections with hepatitis B if you are going to use 3TC (lamivudine). Do not stop taking the drug just at your discretion. • The dosage could be reduced in the presense of renal insufficiency. • Some drugs cannot be used in combination with 3TC or need to be treated with |



| | |
|--|---|
| | caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |
|--|---|

|[AZT\(ZDV\)](#)|[3TC](#)|**ABC**|[AZT/3TC](#)|[3TC/ABC](#)|[d4T](#)|[ddI](#)|
[ddC](#)|[TDF](#)|[FTC](#)|[FTC/TDF](#)

| | |
|--------------------|--|
| Name of drug | ABC |
| Generic name | Abacavir |
| Trade name | Ziagen |
| Dosage from design | Yellow, film coated tablet |
| Symbol | GX623 |
| Active ingredient | 1 tablet contains 300 mg of ABC |
| Storage | Room temperature |
| |  |
| Dosage | <p>Take 1 tablet 2 times daily.</p> <p>Take 2 tablets once daily.</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Skin rash (9%) • Hyperlipemia (8%) |

| | |
|-----------------|--|
| | <ul style="list-style-type: none"> • Hepatic function disorder(6%) • Dizziness (5%) • Diarrhea (4%) • Hypersensitivities (fever, rashes, fatigue, nausea, vomiting, diarrhea, abdominal pain, drowsiness, muscle and joint pain, headache, breathing difficulties, sore throat, and coughing): symptoms tend to manifest themselves within six weeks (avg.11 days) after starting the treatment. If symptoms develop, contact your doctor immediately to check whether to stop taking the drug or not. • The frequency of side effects occurrence based on domestic results of drug use. |
| Cautions | <ul style="list-style-type: none"> • If you stop taking ABC due to the development of hypersensitivity symptoms, please make sure that <u>you will never take drugs containing ABC (abacavir) again.</u> • Some drugs cannot be used in combination with ABC or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution."  |


[AZT\(ZDV\)](#)|[3TC](#)|[ABC](#)|**[AZT/3TC](#)**|[3TC/ABC](#)|[d4T](#)|[ddI](#)|
[ddC](#)|[TDF](#)|[FTC](#)|[FTC/TDF](#)

| | |
|--------------------|--|
| Name of drug | AZT/3TC |
| Generic name | Zidovudine, Lamivudine |
| Trade name | Combivir |
| Dosage form design | White to light yellow, film coated tablet |
| Symbol | GXFC3 |
| Active ingredient | 1 tablet contains 300 mg of AZT and 150 mg of 3TC |
| Storage | Room temperature |
| |  |
| Dosage | <p>Take 1 tablet 2 times daily.</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects |  <ul style="list-style-type: none"> • Nausea (10%) • Anemia (7%) • Diarrhea (5%) • Skin rash (4%) • Hypertriglyceridemia (3%) • Lactic acidosis (Frequency unknown) |

| | |
|-----------------|---|
| | <ul style="list-style-type: none"> The frequency of side effects occurrence is based on domestic results of drug use. |
| Cautions | <ul style="list-style-type: none"> The relapse of hepatitis B could occur if the patient stops taking 3TC (lamivudine). Make sure to check for hepatitis B if you are going to use AZT/3TC (Combivir). Do not stop taking the drug at your discretion. Some drugs cannot be used in combination with AZT/3TC or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and |

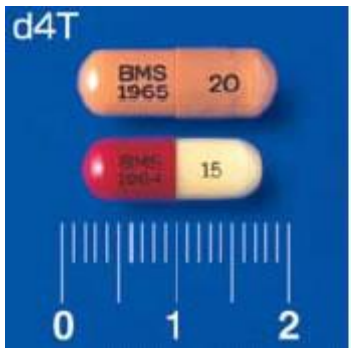

| [AZT\(ZDV\)](#) | [3TC](#) | [ABC](#) | [AZT/3TC](#) | **3TC/ABC** | [d4T](#) | [ddI](#) |
[ddC](#) | [TDF](#) | [FTC](#) | [FTC/TDF](#)

| | |
|--------------------|---|
| Name of drug | 3TC/ABC |
| Generic name | Lamivudine, Abacavir |
| Trade name | Epzicom |
| Dosage from design | Orange, film coated tablet |
| Symbol | GSFC2 |
| Active ingredient | 1 tablet contains 300 mg of 3TC and 600 mg of ABC |
| Storage | Room temperature |

| | |
|-------------------|--|
| |  |
| Dosage | <p>Take 1 tablet once daily.</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Please refer to the description provided in 3TC (lamivudine) and ABC (abacavir). |
| Cautions | <ul style="list-style-type: none"> • Be sure to carefully follow your hepatitis B condition after you stop taking the drug if you have chronic hepatitis B complications. • If you stop taking the drug due to the development of hypersensitivity symptoms, please make sure that you <u>will never take drugs containing ABC (abacavir) again.</u> • Some drugs cannot be used in combination with 3TC/ABC or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |

[AZT\(ZDV\)](#) | [3TC](#) | [ABC](#) | [AZT/3TC](#) | [3TC/ABC](#) | **d4T** | [ddI](#) | [ddC](#) | [TDF](#) | [FTC](#) | [FTC/TDF](#)

| | |
|--------------|-------------|
| Name of drug | d4T |
| Generic name | Sanilvudine |
| Trade | Zerit |

| | |
|--------------------|---|
| name | |
| Dosage from design | 15 mg: Brown and yellow, 20 mg: Light brown, hard capsule |
| Symbol | BMS 1964/BMS 1965 |
| Active ingredient | 1 capsule contains 15 mg or 20 mg of d4T |
| Storage | Room temperature |
| |  |
| Dosage | <p>Take 2 capsules 2 times daily (every 12 hours).</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. <p>Remarks:</p> <ul style="list-style-type: none"> • For patients weighing less than 60 kg, take two 15 mg capsules (30 mg) two times daily. • For patients weighing 60 kg or more, take two 20 mg capsules (40 mg) two times daily. |
| Main side effects | <ul style="list-style-type: none"> • Diarrhea (7%) • Hyperlipemia (7%) • Hepatic function disorder(6%) • Numbness of extremities (5%) • Nausea (4%) • Lipodystrophy (2%) • Lactic acidosis (1%)  <p><i>Numbness of extremities</i></p> <ul style="list-style-type: none"> • The frequency of side effects occurrence is based on |

| | |
|-----------------|---|
| | domestic results , at the time of approval for the usage of drugs, and the results obtained by the usage of drugs. |
| Cautions | <ul style="list-style-type: none"> Some drugs cannot be used in combination with d4T or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |
| Topics | <p><u>Hyperlactic acidemia / Lactic Acidosis</u></p> <p>For those who are taking NRTI, especially d4T/ddI, you may have mitochondria dysfunction. If you have subjective symptoms such as tiredness, nausea, or numbness of hands and feet after several months to several years from the start of taking d4T/ddI, please consult your doctor.</p> |

| [AZT\(ZDV\)](#) | [3TC](#) | [ABC](#) | [AZT/3TC](#) | [3TC/ABC](#) | [d4T](#) | **ddI** |
[ddC](#) | [TDF](#) | [FTC](#) | [FTC/TDF](#)

| | | |
|--------------------|--|--|
| Name of drug | ddI | |
| Generic name | Didanosine | |
| Trade name | Videx EC | Videx |
| Dosage form design | White, hard capsule | White, 3types of tablet |
| Symbol | BMS 125 mg 6671/BMS 200 mg 6672 | VIDEX |
| Active ingredient | 1 capsule contains 125 mg or 200 mg of ddI | 1 tablet contains 25 mg, 50 mg or 100 mg of ddI. |
| Storage | Room temperature | Room temperature. Avoid exposure to light. |

• @



Dosage

Take 2 capsules once daily.

Note: Take the drug at least an hour before or two hours after a meal.

- ddI should be taken with water (the ingredients of ddI are affected by acids. Juice and cow milk promote secretion of the stomach acids).

Remarks:

- For patients weighing less than 60kg, take two 125mg capsules (250mg) in a single dose.
- For patients weighing 60kg or more, take two 200mg capsules (400mg) in a single dose.

Take 2 tablets 2 times daily (every 12 hours).

Note: Take the drug at least an hour before or two hours after a meal.

- ddI should be taken with water, (the ingredients of ddI are affected by acids. Juice and cow milk promote secretion of the stomach acids).
- ddI tablets contains an adjustor for alkalis and acids. One tablet does not contain a sufficient amount of an adjustor. Take two or more tablets in a single dose. For example, take two 50mg tablets for a daily 100mg regimen.

• @

Taking the drug

Taking the drug

Tablets • You can either chew or swallow the broken bits with water, or mix the crushed bits with more than 40 ml of water until they are dissolved. Drink the mixture.

Main side effects

- Diarrhea (11%)
- Hepatic function disorder (7%)
- Increase of amylase (7%) Severe condition will cause pancreatitis.
- Nausea (5%)
- Loss of appetite (4%)
- Numbness (Peripheral neuropathy) (3%)
- Lactic acidosis (0.2%)
- Pancreatitis (Frequency unknown)

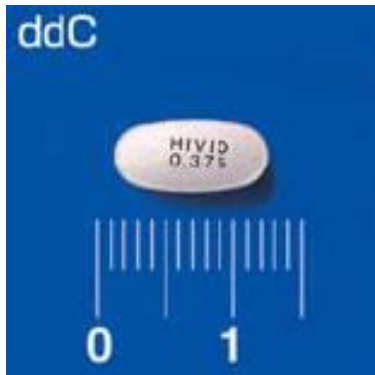



The frequency of side effects occurrence is based on **domestic results**, at the time of approval for the usage of drugs, and the results obtained by the usage of drugs.

Cautions

- Watch out for side effects if you take **ddI (didanosine)** with the drugs like **d4T (sanilvudine)** that can also cause peripheral neuropathy and pancreatitis.
- When combining with **IDV (indinavir)** or **RTV (ritonavir)**, take them two hours before or after taking ddI to avoid drug interactions.
- Taking more than 10 mg of ddI per 1 kg of bodyweight can increase the frequency of developing side effects.
- Some drugs cannot be used in combination with ddI or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution."


|[AZT\(ZDV\)](#)|[3TC](#)|[ABC](#)|[AZT/3TC](#)|[3TC/ABC](#)|[d4T](#)|[ddI](#)|
ddC|[TDF](#)|[FTC](#)|[FTC/TDF](#)

| | |
|--------------------|--|
| Name of drug | DdC |
| Generic name | Zalcitabine |
| Trade name | Hivid |
| Dosage from design | Light orange, tablet |
| Symbol | HIVID 0.375 |
| Active ingredient | 1 tablet contains 0.375 mg of ddC |
| Storage | Room temperature |
| |  |
| Dosage | Take 2 tablets 3 times daily (every 8 hours). <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects |  <ul style="list-style-type: none"> • Hepatic function disorder(4%) • Diarrhea (4%) • Nausea (4%) • Stomatitis (4%) • Peripheral neuropathy (3%) • Anemia (3%) • Lactic acidosis (Frequency unknown) |

| | |
|-----------------|---|
| | <ul style="list-style-type: none"> • Pancreatitis (Frequency unknown) <p>The frequency of side effects occurrence is based on domestic results, at the time of approval for the usage of drugs, and the results obtained by the usage of drugs.</p> |
| Cautions | <ul style="list-style-type: none"> • Taking ddC can seriously affect liver functions if you have complications in your liver, i.e., hepatitis B or C. If you have these conditions, have your blood regularly checked for transaminase concentrations. • Combining ddC with d4T (sanilvudine) tends to trigger peripheral neuropathy. • There is reported cases in which ddC combined with pentamidine isetionate, a drug used to treat Pneumocystis pneumonia, caused acute pancreatitis. <p>However, pentamidine isetionate is still sees some use when the ST mixture cannot be used.</p> <ul style="list-style-type: none"> • Some drugs cannot be used in combination with ddC or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |

| [AZT\(ZDV\)](#) | [3TC](#) | [ABC](#) | [AZT/3TC](#) | [3TC/ABC](#) | [d4T](#) | [ddI](#) |
[ddC](#) | **TDF** | [FTC](#) | [FTC/TDF](#)


| | |
|--------------|-------------------------------|
| Name of drug | TDF |
| Generic name | Tenofovir disoproxil fumarate |
| Trade name | Viread |

| | |
|--------------------|--|
| Dosage from design | Light blue, film coated tablet |
| Symbol | Front: GILEAD, Back: 300 |
| Active ingredient | 1 tablet contains 300 mg of TDF |
| Storage | Room temperature |
| |  |
| Dosage | <p>Take 1 tablet once daily.</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Increase of CK (CPK: creatine kinase) (11%) • Nausea (10%) • Diarrhea (9%) • Hypertriglyceridemia (8%) • Increase of amylase (7%) • Asthenia (6%) • Headache (5%) • Flatulence (excessive gas in the digestive tract) (3%) • Lactic acidosis (Frequency unknown) • Kidney failure (Frequency unknown) <p>The frequency of side effects occurrence is based on overseas clinical trial results.</p> |
| Cautions | <ul style="list-style-type: none"> • The dosage could be reduced in the presence of renal insufficiency. • Watch out for side effects if you take TDF with drugs like ddI (didanosine) that can |


| | |
|--|--|
| | <p>increase a risk of the side effects of ddI.</p> <ul style="list-style-type: none"> • The use of ddI (didanosine)+ 3TC (lamivudine)+TDF or 3TC (lamivudine)+ ABC (abacavir) + TDF, is not recommended because the combinations have failed virologically in many reported cases. • Be sure to carefully follow your hepatitis B condition after you stop taking TDF if you have chronic hepatitis B complications. • Some drugs cannot be used in combination with TDF or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |
|--|--|

|[AZT\(ZDV\)](#)|[3TC](#)|[ABC](#)|[AZT/3TC](#)|[3TC/ABC](#)|[d4T](#)|[ddI](#)|
[ddC](#)|[TDF](#)|**FTC**|[FTC/TDF](#)

| | |
|--------------------|----------------------------------|
| Name of drug | FTC |
| Generic name | Emtricitabine |
| Trade name | Emtriva |
| Dosage from design | Blue and white, hard capsule |
| Symbol | GILEAD-200mg |
| Active ingredient | 1 capsule contains 200 mg of FTC |
| Storage | Room temperature |

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| |  |
| Dosage | <p>Take 1 tablet once daily.</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Diarrhea (11%) • Dizziness (9%) • Nausea (8%) • Abdominal pain (6%) • Headache (5%) • Insomnia (5%) • Asthenia (5%) • Skin rash (4%) • Decrease in leukocytes (4%) • Indigestion (3%) • Abnormal dreams (3%) • Hepatic dysfunction (3%) • Hyperlipemia (3%) • Lactic acidosis (Frequency unknown) <p>The frequency of side effects occurrence is based on overseas clinical trial results.</p> |
| Cautions | <ul style="list-style-type: none"> • The dosage could be reduced in the presence of renal insufficiency. • It is not recommended to take FTC with drugs containing 3TC (lamivudine) because FTC has virologically similar in effect to 3TC. • Be sure to carefully follow your hepatitis B condition after you stop taking the drug if you have chronic hepatitis B complications. |

|[AZT\(ZDV\)](#)|[3TC](#)|[ABC](#)|[AZT/3TC](#)|[3TC/ABC](#)|[d4T](#)|[ddI](#)|
[ddC](#)|[TDF](#)|[FTC](#)|**FTC/TDF**

| | |
|--------------------|---|
| Name of drug | FTC/TDF |
| Generic name | Emtricitabine/Tenofovir |
| Trade name | Truvada |
| Dosage from design | Blue, film coated tablet |
| Symbol | GILEAD-701 |
| Active ingredient | 1 tablet contains 200 mg of FTC and 300mg of TDF |
| Storage | Room temperature |
| |  |
| Dosage | Take 1 tablet once daily. <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Please refer to the descriptions provided in FTC (emtricitabine) and TDF (tenofovir). |
| Cautions | <ul style="list-style-type: none"> • The dosage could be reduced in the presence of renal insufficiency. • It is not recommended to take FTC/TDF with drugs containing 3TC (lamivudine) since the ingredients of the drug, FTC (emtricitabine), is virologically similar in |



| | |
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| | <p>effect to 3TC.</p> <ul style="list-style-type: none"> • Watch out for side effects if you take FTC/TDF with ddI (didanosine) because this combination can increase the risk of the side effects of ddI. • Be sure to carefully follow your hepatitis B condition after you stop taking the drug if you have chronic hepatitis B complications. • Some drugs cannot be used in combination with FTC/TDF or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |
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Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI)


| **NVP** | [EFV](#) | [DLV](#) |


| | |
|--------------------|---|
| Name of drug | NVP |
| Generic name | Nevirapine |
| Trade name | Viramune |
| Dosage from design | White, tablet with a central split line |
| Symbol | |
| Active ingredient | 1 tablet contains 200 mg of NVP |
| Storage | Room temperature |

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|--------------------------|---|
| |  |
| Dosage | <p>Take 1 tablet 2 times daily.</p> <ul style="list-style-type: none"> • Treatment doses are one 200 mg tablet daily for the first 14 days, followed by one 200 mg tablet twice daily. • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Skin rash (17%) They tend to develop within 6 to 8 weeks after the treatment is begun. • Hepatic dysfunction (8%) • Fever (6%) • Diarrhea (4%)  <ul style="list-style-type: none"> • The frequency of side effects occurrence is based on the domestic results of drug use. |
| Cautions | <ul style="list-style-type: none"> • Some drugs cannot be used in combination with NVP or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |

|[NVP](#)|[EFV](#)|[DLV](#)|


| | |
|---------------------|-----------|
| Name of drug | EFV |
| Generic name | Efavirenz |

| | |
|--------------------|--|
| Trade name | Stocrin/capsule |
| Dosage from design | Dark yellow, hard capsule |
| Symbol | 3809 |
| Active ingredient | 1 capsule contains 200mg of EFV |
| Storage | Room temperature |
| |  |
| Dosage | <p>Take 3 capsules once daily just before bedtime, if possible.</p> <ul style="list-style-type: none"> • The recommended administration of EFV is just before bedtime in order to avoid side effects on the nervous system that affect daily activities. • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Dizziness (13%), Abnormal dreams (3%), Insomnia (3%), Drowsiness (2%), Attention-deficit disorder (1%) Neurological symptoms like dizziness may develop immediately after taking EFV, but fade away in 2 to 4 weeks or otherwise you get used to them. • Skin rash (8%) • Hyperlipemia (6%) • Hepatic dysfunction (4%) • Nausea (3%) They tend to develop within 2 weeks after taking the drug. • The frequency of side effects occurrence is based on domestic results, at the time of approval for the usage |

| | |
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| | of drugs, and the results obtained by the usage of drugs. |
| Cautions | <p>When you eat a lot of fat, wait for a few hours before you take EFV!</p>  <ul style="list-style-type: none"> • The drug concentration excessively increases if you take EFV right after a meal that contains a high amount of fat. Take the drug 2 to 3 hours after such a meal. • Some drugs cannot be used in combination with EFV or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |

| [NVP](#) | [EFV](#) | **DLV** |

| | |
|--------------------|---|
| Name of drug | DLV |
| Generic name | Delavirdine |
| Trade name | Rescriptor |
| Dosage from design | White to gray white, film coated tablet |
| Symbol | RESCRIPTOR 200 mg |
| Active ingredient | 1 tablet contains 200 mg of DLV |
| Storage | Room temperature |

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| Dosage | <p>Take 2 tablets 3 times daily.</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Skin rash (10%) • Nausea (7%) • Headache (6%) • Hepatic function disorder(4%) • Diarrhea (4%) • Fatigue (4%) • The frequency of side effects occurrence is based on overseas clinical trial results. |
| Cautions | <ul style="list-style-type: none"> • If you have a condition called achlorhydria (low stomach acid), take the drug with an acidic drink like orange juice to promote the absorption of DLV. • Some drugs cannot be used in combination with DLV or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |



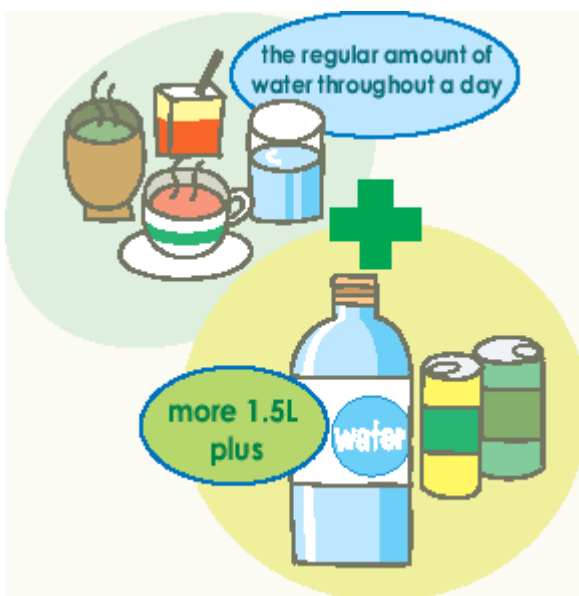
Protease Inhibitors (PI)

| **IDV** | [SQV](#) | [RTV](#) | [NFV](#) | [APV](#) | [FPV](#) | [LPV](#) & [RTV](#) | [ATV](#)

| | |
|---------------------|-----|
| Name of drug | IDV |
|---------------------|-----|

| | |
|--------------------|---|
| Generic name | Indinavir |
| Trade name | Crixivan |
| Dosage from design | White, hard capsule |
| Symbol | CRIXIVAN 200mg |
| Active ingredient | 1 capsule contains 200mg of IDV |
| Storage | Room temperature, No humidity (Place in a bottle containing a desiccator) |
| |  |
| Dosage | <p>Take 4 capsules 3 times daily (every 8 hours).</p> <p>Take the drug on an empty stomach: Take the drug at least an hour before, or two hours after a meal.</p> |
| Side effects | <ul style="list-style-type: none"> • Nausea (14%): because this drug is taken on an empty stomach, you might feel nauseated or even vomit. This can be somewhat alleviated if you eat low fat food like rice or noodles before taking the drug. • Increased bilirubin levels in blood (9%) • Kidney stones (9%): IDV (indinavir) itself could form a kidney stone. The symptoms include pains in the back and abdomen, as well as pains while urinating and blood in urine. <p>One preventative measure is to drink lots</p> |

| | |
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| | <p>of water, especially right before going to bed because the stones often develop while sleeping.</p> <ul style="list-style-type: none"> • Blood in urine (9%) • Ureteral calculus (5%) • Back pain (4%) • Diarrhea (3%) • Bleeding tendency (Frequency unknown) Patients with hemophilia might experience increased tendency of bleeding. Record the amount of blood products you use and keep a close eye on any changes you might notice. • Lipodystrophy (1%) • The frequency of side effects occurrence is based on domestic results, at the time of approval for the usage of drugs, and the results obtained by the usage of drugs. |
| <p>Cautions</p> | <ul style="list-style-type: none"> • Beware of high calorie, fat and protein food: the drug will not be well absorbed if taken shortly after eating these sorts of food. • Do not take IDV with grapefruit juice since it can lower the drug concentration in blood. • Drink enough water: to prevent kidney stones, the main side effect of IDV, drink at least 1.5 liter of water in addition to the regular amount you would take throughout a day. • If you are on ddI (didanosine), IDV should be taken two hours before or after taking ddI. • Some drugs cannot be used in combination with IDV or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |



Topics



Lipodystrophy:

For those who are taking the protease inhibitor, you may have a change in your body figure and may have impaired glucose tolerance and lipid metabolism disorder.

If you develop hypercholesterolemia and hyperglycaemia, or the loss of fat from your arms, legs and face while your trunk gains fat after several months to several years from the start of taking the drugs, please consult your doctor.

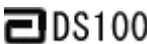


| [IDV](#) | **[SQV](#)** | [RTV](#) | [NFV](#) | [APV](#) | [FPV](#) | [LPV](#) | [RTV](#) | [ATV](#)


| | | |
|--------------|---------------------|------------|
| Name of drug | SQV | |
| Generic name | Saquinavir mesilate | Saquinavir |

| | | |
|--------------------|---|--|
| Trade name | Invirase | Fortovase |
| Dosage from design | Dark green and orange, hard capsule | Light yellow-red, soft capsule |
| Symbol | ROCHE 0245 | ROCHE 0246 |
| Active ingredient | 1 capsule contains 200 mg of SQV | 1 capsule contains 200mg of SQV |
| Storage | Room temperature, Avoid exposure to light | Refrigerator (2-8 • <C), Place the drug in a tightly sealed container |
| |  |  |
| Dosage | <p>For Invirase, take 3 capsules 3 times daily.</p> <p>Note: Take the drug after a meal.</p> <ul style="list-style-type: none"> Be sure to take Invirase within two hours after eating. When taken on an empty stomach, the concentration of Invirase in blood is drastically reduced. | <p>For Fortovase, take 6 capsules 3 times daily.</p> <p>Note: Take the drug after a meal.</p> <ul style="list-style-type: none"> Be sure to take Fortovase within two hours after eating. When taken on an empty stomach, the concentration of Fortovase in blood is drastically reduced. |
| Main side | <ul style="list-style-type: none"> Hepatic function disorder(7%) | |

| | |
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| effects | <ul style="list-style-type: none"> • Hyperlipemia (6%) • Diarrhea (6%) • Elevated triglyceride in blood (6%) • Nausea (5%) • Bleeding tendency (patients with hemophilia) (2%) • Lipodystrophy (1%) • The frequency of side effects occurrence is based on domestic results, at the time of approval for the usage of drugs, and the results obtained by the usage of drugs. |
| Cautions | <div data-bbox="472 911 993 1703"> </div> <ul style="list-style-type: none"> • Do not take SQV (Invirase, Fortovase) with grapefruit juice since it can raise the drug concentration in blood. • Some drugs cannot be used in combination with SQV or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |

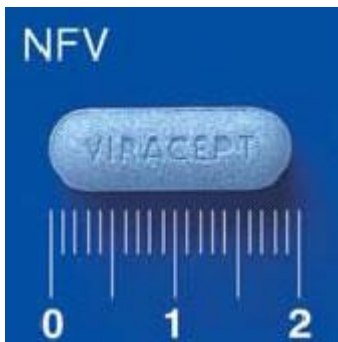
[IDV](#) | [SQV](#) | **RTV** | [NFV](#) | [APV](#) | [FPV](#) | [LPV](#) | [RTV](#) | [ATV](#)



| | | |
|--------------------|--|---|
| Name of drug | RTV | |
| Generic name | Ritonavir | |
| Trade name | Norvir soft gelatin capsule | Norvir liquid |
| Dosage from design | White, ellipsoidal soft capsule | Orange, liquid |
| Symbol |  DS100 | |
| Active ingredient | 1 capsule contains 100mg of RTV | 1ml contains 80 mg of Norvir |
| Storage | Refrigerator (2-8°C). Avoid exposure to light. Do not freeze. If you carry the drug, keep it below 25°C. | Room temperature (20-25°C) Avoid exposure to light. Do not freeze. Do not place in a refrigerator. If crystallized, shake the bottle and dissolve the drug. |
| |  |  |
| Dosage | <p>Take 6 capsules 2 times daily after a meal (every 12 hours).</p> <p>Note: Take the drug after eating.</p> | <p>Take 7.5 ml of Norvir liquid 2 times daily after a meal (every 12 hours).</p> <p>Note: Take the drug after eating.</p> |

| | | | | | | | | | | | | | | | | | | |
|-------------------|---|-----------|-----------------------------|-----------------|-----------------------------|---------|-----------------------------|---------|-----------------------------|--|-----------|----------------------------|-----------------|-------------------------|---------|----------------------------|---------|---------------------------|
| | <ul style="list-style-type: none">If you are taking ddI, RTV should be taken at least two and an half hour apart. <p>Remarks: Gradual dose escalation could prevent the emergence of side effects.</p> <table><tr><td>First day</td><td>Take 3 capsules times daily</td></tr><tr><td>2nd and 3rd day</td><td>Take 4 capsules times daily</td></tr><tr><td>4th day</td><td>Take 5 capsules times daily</td></tr><tr><td>5th day</td><td>Take 6 capsules times daily</td></tr></table> | First day | Take 3 capsules times daily | 2nd and 3rd day | Take 4 capsules times daily | 4th day | Take 5 capsules times daily | 5th day | Take 6 capsules times daily | <ul style="list-style-type: none">If you are taking ddI, Norvir liquid should be taken at least two and a half hours apart. <p>Remarks: Gradual dose escalation could prevent the emergence of side effects.</p> <table><tr><td>First day</td><td>Take 3.75 ml 2 times daily</td></tr><tr><td>2nd and 3rd day</td><td>Take 5 ml 2 times daily</td></tr><tr><td>4th day</td><td>Take 6.25 ml 2 times daily</td></tr><tr><td>5th day</td><td>Take 7.5 ml 2 times daily</td></tr></table> | First day | Take 3.75 ml 2 times daily | 2nd and 3rd day | Take 5 ml 2 times daily | 4th day | Take 6.25 ml 2 times daily | 5th day | Take 7.5 ml 2 times daily |
| First day | Take 3 capsules times daily | | | | | | | | | | | | | | | | | |
| 2nd and 3rd day | Take 4 capsules times daily | | | | | | | | | | | | | | | | | |
| 4th day | Take 5 capsules times daily | | | | | | | | | | | | | | | | | |
| 5th day | Take 6 capsules times daily | | | | | | | | | | | | | | | | | |
| First day | Take 3.75 ml 2 times daily | | | | | | | | | | | | | | | | | |
| 2nd and 3rd day | Take 5 ml 2 times daily | | | | | | | | | | | | | | | | | |
| 4th day | Take 6.25 ml 2 times daily | | | | | | | | | | | | | | | | | |
| 5th day | Take 7.5 ml 2 times daily | | | | | | | | | | | | | | | | | |
| Main side effects | <div></div> <ul style="list-style-type: none">Nausea (34%)Diarrhea (25%)Sensory abnormality (20%)Vomiting (15%)Numbing sensations around the mouth (13%)Hepatic function disorder(12%)Loss of appetite (12%)Change in taste(8%)Lipodystrophy (Frequency unknown)Bleeding tendency (patients with hemophilia, frequency unknown)The frequency of side effects occurrence is based on domestic results, at the time of approval for the usage of drugs, and the results obtained by the usage of drugs. | | | | | | | | | | | | | | | | | |
| Caution s | <ul style="list-style-type: none">The bitter taste of Norvir Liquid can be lessened by eating chocolates or drinking cold chocolate milk right before and after taking the drug.Norvir Liquid contains 43% ethanol, and caution should be exercised if you drive or otherwise get engaged in | | | | | | | | | | | | | | | | | |

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| | <p>hazardous activities.</p> <ul style="list-style-type: none"> • Smoking can lower the drug concentrations in blood. • Some drugs cannot be used in combination with RTV or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |
|--|--|

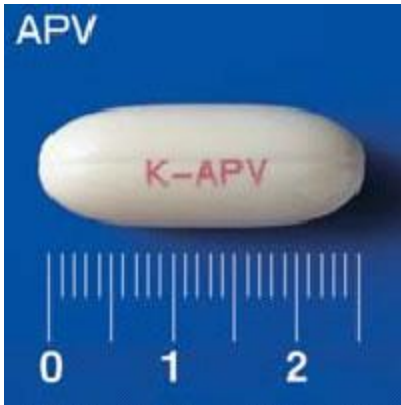

[IDV](#)|[SQV](#)|[RTV](#)|**NFV**|[APV](#)|[FPV](#)|[LPV](#)RTV|[ATV](#)

| | |
|--------------------|--|
| Name of drug | NFV |
| Generic name | Nelfinavir mesilate |
| Trade name | Viracept |
| Dosage from design | Blue, ellipsoidal tablet |
| Symbol | VIRACEPT250 mg |
| Active ingredient | 1 tablet contains 250 mg of NFV |
| Storage | Room temperature |
| |  |
| Dosage | <p>Take 5 tablets 2 times daily. Take 3 tablets 3 times daily.</p> <p>Note: Take the drug after a meal. If you take the drug on empty</p> |

| | |
|-------------------|---|
| | stomach, the absorption of the drug decreases less than half. |
| Main side effects | <div>  <p>Skin rashes develop in about 10 days from starting to take this drug</p> <p>↓</p> <p>Please contact the doctor</p>  </div> <ul style="list-style-type: none"> • Diarrhea (25%) • Skin rash (8%) • Hyperlipemia (6%) • Lipodystrophy (2%) • Nausea (4%) • Bleeding tendency (patients with hemophilia) • Hepatic dysfunction (3%) (Frequency unknown) <ul style="list-style-type: none"> • The frequency of side effects occurrence is based on domestic results, at the time of approval for the usage of drugs, and the results obtained by the usage of drugs. |
| Caution s | <ul style="list-style-type: none"> • Some drugs cannot be used in combination with NFV or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." |

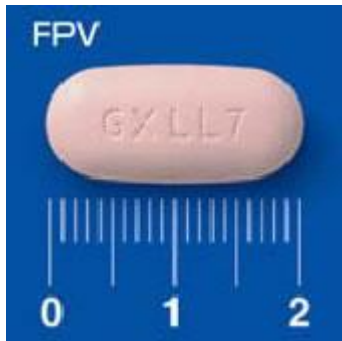
[IDV](#)|[SQV](#)|[RTV](#)|[NFV](#)|**APV**|[FPV](#)|[LPV](#)|[RTV](#)|[ATV](#)

| | |
|--------------|------------|
| Name of drug | APV |
| Generic name | Amprenavir |
| Trade name | Prozei |

| | |
|---------------------------|---|
| Dosage from design | Gray white to light yellow, soft gelatin capsule |
| Symbol | K-APV |
| Active ingredient | 1 capsule contains 150 mg of APV |
| Storage | Room temperature. Avoid high temperature and high humidity. |
| |  |
| Dosage | <p>Take 8 capsules 2 times daily (every 12 hours).</p> <ul style="list-style-type: none"> • Either on an empty stomach or with food. |
| Main side effects | <ul style="list-style-type: none"> • Nausea (46%) • Diarrhea (30%) • Skin rash (23%) • Numbing sensations around the mouth (22%) • Flatulence (17%) • Fatigue (17%) • Headache (15%) • Dizziness (8%) • Lipodystrophy (Frequency unknown) • Bleeding tendency (patients with hemophilia, frequency unknown) • The frequency of side effects occurrence is based on overseas clinical trial results.  |
| Cautions | <ul style="list-style-type: none"> • Do not take APV with high-fat food, as it compromises the absorption of the drug. |

- The absorption of APV could also decrease if you take antacids or ddI (didanosine). Take the drug at least an hour before or after taking them.
- Do not take supplementary vitamin E because it is already contained in this drug.
- The dosage could be reduced with liver impairment.
- Some drugs cannot be used in combination with APV or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution."




|[IDV](#)|[SQV](#)|[RTV](#)|[NFV](#)|[APV](#)|**FPV**|[LPV](#)∕[RTV](#)|[ATV](#)

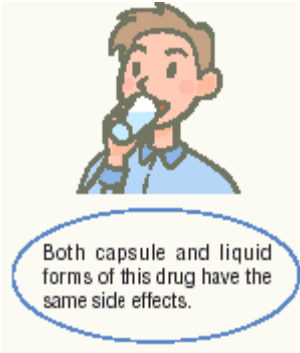
| | |
|--------------------|--|
| Name of drug | FPV |
| Generic name | Fosamprenavir |
| Trade name | Lexiva |
| Dosage from design | Rose pink to white, film coated tablet |
| Symbol | GXLL7 |
| Active ingredient | 1 tablet contains 700mg of FPV |
| Storage | Room temperature |
| • @ |  |

| | |
|--------------------------|---|
| Dosage | <p>For anti-HIV drugs naive patients</p> <ul style="list-style-type: none"> • Take one FPV tablet 2 times and one RTV (ritonavir) capsule 2 times daily. • Take two FPV tablets once and two RTV (ritonavir) capsules once daily. • Take two FPV tablets 2 times daily. <p>For HIV protease inhibitor experienced patients</p> <ul style="list-style-type: none"> • Take one FPV tablet 2 times and one RTV (ritonavir) capsule 2 times daily <ul style="list-style-type: none"> • Either on empty stomach or with food. • For patients with mild or moderate liver function disorder, take one FPV tablet 2 times daily without RTV (ritonavir). |
| Main side effects | <ul style="list-style-type: none"> • Diarrhea (8%) • Nausea (5%) • Skin rash (3%) • Fatigue (3%) • Headache (2%) • Abdominal pain (2%) • Hepatic dysfunction (2%) • Hyperlipemia (2%) • Lipodystrophy (Frequency unknown) • Bleeding tendency (patients with hemophilia) (Frequency unknown) <p>The frequency of side effects occurrence is based on overseas clinical trial results.</p> |
| Cautions | <ul style="list-style-type: none"> • The dosage could be reduced with liver impairment. • Some drugs cannot be used in combination with FPV or need to be treated with caution, thus please obtain a "List of |

Contraindications on Combined Usage of
Drugs and Drugs Requiring Caution."

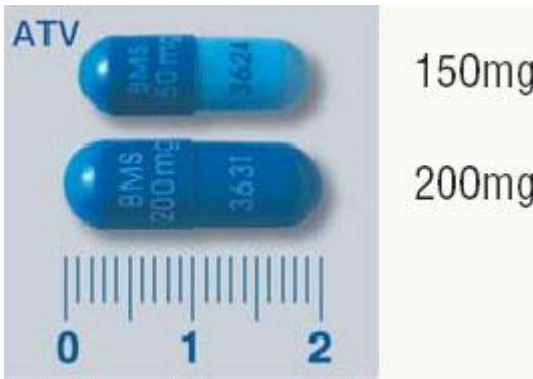
|[IDV](#)|[SQV](#)|[RTV](#)|[NFV](#)|[APV](#)|[FPV](#)|**[LPV](#)**~~RTV~~|[ATV](#)

| | | |
|--------------------|--|--|
| Name of drug | LPV • ERTV | |
| Generic name | Lopinavir and ritonavir combined drug | |
| Trade name | Kaletra soft gelatin capsule | Kaletra liquid |
| Dosage from design | Orange, ellipsoidal soft gelatin capsule | Light yellow to light brown, transparent liquid |
| Symbol |  PK | • @ |
| Active ingredient | 1 capsule contains 133.3mg of LPV and 33.3 mg of RTV | 1 ml contains 80 mg/mL of LPV and 20 mg/mL of RTV |
| Storage | Refrigerator (2-8 • <C). Avoid exposure to light. If you carry the drug, keep it below 25 • <C. | Refrigerator (2-8 • <C). Avoid exposure to light. If you carry the drug, keep it below 25 • <C. |
| • @ |  |  |
| Dosage | <p>Take 3 capsules 2 times daily.</p> <p>Note: Take the drug after a meal.</p> | <p>Adult : Take 5 ml 2 times daily.</p> <p>Child :For a child weighing from 7 kg to less than 15kg, give 12 mg/kg of LPV and 3</p> |

| | | |
|--------------------------|---|--|
| | <p>Remarks:</p> <ul style="list-style-type: none"> Take 4 capsules 2 times daily when taking with EFV (stocrin) and NVP (viramune). | <p>mg/kg of RTV 2 times daily. For a child weighing from 15 kg to 40 kg, give 10 mg/kg of LPV and 2.5 mg/kg of RTV 2 times daily. Maximum dosage is 400 mg of LPV and 100 mg of RTV (5 ml) 2 times daily.</p> <p>Note: Take the drug after a meal.</p> |
| <p>Main side effects</p> |  | <ul style="list-style-type: none"> Diarrhea (16%) Elevated total cholesterol (9%) Elevated triglyceride (9%) Nausea (7%) Asthenia (4%) Abdominal pain (4%) Hepatic dysfunction (4%) Lipodystrophy (Frequency unknown) Bleeding tendency (patients with hemophilia) (Frequency unknown) Bradycardia (Frequency unknown) <p>The frequency of side effects occurrence is based on overseas clinical trial results.</p> |
| <p>Cautions</p> | <ul style="list-style-type: none"> Kaletra Liquid contains 42.4% ethanol, and caution should be exercised if you drive or otherwise get engaged in hazardous activities. Some drugs cannot be used in combination with LPV • ERTV or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of Drugs and Drugs Requiring Caution." <div data-bbox="423 1499 1227 1869" style="border: 1px solid black; padding: 10px; margin-top: 10px;"> <p>Topics</p> <p><u>Immune reconstitution syndrome</u></p> <p>Some patients treated with a combination of anti-HIV drugs may show inflammatory reactions against opportunistic infections (e.g., mycobacterium avium complex, cytomegalovirus, pneumocystis etc) as immune</p> </div> | |

functions are recovering after initiating drug administration. Please pay careful attention to the symptoms can emerge in a week after medication starts, and in around 16 weeks in some cases.

|[IDV](#)|[SQV](#)|[RTV](#)|[NFV](#)|[APV](#)|[FPV](#)|[LPV](#)|[RTV](#)|**ATV**

| | |
|--------------------|---|
| Name of drug | ATV |
| Generic name | Atazanavir |
| Trade name | Reyataz |
| Dosage from design | Blue and light blue for 150mg and blue for 200mg, hard capsule |
| Symbol | BMS 150mg 3624 / BMS 200mg 3631 |
| Active ingredient | 1 capsule contains 150mg or 200mg of Reyataz |
| Storage | Room temperature. |
| |  |
| Dosage | <p>Take 2 capsules once daily.</p> <p>Note: Take the drug during or immediately after a</p> |

| | |
|-------------------|---|
| | <p>meal.</p> <p>Remarks:</p> <ul style="list-style-type: none"> Daily dosage for adults is 400mg, except for those with moderate liver disorder, for whom 300mg is recommended. For some patients, a combination of 300mg of ATV and 100mg of RTV (ritonavir) may be prescribed. |
| Main side effects | <ul style="list-style-type: none"> Elevated total bilirubin levels (47%) Nausea (16%) Increase of amylase (14%) Headache (14%) Skin rash (10%) Abdominal pain (10%) Elevated laboratory data of liver function (9%) Jaundice (8%) Depression (8%) Peripheral neuropathy (8%) Lipodystrophy (8%) Decrease in leukocyte (7%) Bleeding tendency (patients with hemophilia, frequency unknown) The frequency of side effects occurrence is based on overseas clinical trial results. |
| Cautions | <ul style="list-style-type: none"> If you are also taking ddI, Reyataz should be taken at least two hours before or after. 100mg of RTV (ritonavir) with 300mg of ATV is recommended if you are taking it with TDF (Tenofovir) and EFV (stocrin) because the drug concentration in blood could be lowered in combination. Some drugs cannot be used in combination with ATV or need to be treated with caution, thus please obtain a "List of Contraindications on Combined Usage of |



Data Sheet

Check list for infections No. _____

| Date | | / / | / / | / / |
|-------------------|----------------------|-----|-----|-----|
| Hepatitis A | Antibody | | | |
| Hepatitis B | s-antigen | | | |
| | s-antibody | | | |
| | e-antigen | | | |
| | e-antibody | | | |
| Hepatitis C | Antibody | | | |
| | | | | |
| Syphilis | Qualitative TPHA | | | |
| | Quantitative TPHA | | | |
| Amoebic dysentery | Antibody | | | |
| | | | | |
| Toxoplasmosis | Antibody | | | |
| Cytomegalovirus | Antibody | | | |
| Cryptococcus | Antibody | | | |
| | | | | |
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Data Sheet/ **Medical examination record** No. _____

| Date | / / | / / | / / |
|---------------------------------|-----|-----|-----|
| Weight (kg) | | | |
| Leucocyte count (/μl) | | | |
| Lymphocyte (%) | | | |
| CD4 (%) | | | |
| CD8 (%) | | | |
| CD4/CD8 | | | |
| CD4 count (/μl) | | | |
| CD8 count (/μl) | | | |
| Viral load (copies/ml) | | | |
| Hemoglobin (g/dl) | | | |
| MCV (fl) | | | |
| Platelet ($10^4/\mu\text{l}$) | | | |
| AST(GOT) (IU/l) | | | |
| ALT(GPT) (IU/l) | | | |
| Triglyceride (mg/dl) | | | |
| Total cholesterol (mg/dl) | | | |
| | | | |
| | | | |
| Name of drug | | | |
| Compliance to Medication | | | |
| Prevent of PCP | | | |
| Ophthalmologic examination | | | |
| Gynecological examination | | | |
| Other examination | | | |
| Hepatic ultrasonography | | 77 | |

Remarks

Bleeding record (for blood derivatives users)

No. _____

| Date | Time | Name/Dose Label | Site | Course of the condition, Effects, Side effects etc |
|------|------|--------------------|------|--|
| | | | | |
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Medication record

| | | | | | | | | |
|--------------|------|---|---|---|---|---|---|---|
| | Time | / | / | / | / | / | / | / |
| | | | | | | | | |
| Name of Drug | | | | | | | | |
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| | | | | | | | | |
| | | | | | | | | |
| | Time | / | / | / | / | / | / | / |
| | | | | | | | | |
| Name of Drug | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |

Body Temperature Sheet

| Date | | | | | | | | | | | | | | | | | | | | | | | | |
|------|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|
| Time | | | | | | | | | | | | | | | | | | | | | | | | |
| 40°C | | | | | | | | | | | | | | | | | | | | | | | | |
| 39°C | | | | | | | | | | | | | | | | | | | | | | | | |
| 38°C | | | | | | | | | | | | | | | | | | | | | | | | |
| 37°C | | | | | | | | | | | | | | | | | | | | | | | | |
| 36°C | | | | | | | | | | | | | | | | | | | | | | | | |
| 35°C | | | | | | | | | | | | | | | | | | | | | | | | |

() Sheet

| Date | |
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Unit Three

UCSF HIV/AIDS SYMPTOM MANAGEMENT MANUAL

STRATEGIES FOR PEOPLE LIVING WITH HIV/AIDS



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This manual may be fully copied, translated, and shared. Suggested Citation: *Symptom Management Strategies: A Manual for People Living with HIV/AIDS*, San Francisco, California: University of California, San Francisco Regents, School of Nursing, January 2004.

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This manual is intended for use by people living with HIV/AIDS, their formal and informal caregivers, and organizations working with these people. Any part of this manual may be copied or adapted without permission to meet your needs, provided that the parts copied are distributed free of charge and that the source is identified. Accepting monies or donations made for any such copies and distribution of this manual in part or in whole without prior permission are strictly prohibited.

Find us on the World Wide Web at www.ucsf.edu/AIDSnursing.

We would appreciate learning about the use or adaptation of this manual as well as receiving any comments or suggestions. You may send your comments in any of the languages of the manual. Please contact us, care of:

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TABLE OF CONTENTS

| | |
|--|----|
| Preface | i |
| Acknowledgements..... | i |
| General Symptom Management Strategies..... | 1 |
| Anxiety..... | 2 |
| Constipation | 3 |
| Cough..... | 4 |
| Depression..... | 5 |
| Diarrhea..... | 6 |
| Dizziness | 7 |
| Fever | 8 |
| Forgetfulness..... | 9 |
| Loss of Strength (Fatigue) | 10 |
| Nausea..... | 11 |
| Night Sweats | 12 |
| Pain in Arms, Hands, Legs, Feet (Neuropathy) | 13 |
| Shortness of Breath | 14 |
| Skin Abscesses (Boils)..... | 15 |
| Skin Blisters, (Painful) (Herpes Zoster)..... | 16 |
| Skin Rash (Dermatitis)..... | 17 |
| Swelling of Arms, Hands, Legs, Feet | 19 |
| Trouble Sleeping (Insomnia) | 20 |
| Weight Loss (Unplanned) | 21 |
| White Spots in Mouth (Oral Thrush) | 23 |
| Vaginal Itching, Burning, and Discharge | 24 |
| Glossary / Thesaurus | 25 |

PREFACE

This manual is a guide for self and family-based care for the management of symptoms commonly experienced by patients living with HIV/AIDS. Living with HIV/AIDS is a challenge for both the infected and affected individuals (family members, friends, caregivers, community members, employers, co-workers, etc.). Coping with and managing the numerous symptoms in all the stages of the illness can be even more daunting. The purpose of this manual is to provide strategies for controlling symptoms for people managing HIV-related symptoms.

ACKNOWLEDGEMENTS

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The manual further was developed following research done in four Southern African countries that are highly affected by HIV/AIDS: Botswana, Lesotho, South Africa, and Swaziland. This research was supported by the Bristol-Myers Squibb Company's *Secure the Future Foundation* for the project "Self and Family Care Symptom Management for Persons Living with HIV Disease" (RES009, Holzemer, Principal Investigator).

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Thanks to the Bristol-Myers Squibb Company's *Secure the Future Foundation*, which provided financial support for the research that partially made this manual possible.

Caring for your HIV-related problem:

GENERAL SYMPTOM MANAGEMENT STRATEGIES

The first step is always to contact your physician or nurse. By working together, a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, counseling, or other treatments.

All of these are suggestions and may not be possible in all situations. Do what you can.

Always take your medications as prescribed. Report any side effects or irregularities to your doctor or nurse.

Caring for your HIV-related problem:

ANXIETY

Problem: You may experience constant, worrisome thoughts and tension. You may experience: shaking, tight muscles, headache, dizziness, trouble breathing, fast heartbeat, irritability, or restlessness. Other symptoms may include: insomnia (trouble sleeping), difficulty concentrating, blank mind, or upset stomach.

This problem may be due to HIV infection, HIV medications, drugs, health problems, or other daily life situations.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the anxiety should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, counseling, or other treatments.

Self-care: Here some strategies that you may try to help you feel better:

- Try relaxing or stress-reducing activities such as deep-breathing exercises, meditation, personal “quiet time”, massage, listening to music or relaxation tapes, getting involved in activities (e.g. volunteer work), taking walks, leisure reading, taking a warm bath, Tai-Chi, etc.
- Consider attending a support group. These are usually free of charge and are often offered by HIV organizations in your community. If appropriate, check your phone book under "AIDS" or “HIV”, or with your local church. Be sure to check whether a group you are planning to attend has a specific focus and that you are interested in that topic; participate actively.
- Drink less caffeine (coffee, tea, and sodas).
- Eat fewer products containing sugar (including sodas).
- Go for a walk everyday at your own pace, in your home or outside. Exercise has been shown to reduce anxiety, depression, and fatigue.
- Drink a cup of warm milk or herbal chamomile tea before going to bed.
- Take your medication as prescribed. Report any side effects or irregularities to your doctor or nurse.
- You may also want to keep a diary to record you thoughts and feelings.

Caring for your HIV-related problem:

CONSTIPATION

- Problem:** You may experience problems with constipation, not passing stools for a week and/or experiencing a feeling of fullness in the stomach. You may take days before passing a stool.
- Treatment:** There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the constipation should be identified. By working together a treatment plan can be developed for you. This may include prescription or non-prescription medications or other treatment.
- Self-care:** Here are some strategies that you may try to help you feel better.
- Check with your physician or nurse before having an enema. You may use a small teaspoon of Sunlight™ soap (a very mild liquid soap) and lukewarm water.
 - Eat fruits and vegetables and drink warm water after meals.
 - Drink plenty of fluids (water, juice, non-caffeinated beverages) – at least six to eight 8-ounce glasses per day.
 - Eat papaya in the morning with breakfast.
 - Eat a high roughage diet.
 - Do not starve yourself.
 - You may need to do manual removal of impacts. Ask your local nurse about this procedure.
 - Exercise regularly.

Caring for your HIV-related problem:

COUGH

Problem: You may experience different types of cough. It may be persistent and dry, productive yellowish, greenish, or whitish.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the cough should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications (such as antibiotics) or other treatments. They may also treat the pain associated with the cough.

Self-care: Here are some strategies that you may try to help you feel better.

- Avoid rough foods that irritate the throat.
- Use a cough mixture.
- Inhale steam, using hot water with Vicks.
- Drink sips of hot water or warm fluids. You may add generous amounts of lemon.
- Drink tea or coffee.

Caring for your HIV-related problem:

DEPRESSION

Problem: You may feel “blue,” “low,” “depressed,” or “sad.” These feelings may also be associated with insomnia (trouble sleeping), weight loss, weight gain, or a change in your appetite. You may notice that you do not have any interest in things that once gave you pleasure. You may also feel “tired” or “fatigued” much of the time and not be able to think or have difficulty concentrating.

Depression is due both to changes in the usual chemicals of your brain and things going on in your life. HIV, other medications or health problems can cause depression too.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If you feel like you might hurt yourself or others, seek help immediately (eg. by calling your local emergency number, like 911), or going to an emergency room. If possible, the cause of the depression should be identified. By working together, a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, counseling or other treatments.

Self-care: Here are some strategies that you may try to help you feel better:

- Try relaxing or stress-reducing activities such as deep-breathing exercises, meditation, personal “quiet time”, massage, listening to music or relaxation tapes, getting involved in activities (e.g. volunteer work), taking walks, leisure reading, taking a warm bath, Tai-Chi, etc.
- Get involved in activities such as community groups, support groups, church groups, social clubs or sport activities.
- Consider attending a support group. These are usually free of charge and are often offered by HIV organizations in your community. If appropriate, check your phone book under "AIDS" or “HIV”, or with your local church. Be sure to check whether a group you are planning to attend has a specific focus and that you are interested in that topic; participate actively.
- Avoid or reduce your use of alcohol and other mood-altering non-prescription drugs (e.g., cocaine, speed, glue).
- Go for a walk everyday at your own pace, in your home or outside. Exercise has been shown to reduce anxiety, depression, and fatigue.
- Develop a routine of going to bed in the evening and getting up each morning at the same time. A good night’s sleep can help you think more clearly. Naps are okay, but keep them short and early in the day.
- Get up, wash, and get dressed at a regular time each day.
- Take your medication as prescribed. Report any side effects or irregularities to your doctor or nurse.
- Read and learn about depression.

Caring for your HIV-related problem:

DIARRHEA

Problem: You may experience three or more loose or watery stools (bowel movements) per day. (NOTE: If your diarrhea lasts for several days, you should contact your health care provider.)

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the diarrhea should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, or other treatments.

Self-care: Here are some strategies you may try to help you feel better:

- Eat frequent, small meals.

Foods / drinks to consume:

- Oatmeal, strawberries, potatoes, apples (peeled and allowed to brown), pears, bananas, yogurt, porridge.
- Ten glasses of water per day, oral rehydration solution, energy drinks (eg. GatoradeTM), ginger ale, diluted fruit juice, or ginger tea.

Foods / drinks to avoid:

- Caffeine, fast foods, fried foods, luncheon meats, hot dogs, bacon, chips, dairy products (except for yogurt), whole grains, cornmeal, bran, granola, wheat germ, nuts, seeds.
- Caffeinated, alcoholic and carbonated beverages.

Supplements:

- Acidophilus (you can purchase this nutritional supplement at a health food or drug store). Share your plan to take acidophilus with your doctor or nurse before starting this product to make sure it does not interfere with the rest of your treatment plan.
- MetamucilTM

Being prepared:

- When planning activities away from home, consider the availability of bathrooms.
- Consider taking an extra change of underpants with you if you will be away from your home for an extended period of time and an extra roll of toilet paper. Bring along (hand wipes) to clean your hands.
- Use absorbent shields to prevent the leakage of diarrhea onto clothing.

Skin care:

- Keep your skin clean by washing with warm water after each bowel movement if you can. Dry the skin thoroughly.
- If the skin is intact (no open cut), apply a cream containing petroleum (such as Vaseline or A&D ointmentTM) to protect the skin. (If the skin is open, contact your health care provider in case of infection, or for a prescription-strength ointment).
- Consider carrying a squeeze bottle filled with warm water and a spray cleaner with you when you go out, for personal hygiene.

Caring for your HIV-related problem:

DIZZINESS

Problem: You may experience black outs when trying to stand.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the dizziness should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications or other treatments.

Self-care: Here are some strategies you may try to make you feel better.

- Sit down and lower your head to below your knees to encourage circulation to the brain.
- Lie down and raise your feet to above your head.
- Drink plenty of fluids (water, juice, non-caffeinated beverages) – at least six to eight 8-ounce glasses per day.
- Rise slowly when waking up – sit up first.
- Eat high-energy foods.
- Eat a balanced diet.
- Eat green leafy vegetables in order to increase iron intake.
- Ensure adequate ventilation.
- Loosen tight-fitting clothing.

Caring for your HIV-related problem:

FEVER

Problem: You may experience abnormally high body temperature often accompanied by chills and shivering. You may also experience general body aches, irritability, loss of appetite and weakness.

This problem may be due to HIV infection, HIV medications, drugs, health problems or other daily life situations.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the fever should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, or other treatments.

Self-care: Here are some strategies you may try to help you feel better:

- Drink plenty of fluids (water, juice, non-caffeinated beverages) – at least six to eight glasses per day.
- Get plenty of rest to conserve energy and avoid fatigue.
- Take tablets or other medicine as directed by your doctor or nurse to lower your fever or high temperature.
- If you are taking antibiotics, be sure to take all of the medication (complete the course).
- Take your temperature when you feel sick. If it is more than 99°F (38°C), take it again in 3 to 4 hours. Keep a diary to help your health care provider treat your fever. New onset of fevers with temperatures above 101°F degrees (39°C) should be reported to your doctor or nurse within 24 hours. Where clinic nurses visit the patient, they will monitor the temperature and do the necessary referral.
- Avoid sponge baths or using fans as these may cause you to have chills and shivering. Shivering causes the temperature to rise even higher and should be avoided when possible.
- Keep the skin dry and covered.

If you develop chills and shivering:

- Change clothes when sweat soaked.
- Avoid drinking chilled or cold liquids. Drink warm liquids.
- Avoid baths.
- Wear socks or shoes when walking on cold floors.
- Wrap each arm (including the fingers) and each leg (including the toes) with towels or blankets. The rest of your body should be lightly covered with your clothing. It is better not to cover your entire body as this may cause your fever to rise.

Caring for your HIV-related problem:

FORGETFULNESS

Problem: You may experience problems with forgetfulness, poor memory and difficulty concentrating. You may also miss appointments, forget to take medications or forget to do things you usually do. You may note that you cannot follow a story in a book or have problems watching television.

Forgetfulness may be caused by HIV, by an infection in your brain, depression, medications, or other health problems.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the forgetfulness should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, counseling, memory reminders, or other treatments.

Self-care: Here are some strategies you may try to help you feel better:

- Write-up a daily/weekly schedule and try to stick as close to the same schedule as possible.
- Use a date book to write down your appointments or schedule. Remember to write down the appointment or schedule item right away so that it is not forgotten later.
- Ask friends or family members to help you remember things and keep your appointments or schedule.
- Develop a routine (e.g., keep your keys and date book in the same place everyday).
- Organize your medications in an easy way (e.g., pillbox) to help you remember to take them.
- Ask your health care provider to call you before your appointments to remind you of the date and time of the appointment.
- Avoid or reduce your use of alcohol and other mood-altering non-prescription drugs (e.g., cocaine, speed, glue).
- Develop a routine of going to bed in the evening and getting up each morning at the same time. A good night's sleep can help you think more clearly. Naps are okay, but keep them short and early in the day.

Caring for your HIV-related problem:

LOSS OF STRENGTH (FATIGUE)

Problem: You may feel tired or weary, exhausted, or experience a loss of concentration. Some fatigue in life is to be expected. Fatigue may be associated with stress, poor eating habits, inadequate sleep, mental strain, boredom, depression, or other conditions.

HIV infection, HIV medications, drugs or other health problems, such as anemia, can cause fatigue too. If you experience a marked reduction in your energy level or your fatigue persists despite adequate rest, report it to your physician or nurse.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the loss of strength should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications or other treatments.

Self-care: Here are some strategies you may try to make you feel better.

- Do small tasks to avoid fatigue.
- Drink energy drinks (eg. Gatorade) and/or take oral rehydration solution.
- Rise slowly when waking up – sit up first.
- Chew 2 to 3 cloves of garlic three times a day.
- When cooking vegetables ensure that they are not overcooked as vitamins get destroyed.
- Try relaxing or stress-reducing activities such as deep-breathing exercises, meditation, personal “quiet time”, massage, listening to music or relaxation tapes, getting involved in activities (e.g. volunteer work), taking walks, leisure reading, taking a warm bath, Tai-Chi, etc.
- Take breaks at work, mid-morning and mid-afternoon.
- Go for a walk everyday at your own pace, in your home or outside. Exercise has been shown to reduce anxiety, depression, and fatigue.
- Eat more of the following foods: oatmeal and other whole grain cereals, fruit and raw vegetables, whole grain baked goods, yogurt and low or non-dairy products.
- Limit the following foods: sugary foods, fast foods and other high fat foods. Reduce alcohol and caffeine intake, as these tend to make you sluggish later.
- Develop a routine of going to bed in the evening and getting up each morning at the same time. A good night’s sleep can help you think more clearly. Naps are okay, but keep them short and early in the day.
- Take your medication as prescribed. Report any side effects or irregularities to your doctor or nurse.
- Avoid or reduce your use of alcohol and other mood-altering non-prescription drugs (e.g., cocaine, speed, glue).

Caring for your HIV-related problem:

NAUSEA

Problem: You may experience nausea, upset stomach, retching, heaving, sickness of the stomach. At time, nausea is accompanied by vomiting. You may also experience headaches and loss of appetite (no desire for food), which may result in loss of weight.

This problem may be due to infections, HIV medications, other drugs, radiation treatments, emotional stress (anxiety), allergic reactions, or other health problems.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the nausea should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications or other treatments.

Self-care: Here are some strategies you may try to help you feel better:

- Use oral rehydration solution.
- Avoid odors, sights or sounds that trigger the feeling.
- Breathe in fresh air.
- Breathe in pleasant smells such as lemon or lime peels, and ginger.
- Use aromatherapy, such as extract of wild strawberry or ginger.
- Try relaxing or stress-reducing activities such as deep-breathing exercises, meditation, personal “quiet time”, massage, listening to music or relaxation tapes, getting involved in activities (e.g. volunteer work), taking walks, leisure reading, taking a warm bath, Tai-Chi, etc.
- Try to focus your mind on something pleasant (imaging). Look far away to relax your eyes.
- Avoid greasy foods, fried foods, and alcohol.
- Eat small portions of food when least sick.
- Try eating dry foods such as toast and crackers.
- Remain sitting for at least 30 minutes after eating.
- Try to eat and drink when you are not feeling sick.
- Save your favorite foods for when you are feeling well.
- Take your medication as prescribed. Report any side effects or irregularities to your doctor or nurse.
- Take frequent sips of water or suck on ice chips.

Caring for your HIV-related problem:

NIGHT SWEATS

Problem: You may experience sweating that is not related to exercise. Night sweats can occur during the day or night, but usually at night. You may wake up with your clothes and bed sheets soaking.

Night sweats are associated with HIV, or other conditions such as TB, itself and typically are not associated with fever and infection.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the night sweats should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications or other treatments.

Self-care: Here are some strategies you may try to help you feel better:

- Keep your skin warm and dry.
- Wear light cotton clothing and use fewer blankets.
- Open windows to allow ventilation and fresh air.
- Drink plenty of fluids (water, juice, non-caffeinated beverages) – at least six to eight glasses per day.
- Drink cold water.
- Sponge yourself with tepid water.
- Change your clothing and linen regularly.
- Place a towel over your pillow in cases of profuse sweating.
- After you wake up, towel dry, apply lotion to your skin, and then put on dry clothes.
- Have a change of clothes or dry linen nearby, especially when sweats occur at night.
- Talk to your doctor or nurse about taking any medication before going to bed at night.

Caring for your HIV-related problem:

PAIN IN ARMS, HANDS, LEGS, FEET (NEUROPATHY)

Problem: You may experience pain in your arms, hands, legs or feet, with a feeling as if there is water in the joint. You may also experience aching around the waist and knees and be unable to stand up and walk. You may have numbness and tingling of the feet and toes, and a sensation of needle pricks that is very painful. The pain may cause you to be unable to walk unaided.

Pain tingling burning or numbness in your arms, hands, legs, or feet may be due to HIV infection, HIV medications, drugs, or other health problems.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the pain should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications or other treatments.

Self-care: Here are some strategies you may try to help you feel better:

- Apply hot compresses for cold-related pain.
- Soak in cold water for heat-related pain, but no more than 10 minutes.
- Elevate your hands/feet above the level of your head.
- Do passive exercises with your hands/arms/legs/feet, or ask family member or friend to assist.
- Massage your hands/arms/legs/feet.
- Wear loose fitting comfortable shoes with padded soles.
- Avoid long periods of standing or walking.
- Consider wearing white cotton socks to reduce wetness due to sweating.
- Keep your hands/feet warm, but not so warm that they sweat.
- Try relaxing or stress-reducing activities such as deep-breathing exercises, meditation, personal “quiet time”, massage, listening to music or relaxation tapes, getting involved in activities (e.g. volunteer work), taking walks, leisure reading, taking a warm bath, Tai-Chi, etc.
- Have yourself checked by a health professional to exclude diabetes mellitus as the cause of the pain.

Caring for your HIV-related problem:

SHORTNESS OF BREATH

Problem: You may feel an unpleasant sensation of difficulty breathing, inability to take a deep breath, being “winded,” or a “smothering” feeling.

Shortness of breath may be associated with stress, anxiety, racing heartbeats, dizziness, or other ailments/complications.

Some shortness of breath, especially with strenuous activity, is to be expected. However, if you experience a change in your ability to “catch your breath” or have trouble with shortness of breath at rest, report it to your physician or nurse. Weakness due to HIV infection, HIV medications, drugs or other health problems can cause shortness of breath too.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the shortness of breath should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, or other treatments.

Self-Care: Here are some strategies you may try to help you feel better:

- Try relaxing or stress-reducing activities such as deep-breathing exercises, meditation, personal “quiet time”, massage, listening to music or relaxation tapes, getting involved in activities (e.g. volunteer work), taking walks, leisure reading, taking a warm bath, Tai-Chi, etc.
- Sit up straight to expand the chest as much as possible.
- Take a walk daily at your own pace, in your home or outside. Muscles that are weak from lack of activity or exercise can make you feel short of breath with any movement. Routine exercise can reduce your shortness of breath related to muscle weakness.
- Try to use these breathing strategies. The key is to inhale and breathe out slowly, where possible.
 - Pursed Lips Breathing: Breathe in normally through the nose while counting s-l-o-w-l-y to two; purse lips, as if about to whistle; breathe out slowly through your pursed lips (take twice as long as you did to breathe in - count slowly to four).
 - Controlled or Paced Breathing: This is the use of Pursed Lips Breathing with activities which make you winded, such as climbing stairs, walking quickly or lifting heavy objects. The key is to inhale slowly (at rest if possible) and exhale through pursed lips while performing the work. Focus on breathing out slowly and evenly.
- Contact your physician or nurse/clinic for further instructions or other breathing strategies.

Caring for your HIV-related problem:

SKIN ABSCESSSES (BOILS)

- Problem: You may experience painful swollen and closed boils on any part of your body.
- Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the skin abscesses should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications or other treatments.
- Self-care: Here are some strategies that you may try to make you feel better.

To ripen abscess / boil, use one or more of the following strategies:

- Apply hot compresses to the affected areas.
- Place the inside part of papaya peel over the boil over night, then wash with salty water.

If / when the abscess / boil opens:

- Drain the abscess / boil, then wash with salty water (the water should taste like tears) and cover with a clean cloth.
- Add the leaves of aloe tree to your washing water as an antiseptic.
- Wash the abscess / boil with diluted apple cider vinegar.

In general:

- Eat a diet high in protein and vitamin C to promote wound healing.

Caring for your HIV-related problem:

SKIN BLISTERS, (PAINFUL) (HERPES ZOSTER)

Problem: You may experience itchy discharging irritating blisters with pain and a burning sensation. You may also note watery rash in a group or cluster on one side of any part of the body.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the skin blisters should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medication or other treatments.

Self-care: Here are some strategies that you may try to make you feel better.

- Don't scratch or break blisters.
- Apply cold compresses over the blisters.
- Apply juice from aloe leaves to the affected area.

Caring for your HIV-related problem:

SKIN RASH (DERMATITIS)

Problem: You may experience skin rashes or changes in skin condition that may be short or long lasting. You may experience redness, itching, swelling or pain. Depending on the cause, they may occur anywhere on the body.

This problem may be due to different kinds of infection. It may be caused by HIV infection, drug reactions, radiation treatments, emotional stress, allergic reactions, too much sun, or other health problems.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the skin rash should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, or other treatments.

Self Care: Here are some strategies you may try to help you feel better:

- Bathe with antiseptics diluted with water.
- Avoid cold water – always use lukewarm water.
- Air dry or pat dry your skin after bathing.
- Apply moisturizing creams or lotions that do not contain alcohol
- Use unscented moisturizing lotions or creams that do not contain alcohol. Lotions or creams containing aloe vera / natural plant extracts may help.
- Use bandages or a clean cloth for any bleeding discharges or drainage to prevent the spread of the infection to other parts of your body or to other people.
- Bathe or shower with a mild, non-perfumed soap (such as Cetaphil™, Dove™, Sunlight™ bath soap / Sunlight™ bar soap) and lukewarm water. Avoid hot tubs; they dry your skin.
- Drink plenty of fluids.
- Use a warm mist humidifier in dry climates or in very warm apartments. Dry air can irritate the skin.
- Wear light, non-irritating clothing and a hat when in the sun.
- Keep sheets and blankets off sensitive skin. For example, use a pillow at the foot of the bed to hold sheets off your feet.
- Check in your drugstore for anti-irritants or use an oatmeal and water mixture on affected areas of body to reduce the itch.

CONTINUES →

Caring for your HIV-related problem:

SKIN RASH (DERMATITIS) CONT'D

- Use some oils, such as sweet almond, to nourish dry skin.
- Pay special attention to new skin changes and report these to your doctor or nurse.
- Wash your hands frequently.
- Do not share towels or linens.
- Try not to scratch. Keep your fingernails short and clean.

Caring for your HIV-related problem:

SWELLING OF ARMS, HANDS, LEGS, FEET

Problem: You may experience swelling of your arms, hands, legs and feet.

This may be an indication of poor body drainage system.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the swelling should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, or other treatments.

Self Care: Here are some strategies you may try to help you feel better:

- Elevate your hands/feet while at rest.
- Avoid prolonged walking or standing.
- Rub your hands/feet with methyl salicylate ointment or other swelling reducing agents as directed by your doctor or nurse.
- Soak in warm water.
- Drink hot water to increase circulation and elimination.
- Minimize salt and salty foods.

Caring for your HIV-related problem:

TROUBLE SLEEPING (INSOMNIA)

Problem: You may be unable to sleep, sleep prematurely, have sleep that is interrupted by periods of wakefulness.

This problem might be due to HIV disease, infections, medications or stress.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the trouble sleeping should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, or other treatments.

Self-care: Here are some strategies you may try to help you better:

- Develop a routine of going to bed in the evening and getting up each morning at the same time. Naps are okay, but keep them short and early in the day.
- Take a warm bath before going to bed.
- Drink a cup of warm milk or herbal chamomile tea before going to bed, but do not drink so much fluid that you have to get up to go to the bathroom during the night.
- Get a massage.
- Exercise four to six hours before going to bed. Exercising close to bedtime may increase sleep problems.
- Read before going to sleep.
- Use several pillows to make yourself comfortable.
- Listen to music or books on tape.
- Avoid over-the-counter sleep aids because you could become dependent on them.
- Turn on a fan or soft music to block out street noise.
- Wear earplugs.

Caring for your HIV-related problem:

WEIGHT LOSS (UNPLANNED)

Problem: You may experience a loss of 10% or more of your usual body weight, when you did not intend to lose weight. Weight loss of any amount can be important, and should be treated as soon as possible.

Unplanned weight loss may be due to HIV infection, HIV medications, depression, fatigue, an infection, or other health problems.

If you are experiencing nausea/vomiting or diarrhea, refer to the self-care strategies in those categories.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the weight loss should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medication, or other treatments.

Self-care: Here are some strategies you may try to help you feel better:

- Eat and drink a lot.
- Eat frequent, small meals.
- Take multivitamins.
- Add garlic to your food.
- Keep track of your weight by weighing yourself or by looking for changes in the way your clothes fit.
- Cook and eat with friends or family to make meals enjoyable.
- Eat high-protein, high-calorie foods and snacks such as peanut butter and jelly sandwiches, crackers and cheese, pudding and yogurt.
- Add instant breakfast drinks, milk shakes or other supplements to your diet and drink them any time of the day.
- Take a multivitamin with at least 100% Recommended Daily Allowance (RDA) every day.
- Keep foods that are easy to prepare on hand (e.g., frozen and canned foods).
- Eat fresh fruits and vegetables.

CONTINUES →

Caring for your HIV-related problem:

WEIGHT LOSS (UNPLANNED) CONT'D

- When traveling, take high-calorie snack bars or powdered calorie supplements along.
- Do some light exercise to boost your appetite.
- If it is difficult to chew or swallow, or if you have mouth sores:
 - See your health care provider for possible treatment of your mouth sores.
 - Eat cold foods (e.g., popsicles and ice cream) and soft/liquid foods (e.g., mashed potatoes, applesauce, pasta and soups).
 - Soften foods by soaking them in milk or soup, or by putting them in a blender.
 - Avoid spicy, salty, or crunchy foods, and acidic drinks (e.g., orange juice, tomato juice).
 - Drink liquids through a straw to bypass mouth sores.
 - Gargle with a lemon juice solution.
- If food doesn't taste good to you:
 - Add spices (e.g., basil, oregano, garlic) or other flavor enhancers such as lemon juice, lime juice, or vinegar.
 - Marinate meats in sweet wine, fruit juices, beer, Italian dressing or soy sauce.
 - Take good care of your teeth (e.g., brush regularly, see your dentist at least every six months).

Caring for your HIV-related problem:

WHITE SPOTS IN MOUTH (ORAL THRUSH)

Problem: You may experience painful whitish or reddish sores in your mouth. You may have difficulty eating because oral thrush makes food tasteless.

Treatment: There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the white spots should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, or other treatments.

Self-care: Here are some strategies you may try to help you feel better:

- Change your diet to include soft porridge.
- Clean your mouth with warm salty water and/or bicarbonate of soda.
- Apply pure glycerin to the spots.
- Gargle with TCP antiseptic.
- Cleanse your mouth with an alum lump, or suck on it.

Caring for your HIV-related problem:

VAGINAL ITCHING, BURNING, AND DISCHARGE

- Problem:** You may experience profuse, slimy, offensive, purulent, yellowish discharge. At times the color is greenish.
- Treatment:** There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the vaginal itching should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications, or other treatments.
- Self-care:** Here are some strategies you may try to help you feel better:
- Wear cotton underwear and change it frequently.
 - Consider wearing a non-deodorant pantiliner or pad for discharge. Avoid using tampons, as they can increase discomfort.
 - Avoid wearing tight-fitting clothes such as tight jeans or nylon stockings.
 - Eat ½ cup yogurt with acidophilus every day.
 - Use mild soap when bathing, and avoid deodorant soaps, sprays, toilet paper, etc. These may cause further irritation.
 - Avoid shaving your genital area.
 - Avoid douching and toilet paper for padding because they may cause further irritation.
 - You may want to avoid sexual activity until the infection clears up, as it may be uncomfortable for you. However, if you do decide to have sex, use a condom to avoid spreading the infection. It is a good idea not to have oral sex at this time as yeast can occur in a person's mouth as well. Instead of sexual intercourse, practice other types of intimacy such as touching, kissing, caressing, etc.
 - Cleanse perineal area.
 - Take a Sitz bath with **Dettol** or other antiseptic.

GLOSSARY / THESAURUS

(UNDER DEVELOPMENT)

A&D ointment™

Acidophilus: An organism that grows well in acidic media and is used in the making of yogurt.

Aloe vera: A succulent plant of the Liliaceae family. It is used for multiple medicinal purposes.

Alum lump: An odorless, colorless crystal stone used for sores in the mouth and throat.

Aromatherapy: Treatment method for various symptoms, using fragrant substances such as oils, spices and others.

Borstol: An oily suspensive used as a cough mixture.

Chamomile

Diabetes Mellitus

Gatorade™: An energy drink.

Glycerin

Lemon grass

Metamucil™: A bulk fiber.

Methyl salicylate: An anti-fungal and pain-relieving poultice.

Oral rehydration solution: A solution rich in electrolytes, used for rehydration. If packages of oral rehydration solution are not available in your area, you can make it at home. Mix the following ingredients:

- 1 liter of water, boiled and then cooled
- 1 teaspoon salt
- 4 teaspoons sugar

Papaya: A fruit used to relieve constipation. Its skin can be used as a poultice.

Potassium Permanganate: A crystal salt used as an antiseptic.

Sitz bath: Soaking the perineal area in warm water with an antiseptic solution.

Tai-Chi: A Chinese exercise used for relaxation.

TCP Antiseptic: An Antiseptic used for oral sores.

VicksTM: A menthol ointment used for coughs, colds and muscle pain.

Reproductive Choices and Family Planning for People Living with HIV

Counselling Tool



1. Reproductive health services. 2. Family planning services. 3. HIV infections - prevention and control. 4. Contraception - methods.
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Reproductive Choices and Family Planning for People Living with HIV

Counselling Tool

More copies of this tool and information on adaptation, training and translations can be obtained from:

Documentation Centre

Department of Reproductive Health and Research

World Health Organization

1211 Geneva 27, Switzerland

Fax +41 22 791 4189. Phone +41 22 791 4447. Email: rhrpublications@who.int

The document is also available online at the following websites: http://www.who.int/reproductive-health/family_planning/index.html and <http://www.who.int/hiv/pub/en/>

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Introduction for the provider

Preparing to use the tool

- For each topic in this tool, there is a **page for the client** and a **page for the provider**. The two pages are similar, but the provider's side contains more information, suggested questions to ask the client, and a box on how to use the page.
- Studying this tool will help you become familiar with how it works and with the information in it. **Using the flip-chart will become easier with practice.**
- This guide covers only the main points. When you talk with clients, you can add information and discuss matters further, responding to the client's needs and concerns.

Using the tool with clients

- **Place the tool** where the client can easily see it. Try *not* to place the flipchart directly *between* you and the client. You can place it to the side or where both of you look at the client's page.
- Each page shows the client an important question or topic. To use this tool correctly, you usually need the client's answers or information before you will know which page to go to next. The **sign post** → marks points to decide where to go next in the tool.
- Use **only pages and information on the page that address the individual client's needs**. To do this, listen to and assess the client's situation, needs, and wishes.
- Use language that the client will understand and, in general, **do not read the text** to the client. Once the tool becomes familiar, a glance will remind you of key information and your next steps.
- If the client cannot read well, pointing to pictures may help.



Purpose of this tool

This tool is designed to help health workers counsel people living with HIV on sexual and reproductive choices and family planning. It also is meant to help people living with HIV make and carry out informed, healthy, and appropriate decisions about their sexual and reproductive lives. This tool addresses:

- How to enjoy a healthy sexual life.
- For clients who do not want a baby, how to prevent pregnancy and further transmission of HIV.
- For clients thinking of having a child, points to consider in making a decision.

About this tool

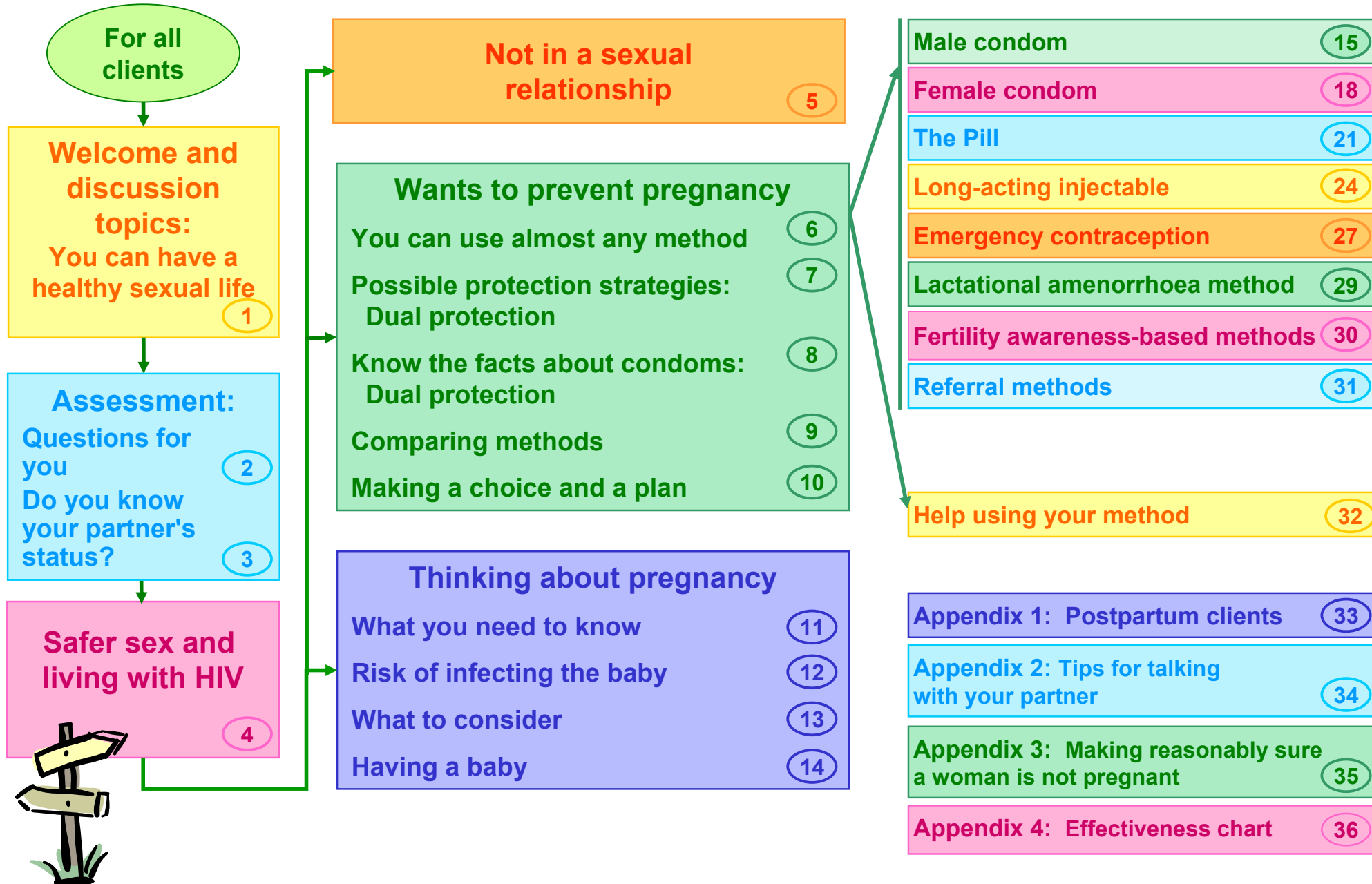
This tool is part of the WHO materials on Integrated Management of Adolescent and Adult Illness (IMAI). The tool provides:

- Essential information you need to offer good advice.
- Tips and guidance on how to communicate with clients.
- Illustrations to make the information more clear.

Counselling process

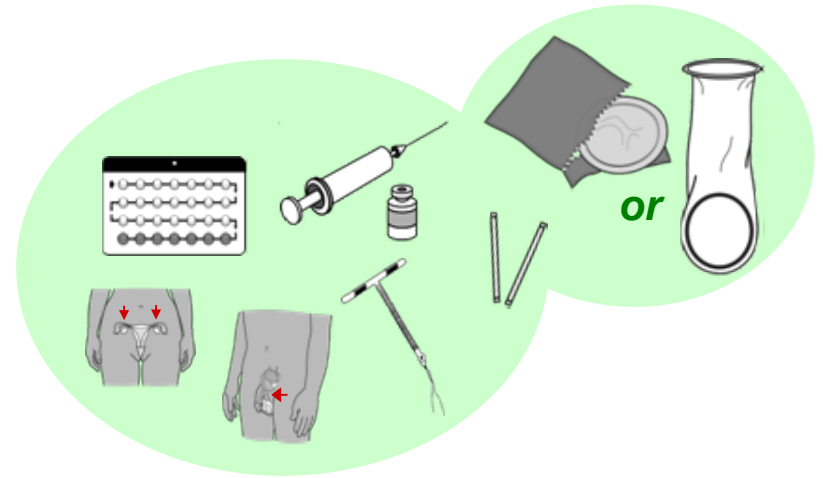
This tool follows the IMAI 5As process for counselling and shared decision-making: **Assess, Advise, Agree, Assist, Arrange**.

Road map of this counselling tool

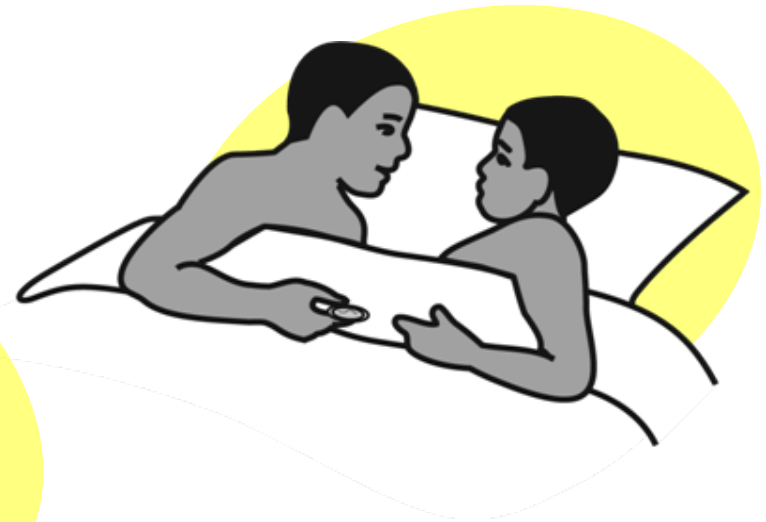


You can have a healthy sexual life

- Preventing pregnancy
- Preventing infection
- Having a healthy baby



*Let's discuss
the choices*



You can have a healthy sexual life

For all
clients

Preventing pregnancy

- ▶ You can use almost any family planning method.

Preventing infection

- ▶ Condoms help prevent both pregnancy and infection.

Having a healthy baby

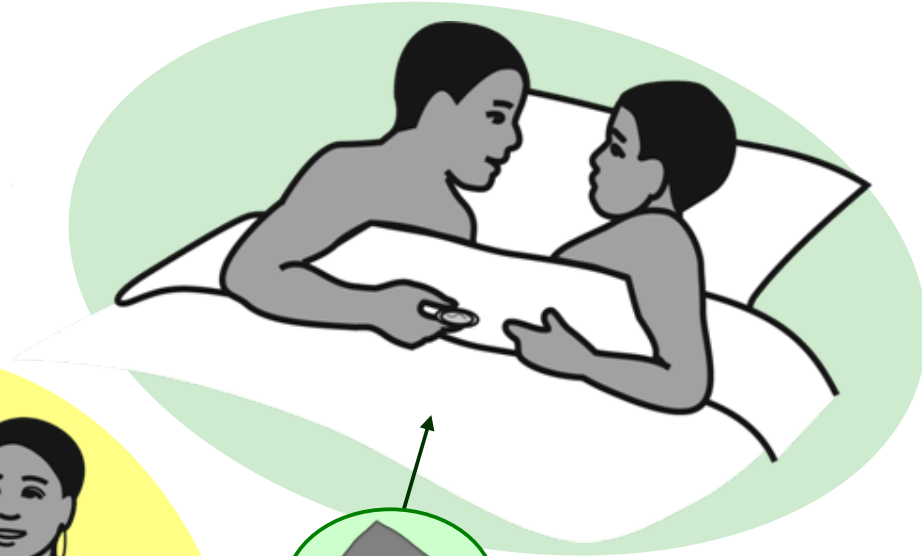
- ▶ You can have a baby. There are special issues to think about before you decide.

How to use this page:

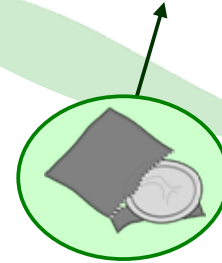
- **Welcome** the client warmly.
- Mention these 3 types of choices and **offer to discuss**.
- **Give the main messages** (at arrows) about the choices.
- Invite the client **to plan for healthy behaviour**. Offer your help.
- Ask for questions, and follow up at once.

Next step: Explain that you need to ask some questions first to understand how best to help (go to next page).

Questions for you



?



?

?

Questions to ASSESS situation and needs

For all
clients

HIV infection

- When diagnosed? Now well / unwell?
- Medications? If yes, what? Started when?

Sexual relationships

- Now in a sexual relationship?
- If yes: Steady partner/spouse? Occasional partners?
How many partners in last 3 months?
- Are your partners of the opposite sex, the same sex, or both?

How you protect yourself and partner(s)

- Doing something now to avoid HIV transmission? What?
- Do you or your partner have any signs or symptoms of sexually transmitted infection—open sores, unusual discharge? Have you had any STIs in the last few months?
- Want to avoid pregnancy? Doing something now to avoid pregnancy? What?
- Your current method of protection: How is it going? Are you satisfied to continue? Any worries? Want something else?
- Do you have children? Thinking about having a baby—now or in the future?
- Have discussed with partner? Partner's views, reaction?

How to use this page:

- Assure the person that all clients are asked these same questions.
- Explain policy on privacy and confidentiality.
- Ask if the client has any specific questions, needs, or concerns.
- Encourage the client's healthy behaviours or intentions.
- Listen carefully for the person's needs—for correct information, for help with making choices, for support to carry out plans.

Next step: Discuss HIV status of couples and issues of testing and disclosure (go to next page).

Do you know your partner's HIV status?



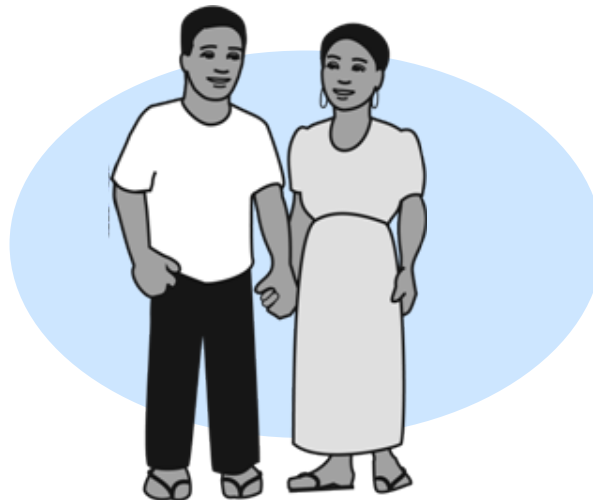
NO HIV HIV

?



HIV HIV

?



UNKNOWN HIV
STATUS

Do you know your partner's HIV status?

For all
clients

Questions about sexual relationships:

- Does client know the HIV status of sex partner(s)?
- Does partner(s) know client's HIV status?

If a partner's status is unknown:

- Discuss reasons that client's partner(s) should be tested for HIV.
 - Even if you are HIV positive, your partner may not be infected.
 - When both partners know their status, they can then know how best to protect themselves.
- When status is unknown, assume your partner is negative and needs protection from infection. Important to use condoms.

If a partner is HIV negative:

- Explain that it is common for a person who is HIV positive to have a partner who is HIV negative.
- HIV is not transmitted at every exposure, but HIV-negative partners are at a high risk of infection.
- Important to always use condoms or avoid penetrative sex.

If both you and your partner are HIV positive:

- If mutually faithful, the couple may choose not to use condoms and may choose another method for pregnancy protection.
- If not mutually faithful or faithfulness is uncertain, condoms should be used or penetrative sex avoided to prevent STIs.

How to use this page:

- Discuss HIV status of client and partner(s) so they can know how to best protect themselves.
- If client has not disclosed HIV status to partner, discuss benefits and risks of disclosure.
- Help client develop strategy for disclosure, if client is ready.
- Strongly encourage and help with partner testing and counselling.

Next step: Discuss safer sex and living with HIV (go to next page).

Preparing to disclose HIV status

- Who to tell?
- When to tell?
- How to tell? Make a plan.
- What you will say? Practice with client.
- What will you say or do if...?
- If there is a risk of violence, discuss whether or not to disclose, or how to disclose with counsellor or friend present.

Safer sex and living with HIV

- Can still enjoy sexual intimacy
- There are ways to lower risk
- Some sexual activities are safer than others



*Any
questions
?*

ADVISE: Safer sex and living with HIV

For all
clients

Can still enjoy sexual intimacy

- There are ways to keep risk of infection low—both the risk of infecting someone else and getting another infection yourself.
- Disclosing your HIV status to your partner and knowing your partner's status helps decide how to have a healthy sexual life.
- You need to protect your partner even if you are on antiretroviral treatment.
- Do not assume a sexual partner has no STIs. Protect yourself.

Ways to lower risk

- **Mutual faithfulness**—two partners faithful to each other
- **Limiting number of sexual partners**
- **Safer sex**—for example, condoms or avoiding penetrative sex
- **Early treatment of STIs and avoiding sex if you or partner has an STI**
- **Not having sex**—need to be prepared to use condoms if you return to sexual activity

Some sexual activities are safer than others

- **Examples of acts with no risk:** Pleasuring self, massage, hugging, kissing on lips
- **Examples of low-risk acts:** vaginal or anal intercourse using condom, oral sex (safer with condoms or other barrier)
- **Examples of high-risk acts:** anal intercourse without a condom, vaginal intercourse without a condom
- These apply whether client's partner(s) is same or opposite sex.

How to use this page:

- Help clients feel that they can have a healthy and safe sex life.
- Ask tactfully but clearly about client's concerns and answer honestly, directly and without embarrassment.
- Ask for questions about sexual activities. Ask for clarification, if needed, and check understanding.
- Do not act surprised or express judgment. You are asking clients to trust you with intimate details.

Next step:



Depending on client's needs:

- Not in a sexual relationship → 5
- Choosing a method → 6
- Has a method in mind, or Likes current method → 7
- Problems with current method → 32
- Thinking about pregnancy → 11
- Postpartum clients → 33

Not in a sexual relationship

Always be prepared for
a return to sexual
intimacy



ADVISE: Not in a sexual relationship

Not in a sexual relationship

- Some people living with HIV or taking antiretroviral do not have a regular sexual partner.
- Is this a personal choice or a result of client's situation—for example, not feeling well, not interested in sex, or has not met someone?
- When clients start to feel better on treatment, they may change their minds about sexual intimacy or about having a baby.

Always be prepared for a return to sexual intimacy

- Methods that can be used when needed include male and female condom and emergency contraception (when no regular method was used).
- Consider providing these methods.

You can discuss:

- *"Remember, your situation can change very quickly."*
- *"How will you protect yourself from pregnancy? Are you continuing to use contraception during the time you are not having regular sex? If not, what is your plan?"*
- *"How will you protect yourself and your partner from infections? Condoms? Nonpenetrative sex? Have you thought about this?"*
- *"You may want to continue not to have sex. What makes avoiding sex difficult? What could help?"*

How to use this page:

- Assess whether having no sexual relationship is the client's choice or because of client's situation or health.
- Help clients be prepared for a return to sexual intimacy.

Next step:

- Needs help talking to partner
- Needs backup methods

▶ Male condoms

▶ Female condoms

▶ Emergency contraception



34



15



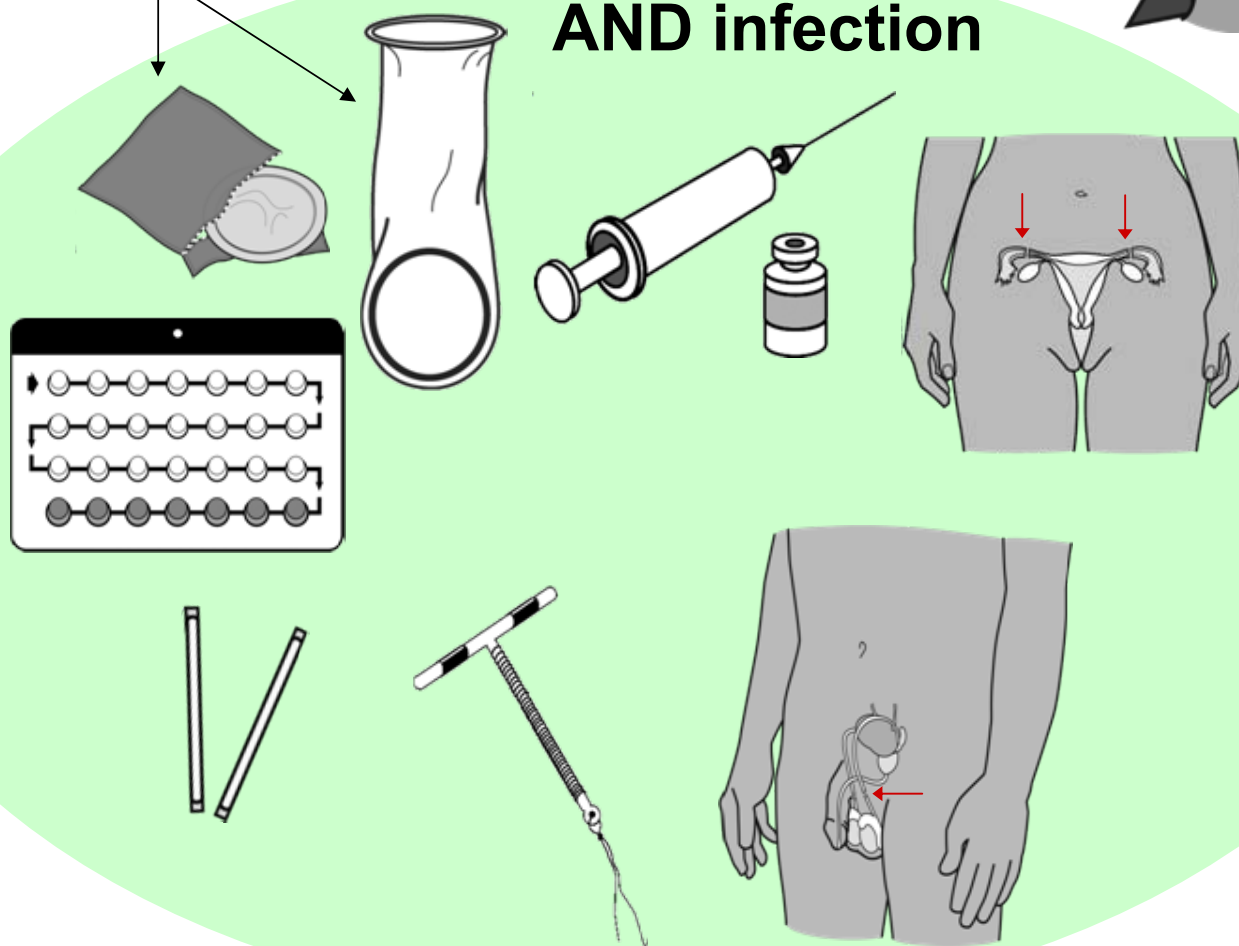
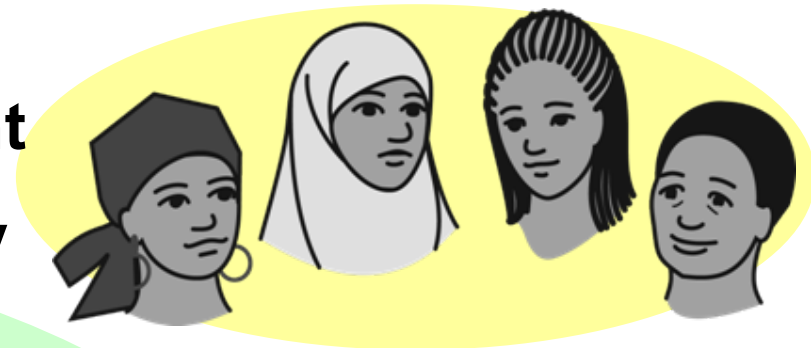
18



27

You can use almost any family planning method

- Women with HIV or AIDS can use most methods—even on treatment
- Condoms help prevent pregnancy AND infection



ADVISE: You can use almost any family planning method

Can use most methods **except**:

- Spermicides—might increase infection risk for uninfected woman.
- IUD if the woman might have gonorrhoea or chlamydia, or is unwell with AIDS-related illness.
- All other methods can be used.

Generally, antiretrovirals and contraceptives do not conflict

- *"You can use most contraceptive methods even on antiretrovirals."*
- Rifampicin (used for TB treatment) lowers effectiveness of contraceptive pills and implants. Other antibiotics do not have this problem.
- Some antiretrovirals (protease inhibitors and NNRTIs*) *may* lower effectiveness of hormonal methods. This is not known for sure. (NRTIs* are not a concern.) Correct use of the method and use of condoms can make up for any decrease in contraceptive effectiveness.
- Some women may have other conditions that affect choice of a method (see method sections).

Condoms can help prevent both pregnancy and infection

- Only male and female condoms also help prevent infections.
- Important to use a condom correctly and with every act of vaginal or anal intercourse.

How to use this page:

- Ask clients what they have heard about contraceptives, HIV, and antiretrovirals. Correct any misunderstanding gently but clearly.
- Explain that people living with HIV can use much the same contraceptive options as other people.
- Mention which methods you offer and which you can refer for.
- **Ask client if she or he is now using a method. If not, does the client have a method in mind?**

Next step: Consider protection strategies (go to next page).

* NNRTI = non nucleoside reverse transcriptase inhibitor, NRTI = nucleoside reverse transcriptase inhibitor.

Possible protection strategies

Prevent both
pregnancy and infection

Condoms



*Male
condoms*

OR



*Female
condoms*

**Condoms
AND ALSO
another family
planning method**



For example:

AND



**Other
safer sex**

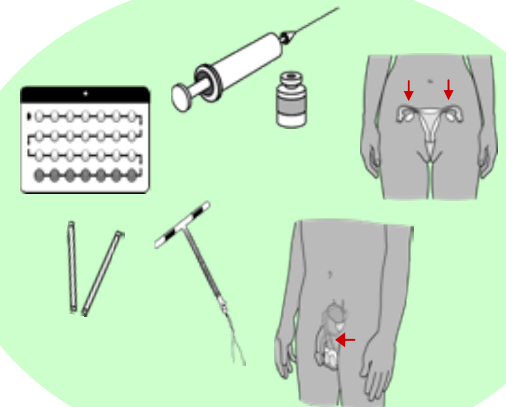


**No
sex**



Prevent pregnancy—
but not infection

**A family
planning
method
without use of
condoms**



ADVISE: Possible protection strategies

Prevent both pregnancy and infection

Condoms alone

- Only way to help prevent transmission of HIV and other STIs during vaginal or anal intercourse.
- Can be very effective to prevent pregnancy—when used consistently and correctly.

Condoms and another family planning method

- More effective protection from pregnancy than condoms alone, particularly if partner will not always use condoms.

Other safer sex

- Non-penetrative sex instead of intercourse.

No sex (abstinence)

- For more, [go to page 5](#).

Prevent pregnancy—but not infection

A family planning method without use of condoms

- Helps prevent pregnancy but not infection.

If both partners know they have HIV

- If mutually faithful, this couple may choose to use a family planning method other than condoms.

How to use this page:

- Mention client's current means of protection (or lack of protection). Praise any current protective behaviour.
- Discuss how client's current or preferred family planning method could fit into a protection strategy.
- If appropriate, point out options that offer more protection than current practices.
- Discuss options that could suit this client.

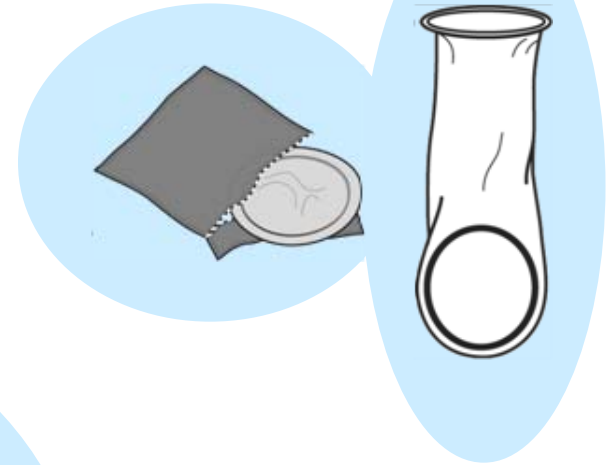
Next step:

- **Problems using condoms, go to next page.**



- **Wants to choose a method** → [9](#)
- **Problems with current method** → [32](#)
- **Has a new method in mind:**
 - ▶ **Male condom** → [15](#)
 - ▶ **Female condom** → [18](#)
 - ▶ **The Pill** → [21](#)
 - ▶ **Long-acting injectables** → [24](#)
 - ▶ **LAM** → [29](#)
 - ▶ **Fertility awareness** → [30](#)
 - ▶ **Referral methods** → [31](#)

Know the facts about condoms



Know the facts about condoms

You should know that:

- Correct and consistent use of condoms protects you and your partner from STIs and pregnancy.
- Using condoms is a responsible act that shows your concern for your own and your partner's health.
- Many married couples use condoms. They are not only for sex outside marriage.
- Most people who use condoms do not have HIV and are healthy.
- Proposing condom use does not mean a person is infected with HIV. It means that the person is responsible and caring. It does not imply mistrust.
- Condoms are high-quality and do not have holes.
- Condoms do not contain or spread HIV.
- Nearly everyone can use male condoms, regardless of penis size.
- Using condoms may change the sensation of sex, but sex is still enjoyable. Some couples find sex even more enjoyable with condoms.
- Male condoms do not make men sterile, impotent, or weak and do not decrease their sex drive.

How to use this page:

- Discuss with the client why some people do not use condoms.
- Ask if client's partner has concerns about condoms.
- Respond to any misunderstandings with accurate statements.
- If a woman's partner will not use condoms, discuss possible approaches. See box below.

Next step:

- **Male condoms** → 15
- **Female condoms** → 18
- **For comparing methods, go to next page.**



If a woman's partner will not use condoms

- Ask if she knows why. Help her plan how to negotiate condom use with her partner.
- Help her choose another family planning method to prevent pregnancy.
- Discuss and offer female condoms, if available.
- Explain that without use of condoms, she may be infected with HIV, or transmit HIV if she is infected, and be at risk of other STIs.
- If she has not disclosed her HIV status, encourage disclosure to partner and family, unless she would risk violence.
- Invite her to bring her partner for counselling, advice and support as a couple.

Comparing family planning methods

Any of these methods can be used

Effective but must use every time you have sex



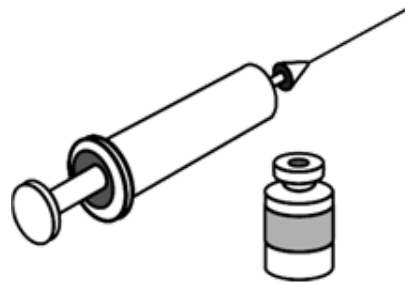
Male condom



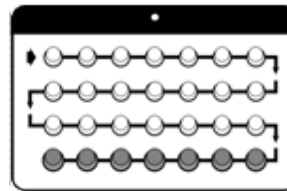
Female condom

IMPORTANT!
Only condoms—
used consistently
and correctly—
can help prevent
pregnancy and
STIs/HIV

Very effective but must use as directed

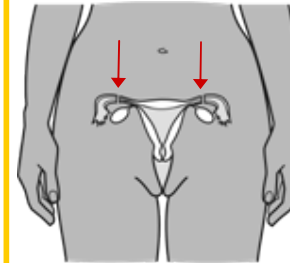


Injectables

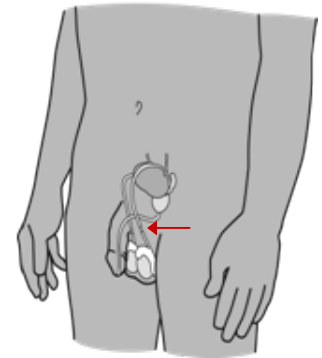


Pills

Most effective and easy to use



Female sterilization (permanent)



Vasectomy (permanent)



IUD



Implants

AGREE: Comparing methods

Effectiveness (see also Effectiveness chart, page 36)

- For some methods, effectiveness depends on the user. Does client think she can use the method correctly?
- How important is it to the client to avoid pregnancy?

Partner's help

- Male condoms and vasectomy are used by men.
- Man must cooperate for female condom.
- Will partner approve, help, or take responsibility?

Permanent, long-term, or short-term

- Sterilization and vasectomy are permanent. (If currently sick, may be best to wait until well before choosing a permanent method.)
- IUDs and implants can stay in place for many years if desired.

Protection from STIs

- Only male and female condoms help protect against pregnancy and infections—if used consistently and correctly.

- ✗ **Spermicides or diaphragm with spermicides:** Should not be used by women with HIV or at high risk of HIV.
- ? **IUD** may be inserted if woman has no HIV-related illness, does not have gonorrhoea or chlamydia, and is not at very high individual risk of these infections.
- ? **LAM:** Breast milk can pass HIV to baby, but exclusive breastfeeding for the first 6 months is safer than mixed feeding.

How to use the page:

- If client has not decided on a method, compare available methods in light of client's situation and preferences. Explore client's feelings on issues such as those mentioned here.
- Ask about good and bad experiences with family planning. *Past success predicts future success.*
- Ask client which methods interest her or him most.

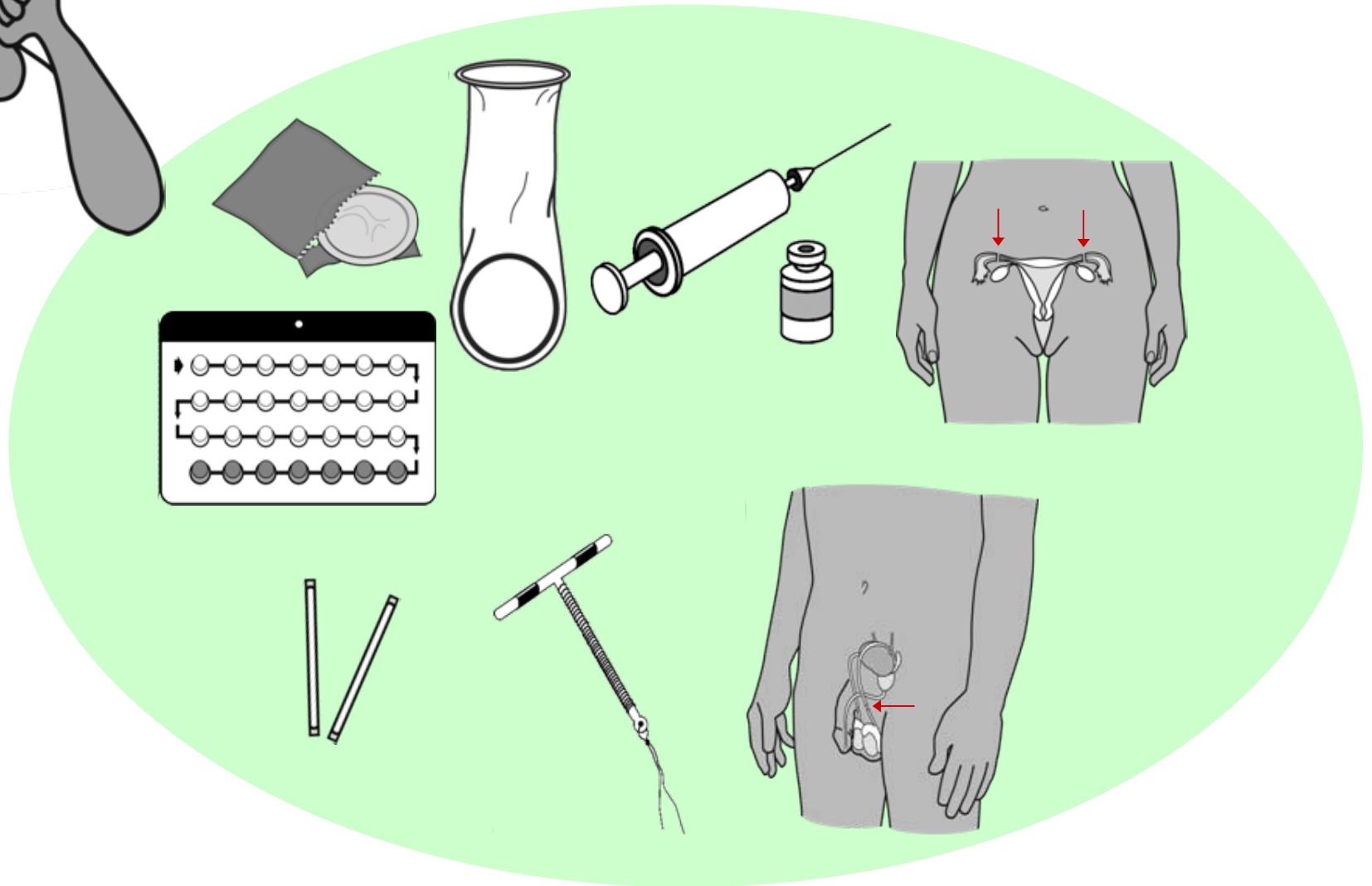
Next step:

- **Focus on method(s) that interest the client:**



- ▶ **Male condom** → 15
- ▶ **Female condom** → 18
- ▶ **The Pill** → 21
- ▶ **Long-acting injectables** → 24
- ▶ **LAM** → 29
- ▶ **Fertility awareness** → 30
- ▶ **Referral methods** → 31

Making a choice and a plan



ASSIST, ARRANGE: Making a choice and a plan that works

Client's choices? (Could include several choices.)

- For a contraceptive method?
- Other safer sexual activities?

Making a plan. Ask client to think about and discuss:

- How to get supplies?
- Learning to use condoms, other methods (**see pages 16-29**).
- What steps to take? Examples: disclosing status? learning partner's status? discussing plan with partner?
- What will be first step? When will client take this first step?
- Can partner help? (**see page 33 on talking with partner**).
- Does client want to start a method today? If so, use pregnancy checklist to make reasonably sure client is not pregnant when starting method (**see page 34**).

Meeting challenges

- What could prove difficult?
- How to handle difficulties—think what to say or do.
- What fall-back plan if can't keep to first choice?
- Explain emergency contraception, if available (**see page 28**).
- Encourage: Everyone makes mistakes. Keep trying.

Confirming

- Ask if client feels ready and able to carry out plan.

How to use this page:

- Ask client to discuss which options would work best.
- Ask client to state choices and make a commitment to them.
- Is client making healthy choices? If so, confirm and praise. If not, counsel further.
- Help client make a step-by-step plan. Discuss questions such as those listed.
- Go to other pages as needed.

ARRANGE: **Closing steps**

- Provide supplies—condoms, another contraceptive method—or refer.
- Schedule next meeting.
- Invite client to return at any time—especially for more supplies, having problems, wants to change plan, thinks might have been exposed to STI or risk of pregnancy, or might be pregnant.
- Mention single most important behaviour for client to remember (such as use a condom each time or take a pill each day).

Thinking about pregnancy: What you need to know

- It's your decision about getting pregnant
- There are some risks to think about



ADVISE: Thinking about pregnancy: What you need to know

It's your decision about getting pregnant

- **Pregnancy risks and risks of infecting the baby are not as high as many people think.**

Risks to baby

- **If mother is living with HIV, the baby may get HIV** during pregnancy, childbirth, or breastfeeding. Most babies do not get infected (**see next page**). Treatment lowers risk.
- **If mother is living with HIV, there is greater chance of stillbirth, premature birth, or low birth weight.**

Risks to mother

- **HIV infection raises risk of childbirth complications** such as fever and anaemia, particularly with delivery by caesarean section.
- **Pregnancy will not speed up the course of HIV infection**, but best to avoid pregnancy in some health situations (**see page 13**).

Risks to partner

- If woman is uninfected and partner infected, she may have to risk getting HIV to get pregnant.
- If man is uninfected and woman is infected, artificial insemination will avoid risk to him.

How to use this page:

- This section can be used with women who are considering getting pregnant, and those who have concerns about a current pregnancy.
- Accurately describe possible risks.
- Ask client for reactions, explore concerns.
- Ask about partner's wishes and attitudes.

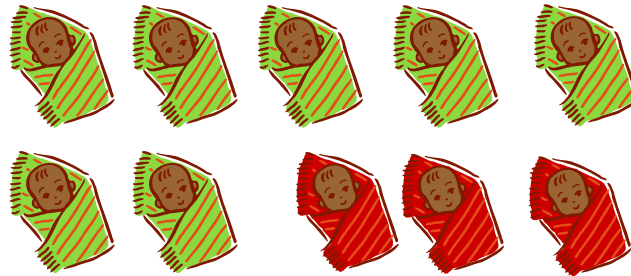
Next step:

- **Client wants more information about pregnancy, go to next page.**

Risk of infecting the baby

If 10 women with HIV have babies...

*Without special care,
3 babies will be
infected with HIV*



*With special care,
1 baby will be
infected with HIV*



Risk of infecting the baby

- Babies may get infected with HIV during pregnancy, childbirth, or breastfeeding.
- Most babies of women with HIV do NOT become infected with HIV.
- If 10 women with HIV have babies...
 - 3 of 10 will be infected if the mother and the baby do not receive special care
 - Only 1 of 10 will be infected with HIV if the mother and the baby do receive special care
 - Special care includes antiretroviral prophylaxis for the mother during pregnancy and labour, and to the baby; antiretrovirals for the mother if she needs it for her own health; exclusive breastfeeding or replacement feeding options that are acceptable, feasible, affordable, sustainable, and safe.
- HIV viral tests can be used at any time starting at 6 weeks of age to identify HIV infection in the baby.
- HIV antibodies tests also can be used. They can tell whether the baby was *exposed* to HIV, but they cannot tell if a baby is *infected* with HIV until 9 to 12 months of age.

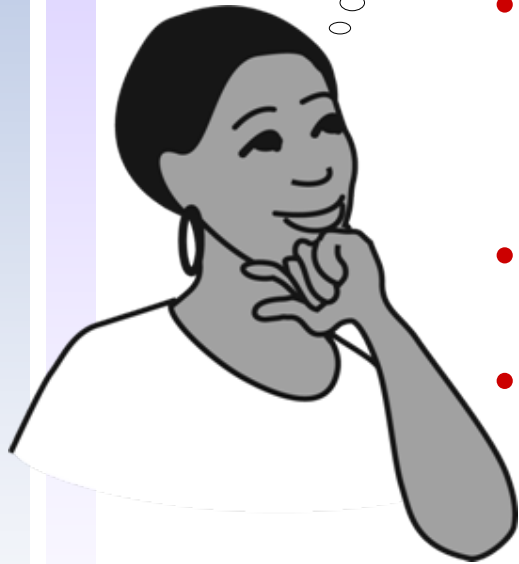
How to use this page:

- Discuss the graphic on the client's page, and explain the points to the left.
- Ask the woman how she feels about these risks to her baby.
- Ask how she thinks she might feel if her baby were infected. (Be careful not to suggest that she should feel bad.)

Next step:

- **Client wants to know more about pregnancy, go to next page.**

A good idea for you now? What to consider



- Your health
- Medical care



- Your partner's and family's support
- Telling others your HIV status



- Feeding your baby



AGREE: A good idea for you now? What to consider

Your health now

Pregnancy possible: if health good, CD4>200*, or clinical Stage 1 or 2 where CD4 count not available, on prophylaxis to prevent opportunistic infections, or antiretrovirals if eligible, no sign or symptoms of TB .

*Consider starting women with CD4 counts 200-350 on antiretrovirals before pregnancy

Pregnancy may cause problems now. Delay pregnancy and re-evaluate later if health worsening, CD4 <200, TB unknown, no prophylaxis to prevent opportunistic infections, in first 6 weeks of antiretrovirals.

Pregnancy not a good idea now if health poor, clinical Stage 3 or 4, on TB treatment, CD4 <100, waiting to start antiretrovirals.

Medical care for you and your baby

- Are services available? Where?

Your partner's support

- Have a steady partner? Partner knows your HIV status?
- Partner supportive and will help with baby?
- Partner knows own status or is willing to be tested?
- Partner's health?

Family support

- Family supportive? Or would they reject a child with HIV?
- Family members are close by and can help?

Telling others your HIV status

- Have told others? Planning to? Who can't be told? (See page 3.)

How to use this page:

- Help a woman or couple consider whether having a baby is a good idea at this time.
- Answers to these questions can help a woman or couple make a wise decision.
- **AGREE:** Ask if the woman or couple can reach a decision. If so, what decision? If not, what will help with making the decision?

Next Step:

- **Wants pregnancy now, go to next page.**
- **Wants to prevent pregnancy**

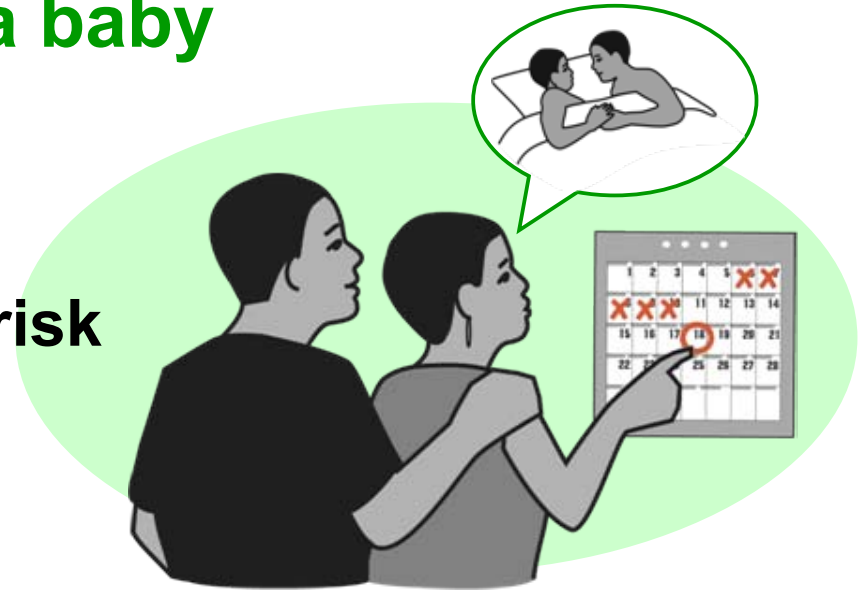


Feeding your baby (see page 29)

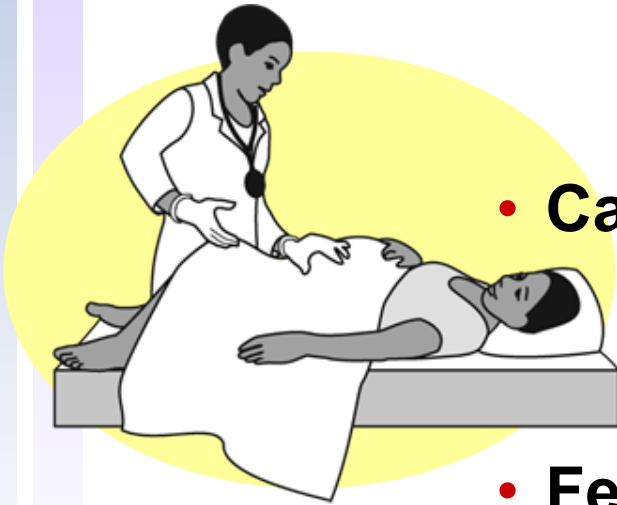
- Able to feed infant in recommended way to lower chances of passing HIV?

Having a baby

- Taking the least risk



- Care and treatment during pregnancy



- Feeding the baby
- Taking care of the baby



ASSIST, ARRANGE: **Having a baby**

Note: HIV infection can make it more difficult to get pregnant.

Taking the least risk

- Testing of either partner, if HIV status unknown, to help decide how to decrease transmission risk while trying for pregnancy.
- If man is uninfected, artificial insemination will avoid risk to him.
- If woman is uninfected, advise having sex without condoms only on day before expected ovulation (13th day after start of monthly bleeding, if cycles are 28 days).

Care and treatment before and during pregnancy

- Antiretroviral regimens may need to be altered before trying for pregnancy—for example, efavirenz can cause birth defects if taken during first trimester of pregnancy.
- Avoid unprotected sex during pregnancy—for example, by using condoms. Lessens chance of infection dangerous to the baby.
- Refer for antenatal care—and for care to prevent mother-to-child transmission (PMTCT), if available.

Feeding the baby

- If no safe replacement infant formula is available, a woman with HIV should breastfeed exclusively (no other food or liquids) for the first 6 months and then wean in 2 days to 3 weeks. Discuss with PMTCT counselor.

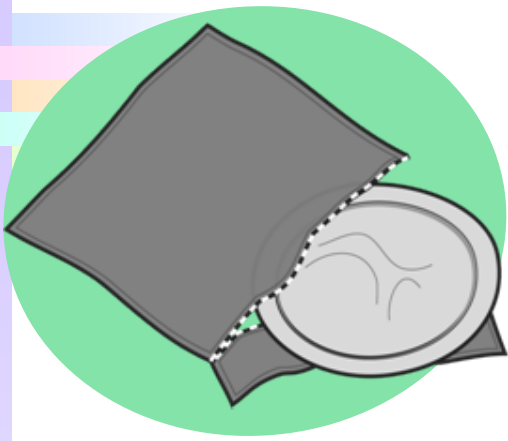
Taking care of the baby

- Who will help—baby's father? Woman's mother, sisters, friends?
- Where to take the baby for health care?

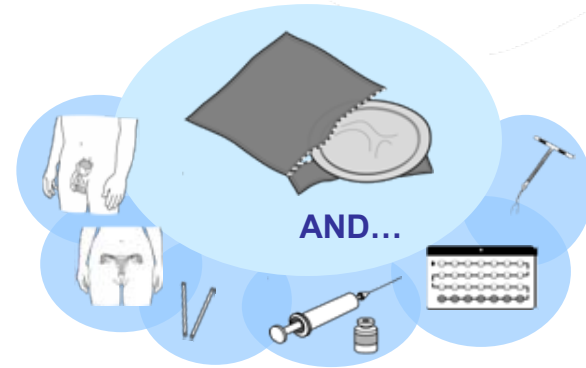
How to use this page:

- **ASSIST** (*also for women already pregnant*): Help woman or couple think about how to manage pregnancy, delivery, and child care.
- Discuss difficulties and how they can be overcome.
- **ARRANGE:** Refer for further care.

The male condom



- **Very effective when used correctly EVERY TIME**
- **Protects you and your partner from infection**
- **Can be used alone or with another method**
- **Easy to get, easy to use**
- **Partners usually need to discuss**





The male condom

- **Very effective when used correctly EVERY TIME**
- **Protects you and your partner from infection**
- **Can be used alone or with another family planning method (for dual protection)**
- **Easy to get, easy to use**
- **Partners usually need to discuss**

You can discuss:

- “What have you heard about condoms? Do you have concerns?”
- “Would you be able to use condoms consistently and correctly?”
- “Would your partner agree to use condoms?”
- “Would you be able to keep a supply of condoms on hand?”

About the male condom:

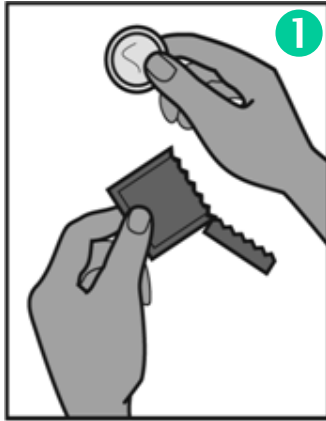
- A rubber sheath that covers the penis during sex.
- Almost all men can use male condoms, even men with large penises. Only those with a serious allergy to latex cannot use them.
- When condoms are used **correctly every time**, they are very effective in preventing pregnancy, STIs, and HIV infection.
- Use during ALL contact between penis and vagina or anus.

Benefits when used consistently and correctly:

- Protects partner(s) from HIV infection.
- Protects from other STIs.
- Prevents pregnancy.
- You can use another family planning method (except the female condom) along with male condoms for extra protection from pregnancy
- Also used as backup for another method of family planning (for example, if client missed pills or is late for injection).
- Sold in many shops and available free at many health clinics.
- Use becomes easy with a little experience.
- Most couples find that they still enjoy sex with condoms.
- Discussion can be difficult. For tips, **see pages 8 and 34.**
- If partner does not want to use condoms: “We can discuss and practice what you might say.”

Next step: For how to use condoms, go to next page.

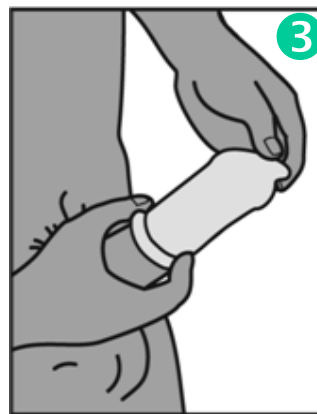
How to use a male condom



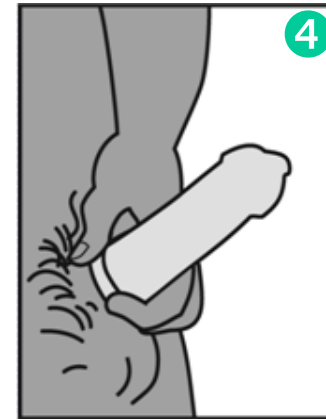
Use a **new condom** for each sex act



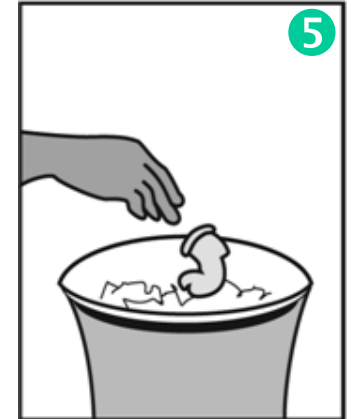
Before any contact, place condom on tip of erect penis **with rolled side out**



Unroll condom all the way to base of penis



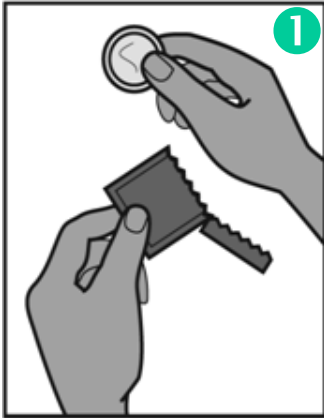
After ejaculation, hold rim of condom in place, and withdraw penis while it is still hard



Use only once
Throw away used condom safely

How to use a male condom

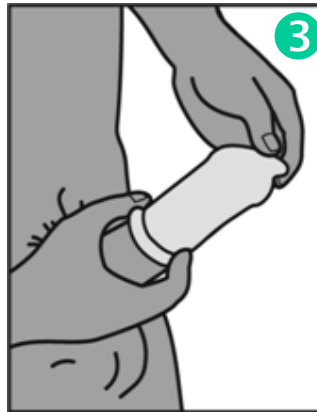
Male
Condom



Use a **new condom** for each sex act



Before any contact, place condom on tip of erect penis **with rolled side out**



Unroll condom all the way to base of penis



After ejaculation, hold rim of condom in place, and withdraw penis while it is still hard



Use only once
Throw away used condom safely



- Check the expiry or manufacturing date.
- Condoms should be used within 3 years of manufacturing date.
- Open package carefully.



- Put condom on before penis touches vagina or anus.



- If condom does not unroll easily, it may be backwards or too old. If old, use a new condom.
- Lubricants can be used (water-based, not oil-based) and **should** be used during anal intercourse.



- Move away from partner first.
- Do not spill semen on vaginal opening or anus.



- Always throw away in bin or trash can as appropriate.

Next step: For what to remember about condoms, go to next page.

What to remember

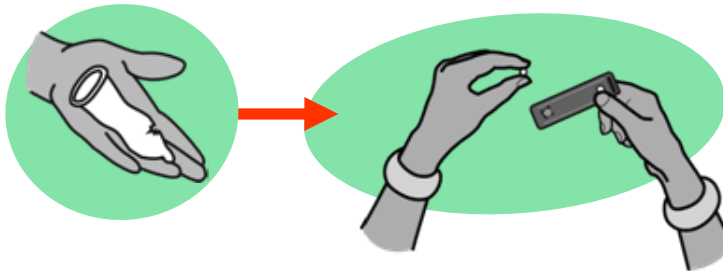
- Use correctly EVERY TIME



- Keep plenty on hand



- If condom breaks, consider emergency contraception



- Water-based lubricants only



- No oil-based lubricants



- Store away from sun and heat



What to remember

Male
Condom



- Use a condom correctly **EVERY TIME**



*"For full protection, you need to use a condom **EVERY TIME** you have vaginal or anal sex."*

- Use every time to avoid infecting partner. If cannot use a condom every time, another method of family planning can prevent pregnancy but not infection.

- Make sure you always have enough condoms



- "Get more condoms **before** you run out."

- If a condom breaks, consider using emergency contraception as soon as possible



- Condoms rarely break if properly used.
- **Offer emergency contraceptive pills** to take home in case condom breaks or slips.
- If condoms break often, make sure they are not damaged or old. Review instructions for proper use. Also, try lubricated condoms, or use water or water-based lubricant on outside of condom.
- Do not use if unopened package is torn or leaking, or the condom is dried out.

- Use only water-based lubricants



- **Oils weaken condoms** so condoms can break. Do not use oil-based materials such as cooking oil, baby oil, coconut oil, petroleum jelly, butter.
- **Water-based materials are OK.** They include glycerine, certain commercial lubricants, clean water, saliva.
- Tell client whether condoms offered are lubricated or not.

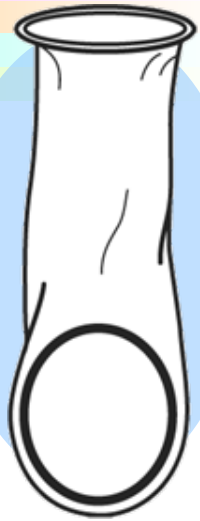
- Store condoms away from direct sunlight and heat



- Sunlight and heat can make condoms weak and they can break.

*Next step: Go back to 10 for **ASSIST** and **ARRANGE**.*

The female condom



- **Effective when used correctly EVERY TIME**
- **Protects you and your partner from infection**
- **Can be used alone or with another method**
- **May be expensive and hard to find**
- **Inserted by the woman but needs partner's cooperation**



The female condom

Female
Condom



- **Effective when used correctly EVERY TIME**
- **Protects you and your partner from infection**
- **Can be used alone or with another family planning method (for dual protection)**
- **May be expensive and hard to find**
- **Inserted by the woman, but needs partner's cooperation**

You can discuss:

- "What have you heard about condoms? Do you have concerns?"
- "Would you be able to use condoms consistently and correctly?"
- "Would your partner agree to use condoms?"
- "Would you be able to keep a supply of condoms on hand?"

About the female condom:

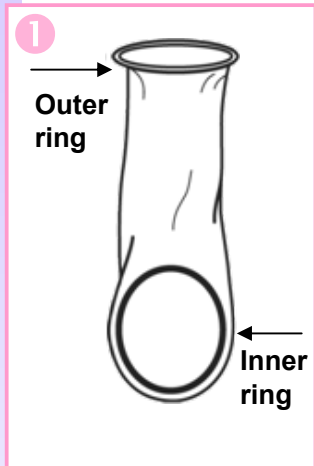
- A loose plastic sheath that is inserted into the vagina before sex.
- No medical conditions limit use. No allergic reactions (made of plastic, NOT made of latex like most male condoms).
- When female condoms are used correctly every time, they are effective in preventing pregnancy.
- May be less effective than male condom.
- Insert before any sexual contact.

Benefits when used consistently and correctly:

- Protects partner(s) from HIV infection.
- Protects from other STIs.
- Prevent pregnancy.
- You can use another family planning method (except the male condom) along with the female condom for extra protections from pregnancy. Also used as backup for another method of family planning (for example, if client missed pills or is late for injection).
- If partner does not want to use condoms:
"We can discuss and practice what you might say." For tips, **see page 34.**

Next step: For how to use female condoms, **go to next page.**

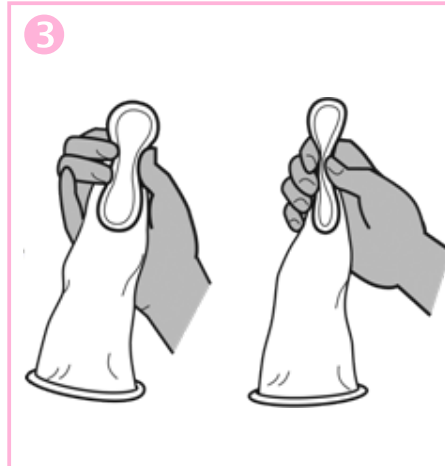
How to use a female condom



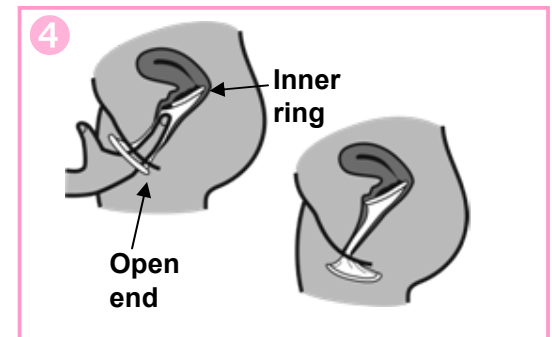
- Open package carefully
- Make sure the condom is well-lubricated inside



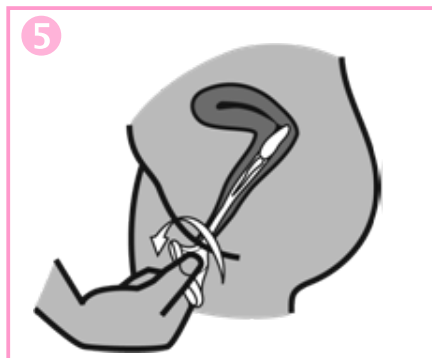
- Choose a comfortable position—squat, raise one leg, sit, or lie down



- Squeeze the inner ring, at the closed end



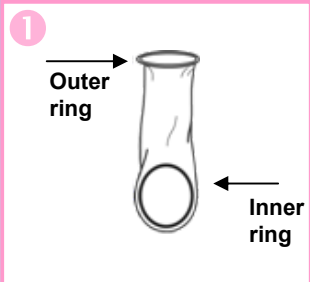
- Gently insert the inner ring into the vagina
- Place the index finger inside condom, and push the inner ring up as far as it will go
- Make sure the outer ring is outside the vagina and the condom is not twisted
- **Be sure that the penis enters inside the condom and stays inside it during intercourse**



- To remove, twist outer ring and pull gently
- Reuse is not recommended
- Throw away condom safely

How to use a female condom

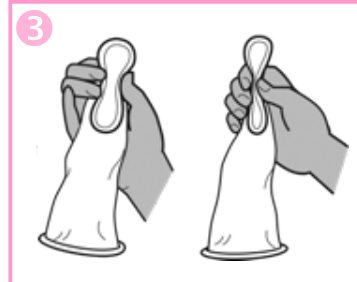
Female
Condom



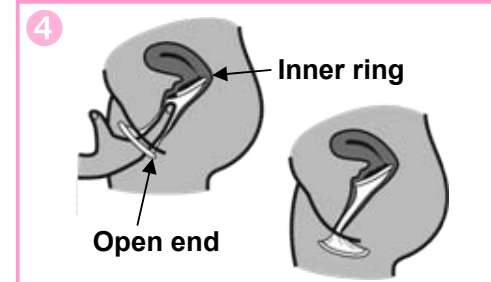
- Open package carefully
- Make sure the condom is well-lubricated inside



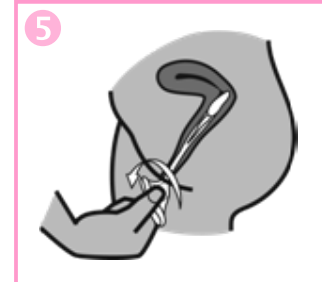
- Choose a comfortable position—squat, raise one leg, sit, or lie down



- Squeeze the inner ring, at the closed end



- Gently insert the inner ring into the vagina
- Place the index finger inside condom, and push the inner ring up as far as it will go
- Make sure the outer ring is outside the vagina and the condom is not twisted
- **Be sure that the penis enters inside the condom and stays inside it during intercourse**

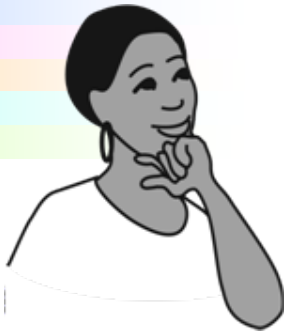


- To remove, twist the outer ring and gently pull
- Throw away condom safely

- Couples should **use a new condom for each act of intercourse.**
- Condom should be inserted *before* penis touches vagina.
- Condom can be inserted up to 8 hours ahead of intercourse.
- Condom is lubricated, but it may need extra lubricant inside so it is not moved out of place during sex. More lubricant can be added either inside condom or on the penis. Lubricant can be water-based or oil-based.
- When finished, the woman must move away from her partner and take care not to spill semen on vaginal opening.
- The condom should be thrown away properly, in a bin or trash can as appropriate.

Next step: For what to remember about female condoms, **go to next page.**

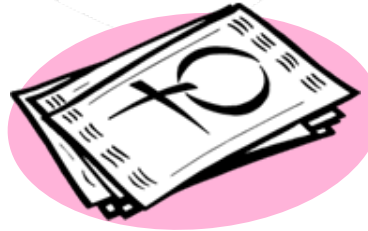
What to remember



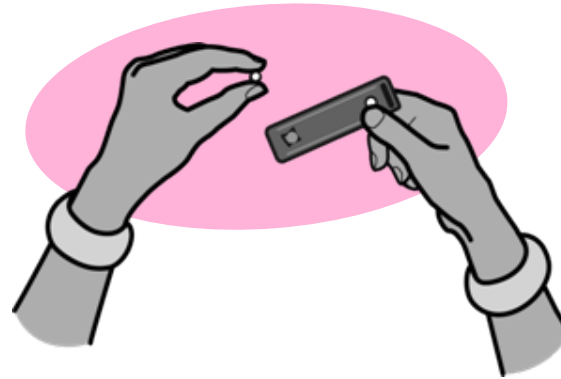
- Use **EVERY TIME**



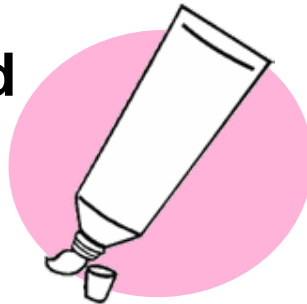
- Keep enough on hand



- If not used correctly, consider emergency contraception



- Can use more lubricant if needed





What to remember

- Use a condom **EVERY TIME** you have sex
- Make sure you keep enough condoms on hand
- If condom is not used correctly, consider using emergency contraception as soon as possible
- Can use more lubricant if needed



*"You need to use a condom **EVERY TIME** you have sex for full protection from pregnancy and infection."*

- Use every time to prevent infecting partner.
- If client is not using a condom every time, discuss reasons and try to find solutions.
- She may also consider using another family planning method along with the condom.



• *"Get more condoms **before** you run out."*



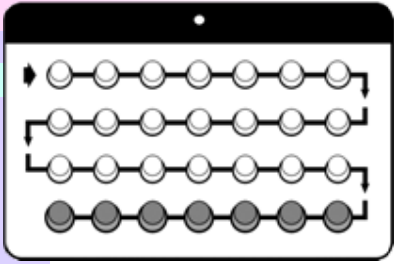
- If female condom does not stay in place or gets pushed inside the vagina, or if the penis was not inside the condom, emergency contraception can help prevent pregnancy.



- All female condoms are lubricated. This may make the female condom slippery at first.
- Can use additional lubricant inside if needed. Can reduce noise during sex and makes sex smoother.
- Any kind of lubricant can be used with the female condom.

Next step: Go back to 10 for ASSIST and ARRANGE.

The Pill



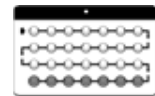
- Take a pill every day
- Women with HIV or on ART can use safely and effectively
- Does not protect against STI or HIV transmission
Use condoms to prevent infection
- Less menstrual bleeding and cramps
- Most common side-effects:
headaches, nausea, spotting





The Pill

The Pill



- **Take a pill every day**
- **Women with HIV or on antiretrovirals can use safely and effectively**
- **Does not protect against STIs or HIV transmission**
- **Helps reduce menstrual bleeding and cramps**
- **Most common side-effects: mild headaches, nausea (upset stomach), spotting or bleeding between periods**



About the Pill:

- Contains both estrogen and progestogen hormones.
- Works mainly by stopping production of eggs.
- Explain common myths: For example, pills dissolve into blood and do not collect in stomach.

- Not harmful for most women's health.
- In case some antiretrovirals may reduce pill effectiveness (see page 6). Stress importance of taking a pill every day and at the same time.

- **Discuss use of male or female condoms** to prevent HIV transmission and for STI prevention.
- Condom use can also help in case antiretrovirals make the Pill less effective.

- Less menstrual bleeding can help reduce anaemia.

- May also experience: tender breasts, dizziness, slight weight gain or loss, amenorrhoea (no monthly bleeding).
- About half of all users never have any side-effects.
- Side-effects often go away or diminish within 3 months.
- Skipping pills may make bleeding side-effects worse and risks pregnancy.
- Invite her to return if she has questions or problems.

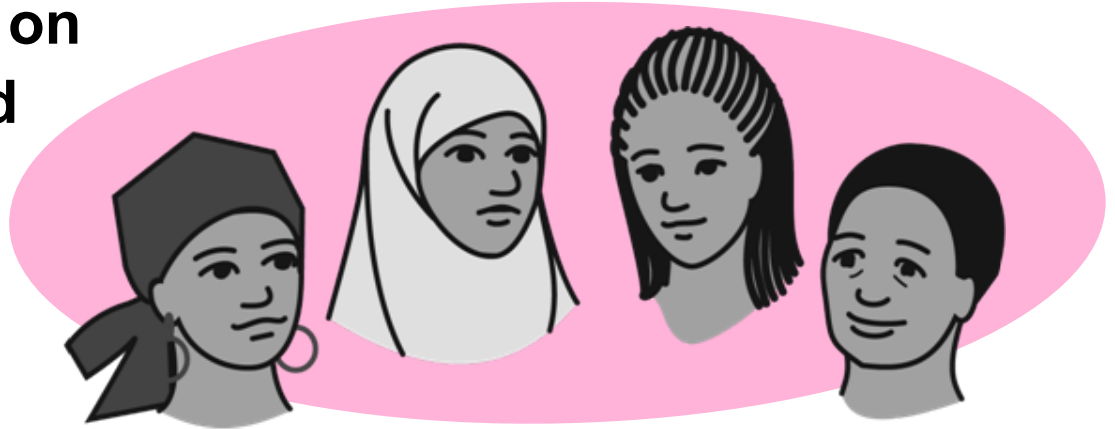
You can discuss:

- "What have you heard about the Pill? Do you have concerns?"
- "If side-effects happened to you, what would you think or feel about it? What would you do?"
- "Would you remember to take a pill each day? What would help?"
- "Would you be able to use condoms consistently to prevent STIs?"
- What to do if pill supply runs out

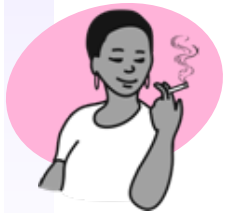
Next step: For who can use the Pill, go to next page.

Who can and cannot use the Pill

Most women with HIV or on ART can use this method safely and effectively



But usually cannot use the Pill if:



**Smokes cigarettes
AND
age 35
or older**



**High blood
pressure**



**Taking
rifampicin**



**Gave birth
in the last 3
weeks**



**Breastfeeding
6 months
or less**

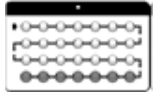


**May be
pregnant**



**Some other
serious health
conditions**

Who can and cannot use the Pill



Most women with HIV or on antiretrovirals can use this method except in these cases:

- **Smokes cigarettes AND age 35 or older**
 - **High blood pressure**
 - **Taking rifampicin**
 - **May be pregnant**
 - **Gave birth in the last 3 weeks**
 - **Breastfeeding 6 months or less**
 - **Some other serious health conditions**
- Usually cannot use the Pill with any of these serious health conditions*

Continuing users

If a woman comes back with any of these serious health conditions, she usually should switch to another method.

*What is migraine?

Ask: "Do you often have very painful headaches, perhaps on one side or throbbing, that cause nausea and are made worse by light and noise or moving about? Do you see a bright spot in your vision before these headaches?" (migraine aura)

Next step: For how to use the Pill, go to next page.

"Usually, women with HIV can use the Pill unless they have certain health conditions. We can see if the Pill is safe for you."

- Check blood pressure (BP) if possible. If systolic BP 140+ mm Hg or diastolic BP 90+ mm Hg, help her choose another method (but not a monthly injectable.) (If systolic BP 160+ mm Hg or diastolic BP 100+ mm Hg, also should not use long-acting injectable.)
- If BP check not possible, ask about high BP and rely on her answer.

- Rifampicin and certain epilepsy drugs (phenytoin, carbamazepine, barbiturates, primidone, topiramate, oxcarbazepine) make the Pill less effective. Generally, choose another method.

- Can use pregnancy checklist, **page 35**, or pregnancy test to be reasonably certain she is not pregnant.

- Ever had stroke or problem with heart or blood vessels, including blood clot in lungs or deep in legs. (Women with superficial clots, including varicose veins, CAN use the Pill.)
- Migraine headaches*: She should not use the Pill if she is over 35 and has migraines, or at any age if she has migraine aura. Women under 35 who have migraines *without* aura and women with ordinary headaches CAN usually use the Pill.
- Ever had breast cancer.
- Has several risk factors for heart disease, such as high blood pressure, diabetes, smoking, older age.
- Gallbladder disease.
- Soon to have surgery? She should wait to start the Pill if she will not be able to move about for more than 1 week.
- Serious liver disease or jaundice (yellow skin or eyes).
- Diabetes for more than 20 years, or severe damage caused by diabetes.

Using the Pill

Take one pill each day



If you miss pills—

- Always take a pill as soon as you remember



If you miss 3 or more pills or start a pack 3 or more days late—



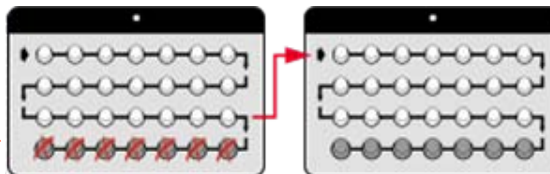
1 Continue taking pills and use condoms or avoid sex for the next 7 days



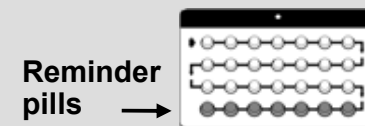
OR



2 If you missed 3 pills or more in week 3, ALSO skip the reminder pills and go straight to a new pack

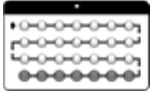


If you miss any reminder pills—



Throw away the missed pills and continue taking pills, one each day





Using the Pill

- She may be able to start the Pill today



A woman can start the Pill on any day of the menstrual cycle if it is reasonably certain that she is not pregnant.

If menstrual bleeding started in past 5 days:

- She can start NOW. No extra protection needed.

If menstrual bleeding started more than 5 days ago or if amenorrhoeic (not having menstrual periods):

- She can start NOW if reasonably certain she is not pregnant, **see page 35**. **No need to wait for next menstrual period** to start the Pill.
- She should **avoid sex or use condoms for 7 days** after taking first pill.

“Take one pill each day”

If you miss pills—

- Take a pill as soon as you remember



- Most important instruction. Show how to follow arrows on packet.
- Explain that the hormonal pills are in weeks 1, 2 and 3. The pills for week 4 are “reminder pills” and do not contain hormones.

If you miss 3 or more pills or start a pack 3 or more days late—

- Use condoms or avoid sex for the next 7 days



Important: Waiting too long between packs increases risk of pregnancy.

Emergency contraception can be a choice if she misses 3 or more pills in the first week or starts a pack 3 or more days late. (**See page 27.**)

- Skip the reminder pills if you missed 3 pills in week 3



She may have no menstrual bleeding that month.

If you miss any reminder pills—

- Throw away missed reminder pills and continue taking pills

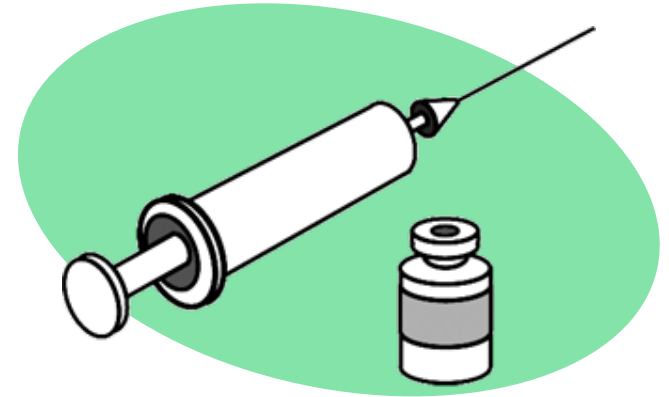


Skipping reminder pills is not harmful.

Next step: Go back to 10 for ASSIST and ARRANGE.

Long-acting injectable

- **Women with HIV can use safely and effectively**
- **An injection every 2 or 3 months**
- **Does not protect against STIs or HIV transmission**
Use condoms to prevent infection
- **Often takes longer to get pregnant after stopping**
- **Most common side-effects: More bleeding and spotting at first and then no monthly bleeding, weight gain**



Long-acting injectable

Injectable



- Women with HIV can use safely and effectively
- An injection every 2 or 3 months
- Does not protect against STIs or HIV transmission
- Often takes longer to get pregnant after stopping
- Most common side effects: menstrual changes, no monthly bleeding, weight gain



About injectables:

- 3 months between injections of DMPA or 2 months between injections of NET-EN.
- Contains progestogen. Works mainly by stopping production of eggs.
- **Very effective**, provided she comes back at scheduled time.
- Injections are not harmful for most women's health. For breastfeeding women, they do not affect the quality of the breast milk.

- To prevent infection, also use condoms consistently and correctly.

- After stopping, can take several months more than usual before a woman can get pregnant. Injectables do not make women permanently infertile.

- **Menstrual changes:** Irregular bleeding and spotting are common especially during first few months of use.
- **Amenorrhoea:** Monthly bleeding often stops after several injections. Does not permanently affect fertility. Blood does not build up inside body. (Pregnancy is very unlikely if she was not very late for previous injection.)
- **Also very common:** Weight gain. Bone mineral density decreases slightly during DMPA use but increases again after use stops. Not known whether this increases risk of fracture later in life.
- **Less common:** Mild headaches, dizziness, nausea.
- Invite her to return if she has questions or problems.

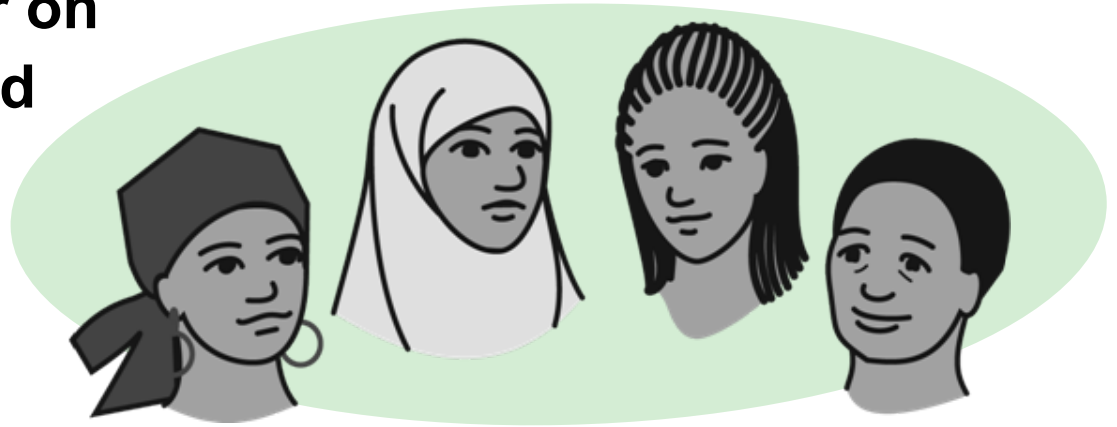
You can discuss:

- "What have you heard about injectables? Do you have concerns?"
- "If side-effects happened to you, what would you think or feel about it? What would you do?"
- "Would you be able to come back on time for injections? How would you remember?"

Next step: For who can use injectables, go to next page.

Who can and cannot use a long-acting injectables

Most women with HIV or on ART can use this method safely and effectively



But usually cannot use this injectable if:



Very high blood pressure



**Breastfeeding
6 weeks
or less**



**May be
pregnant**



**Some other
serious health
conditions**

Who can and cannot use a long-acting injectable

Injectable



Most women with HIV or on antiretrovirals can use this method except in these cases:

- **Very high blood pressure**
- **Breastfeeding 6 weeks or less**
- **May be pregnant**
- **Some other serious health conditions**

Usually cannot use with any of these serious health conditions



"Usually, women with HIV can use the injectable unless they have certain health conditions. We can see if the injectable is safe for you."

- Check blood pressure (BP) if possible. If systolic BP 160+ mm Hg or diastolic BP 100+ mm Hg, help her choose another method (but not the Pill or monthly injectables).
- If BP check not possible, ask about high BP and rely on her answer.

- Ask her to come back when baby is 6 weeks old.

- Can use pregnancy checklist, **page 35**, or pregnancy test to be reasonably certain she is not pregnant.

- Ever had stroke or problem with heart or blood vessels, including blood clot in lungs or deep in legs. (Women with superficial clots, including varicose veins, CAN use this injectable.)
- Has several risk factors for heart disease, such as hypertension, diabetes, smoking, older age.
- Diabetes for more than 20 years, or severe damage caused by diabetes.
- Ever had breast cancer.
- Unexplained vaginal bleeding: If the bleeding suggests a serious condition, help her choose a method without hormones to use until the unusual bleeding is assessed.
- Serious liver disease or jaundice (yellow skin or eyes).

Continuing users

If a woman returns with any of these serious conditions, she should usually switch to another method.

Next step: For how to use injectables, go to next page.

Using the injectable

- Injection in your arm or buttock
- Don't rub afterwards
- Important to come back on time

Remember:

- Name of injection is _____
- Date of next injection is _____
- Come back even if late



Using the injectable

Injectable



She may be able to start the injectable today



A woman can start the injectable on any day of the menstrual cycle if it is reasonably certain that she is not pregnant.

If menstrual bleeding started in past 7 days:

- She can start NOW. No extra protection needed.

If menstrual bleeding started more than 7 days ago or if amenorrhoeic (not having menstrual periods):

- She can start NOW if reasonably certain she is not pregnant (**see page 35**). **No need to wait for next menstrual period** to start the injectable.
- She should **avoid sex or use condoms for 7 days** after the first injection.

- **Injection in arm or buttock**
- **Don't rub afterwards**
- **Important to come back on time**



- Every 3 months for DMPA. Every 2 months for NET-EN.

Remember:

- **Name of injection is _____**
- **Date of next injection _____**
- **Come back even if you are late**



- Tell her name of injection and date of next injection. Write these on a card and give the card to the woman.



- **Up to 2 weeks late:** Can have injection without need for extra protection.
- **More than 2 weeks late:** Can have next injection if reasonably certain she is not pregnant (**see page 35**). She should use condoms or avoid sex for 7 days after injection. Consider emergency contraception if she had sex *after* the 2 week "grace period".
- **Discuss how she can remember the next injection date.**

Next step: Go back to 10 for ASSIST and ARRANGE.

Emergency contraception

Safe ways to prevent pregnancy soon after unprotected sex



Emergency contraception (EC)



- There are safe ways to prevent pregnancy after unprotected sex
- How long ago did client have unprotected sex?



- A woman may want to consider EC if:
 - no method was used
 - method was used incorrectly (for example, missed pills, late for injection)
 - method failed (for example, slipped or broken condom, expelled IUD)
 - sex was forced
- If she can answer “yes” to any of the questions on the pregnancy checklist, **page 35**, she is probably not fertile and would not need EC. But if she is worried, she can still use EC.

— Up to 5 days ago?



Emergency contraceptive pills:

- She should **take pills as soon as possible** after unprotected intercourse. They can be taken up to 5 days after. **See next page.**



Emergency copper IUD:

- More effective than pills, but those who may have gonorrhoea or chlamydia should not use it because of risk of pelvic infection (**see page 9**).
- Can be used up to 5 days after unprotected intercourse.
- Good choice for women who want to keep using an IUD.

— More than 5 days ago?



- Could she have been exposed to STIs?



You can discuss:

- “Could unprotected sex happen again?”
- “Do you need dual protection from pregnancy and STIs/HIV?”
- “Do you have a regular method? Are you satisfied with it?”
- “If not, would you like to start using a regular method or switch methods?”

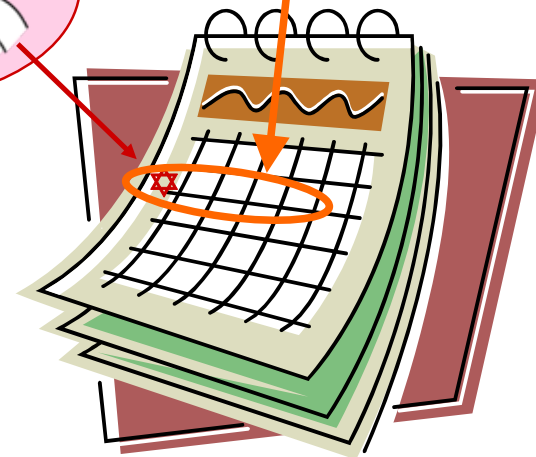
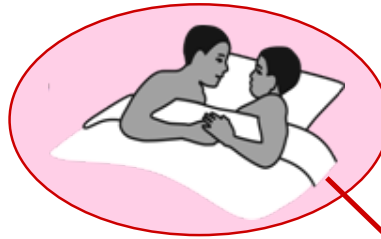
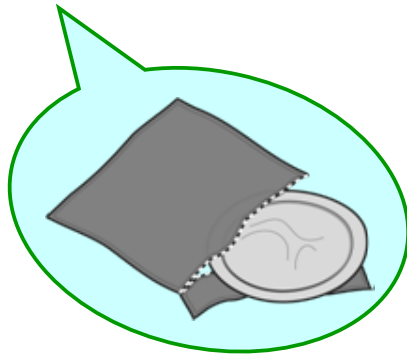
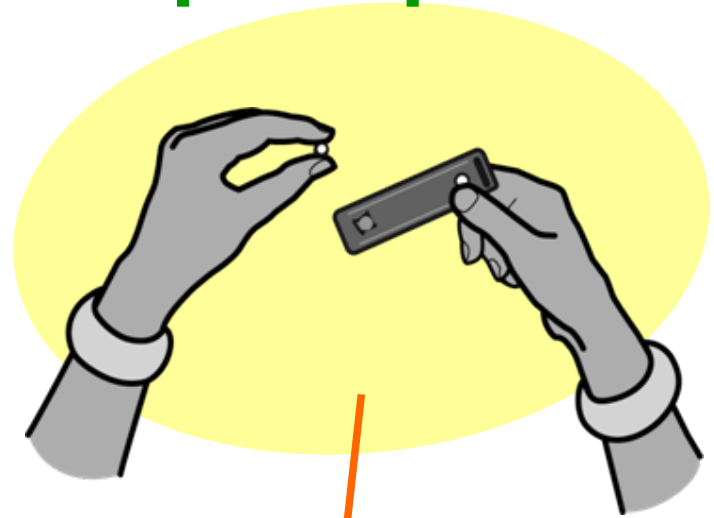
- Advise her that emergency contraception can be used only up to 5 days.
- Ask her to come back if her next monthly bleeding is more than 1 week late.

- If exposure to STIs is a possibility, offer presumptive STI treatment (same as treatment dosage), if available, or refer for further counselling, support, and treatment.

Next step: For more about emergency contraceptive pills, go to next page.

Emergency contraceptive pills

- Take as soon as possible
- Will not cause abortion
- Will not prevent pregnancy next time you have sex



Emergency contraceptive pills (ECPs)



- Take as soon as possible after unprotected sex



- **She should take pills as soon as possible after unprotected sex.** They can be taken up to 5 days after, but become less effective with each day that passes.

Levonorgestrel-only ECPs

- Work better and cause less nausea and vomiting than combined ECPs.
- **Dosage:** 1.5 mg of levonorgestrel in a single dose.

Combined estrogen-progestogen ECPs

- Use if levonorgestrel-only pills not available.
- **Dosage:** 2 doses of 100 mcg of ethinylestradiol plus 0.5 mg of levonorgestrel, 12 hours apart.

- **Any woman can take ECPs**, even if she cannot take the Pill regularly, because ECPs are a relatively small, one-time dose.

- Will not cause abortion
- Do not prevent pregnancy next time you have sex
- Not for regular use
- May cause nausea, vomiting, spotting or bleeding



- “ECPs prevent pregnancy. **They do not cause abortion.**” They work mainly by stopping release of the egg.
- If she had *other* acts of unprotected sex since her last menstrual period, she may already be pregnant, and ECPs will not work. If she takes ECPs when already pregnant, they do not harm the pregnancy. **She should return if her next menstrual period is more than 1 week late.**



- **Discuss:** No protection in future acts of intercourse.
- Less effective than most regular methods.
- Provide condoms and, if she wants, another continuing method.



- If she is taking combined ECPs, she can take medicine (meclazine hydrochloride) to prevent nausea.
- If she vomits within 2 hours after taking ECPs, she should return for another dose as soon as possible.
- She may have spotting or bleeding a few days after taking pills.



Next step: Go back to 10
for **ASSIST** and **ARRANGE**.

LAM

Lactational amenorrhoea method

- A contraceptive method based on breastfeeding
- LAM depends on breastfeeding often, day and night, and giving no other food or liquids
- Can prevent pregnancy for up to 6 months after childbirth
- Breastfeeding risks passing HIV to the baby, but exclusive breastfeeding is safer than mixed feeding
- Avoid slow weaning
- Use condoms, too, to avoid infection



LAM

Lactational amenorrhoea method

LAM



- A contraceptive method based on breastfeeding
- LAM depends on breastfeeding often, day and night, and giving no other food or liquids
- Effective for up to 6 months after childbirth
- Breastfeeding risks passing HIV to the baby, but exclusive breastfeeding is safer than mixed feeding
- Avoid slow weaning
- Use condoms, too, to avoid infection

About LAM:

- “Lactational”—related to breastfeeding. “Amenorrhoea”—not having monthly bleeding.
- Antiretrovirals can be taken during breastfeeding and may help protect the baby from HIV infection.

- Using LAM means choosing to breastfeed this way to prevent pregnancy. It works by preventing ovulation.
- *“How would breastfeeding your baby in this way suit you?”*

- If monthly bleeding has not returned.
- Very effective when used correctly, but less effective as commonly used (if not fully breastfeeding).

Women with HIV should be counselled to choose the feeding option that best suits their situation:

- If safe replacement feeding is available, it avoids all risk of passing HIV to the baby.
- If no safe replacement feeding is available, a woman with HIV should breastfeed exclusively for the first 6 months.

- She should stop breastfeeding over 2 days to 3 weeks. Rapid weaning decreases risk of transmitting HIV to the baby.

Next step: Go back to 10 for **ASSIST** and **ARRANGE**.

Fertility awareness-based methods

- Learn the days of the menstrual cycle when you can get pregnant
- To prevent pregnancy, either avoid sex OR use a condom on days that you could get pregnant
- To avoid infection, use condoms all the time
- Can be effective if used correctly
- No side-effects
- Needs partner's cooperation



Fertility awareness-based methods



- **Learn the days of the menstrual cycle when you can get pregnant**



- **To prevent pregnancy, either avoid sex OR use a condom on days that you could get pregnant**



- **To avoid infection, use condoms all the time**



- **Can be effective if used correctly**



- **No side-effects**



- **Needs partner's cooperation**



You can discuss:

- "What have you heard about these methods? Do you have concerns?"
- "Do you think you can abstain or use condoms on all fertile days?"
- "Would you need to use condoms all the time to prevent HIV and STIs?"

About fertility awareness-based methods:

- A woman learns the fertile days of her menstrual cycle.
- **There are different ways to identify the fertile days:**
 - Calendar methods: use cycle length to calculate the fertile days of each cycle.
 - Cervical mucus methods: identify fertile days from changes in cervical secretions
 - Depending on the method, the woman assumes she is fertile for 7 to 18 days each cycle, on average.
- Methods can be used alone or in combination.
- If she becomes unwell or begins taking antiretroviral or other medication, these methods may be less reliable.
- **Refer for further advice or counselling.**

- **If at risk for HIV and STIs**, advise her to use condoms all the time, on both fertile and infertile days.
- **If not at risk**, she can use male or female condoms on fertile days only to prevent pregnancy.
- To prevent pregnancy, faithful couples who are both HIV-positive may decide to use condoms only on fertile days.

- But this is one of the least effective family planning methods when not used correctly.

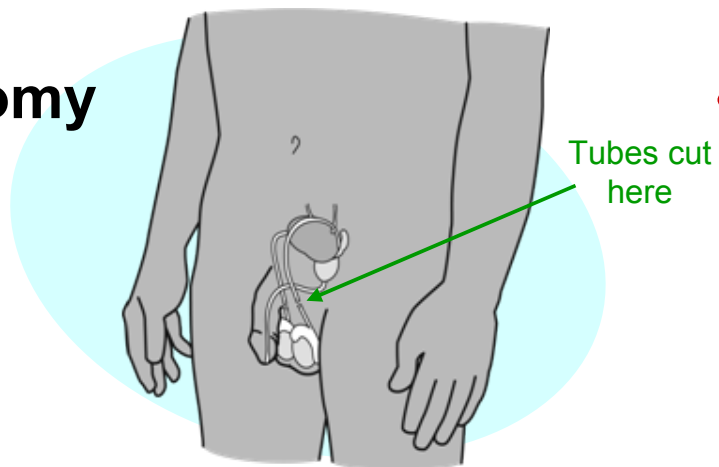
- Does not involve any medication.

- Both partners must agree to avoid intercourse or use a condom on days when needed.

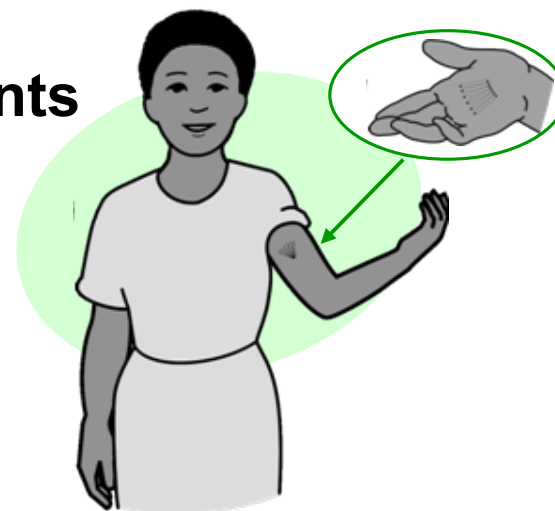
Next step: Go back to 10
for **ASSIST** and **ARRANGE**.

Referral methods

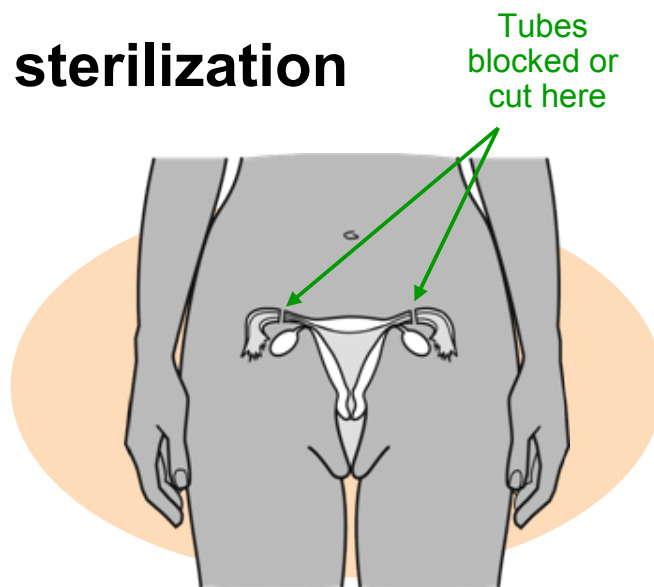
- **Vasectomy**



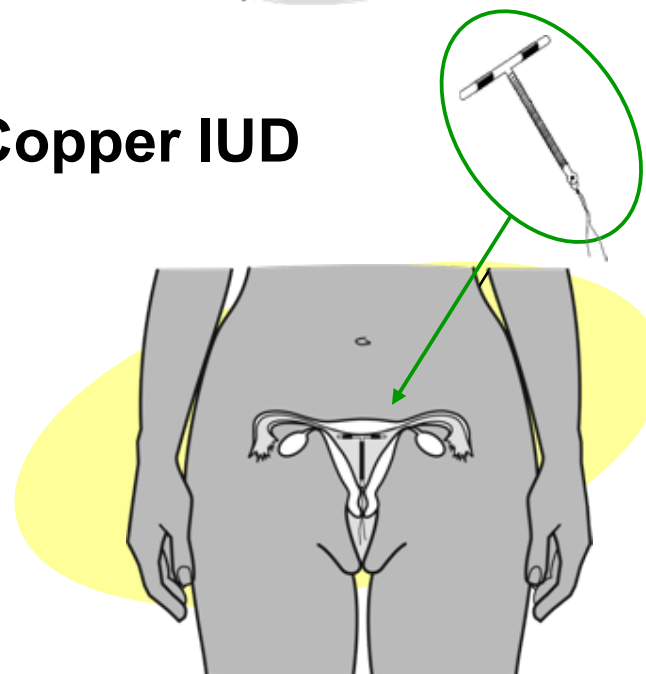
- **Implants**



- **Female sterilization**



- **Copper IUD**



Referral methods

Note: None of these methods prevents infection. Use condoms consistently and correctly.

Vasectomy

- Safe, simple surgical procedure (simpler than female sterilization).
- Very effective and permanent—for men or couples who will not want more children.
- Many men with HIV can safely have vasectomy.
- Not recommended for men with AIDS symptoms.
- No effect on erections or ejaculation.

Female sterilization

- Safe surgical procedure
- Very effective and permanent—for women or couples who will not want more children.
- Many women with HIV can safely have sterilization.
- Not recommended for women with AIDS symptoms.

Copper IUD

- Small flexible device that fits inside the womb.
- Women with HIV can safely use IUD if no STI risk.
- Very effective for at least 12 years (approved for 10 years).
- Can be removed whenever user wants, and she can get pregnant again.
- May increase menstrual bleeding and cramps.

How to use this page:

- If client will want no more children, describe vasectomy and female sterilization.
- If client wants a long-term reversible method or wants no more children without a surgical procedure, describe implants and IUD.

Implants

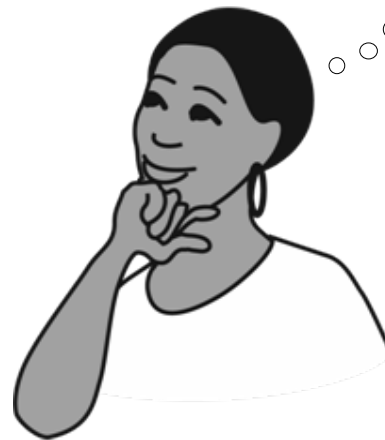
- Small plastic tubes placed under skin of upper arm.
- Women with HIV can use safely and effectively.
- Very effective for 4 to 7 years, depending on woman's weight and type of implant.
- Can be removed whenever user wants, and she can get pregnant again.
- Usually changes monthly bleeding.

Next step: Go back to 10 for **ASSIST** and **ARRANGE**

Help using your method

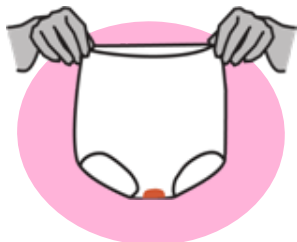


- Any questions or problems?



- Any side-effects?

Bleeding
changes?



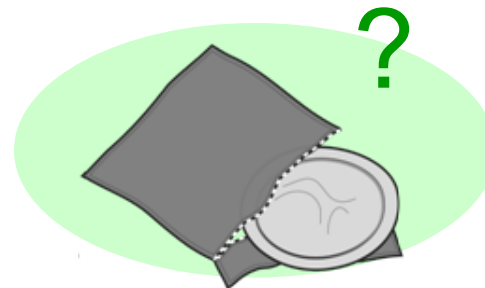
Nausea or
vomiting?



Headaches?



- Any problems using condoms?



For returning family planning users: **Help using your method**

Any questions or problems?



Reassure her that side-effects are normal

- Most are not harmful or signs of illness. Often go away after 3 months or so.
- She may have more than one side-effect.
- For pill users, switching to a different brand may help.

Side-effects?

• **Bleeding changes?**



Injectables users:

- **Spotting, bleeding between periods is common**, especially in the first few months of use. Not harmful, not a sign of illness.
- **No monthly bleeding (amenorrhoea)**. Common, especially after 1st year of use. Not harmful, not a sign of illness.
- **Very heavy bleeding**. Rare. *If bleeding continues*, check for abnormal gynaecological conditions and for anaemia (low iron). Help her choose another method if the bleeding threatens her health or is unacceptable to her.



Pill users: **Spotting or bleeding between periods** is common, especially in the first few months of pill use. Spotting also may be due to skipping pills, vomiting or diarrhoea, or taking rifampicin or some epilepsy medications.

• **Nausea or vomiting?**



- **Vomiting within 2 hours** after taking active pill: Take another active pill from separate pack. **Nausea** may be reduced by taking pill after a meal each day.
- **Severe diarrhoea or vomiting for more than 2 days**: Follow instructions for missed pills.

• **Headaches?**



- **Mild headaches**: Take pain relief pills if needed.
- If headaches become more frequent or severe (migraine) while using the Pill, she usually should switch to another method.

Problems using condoms?



- Explain risks of not using a condom every time and help client discuss with partner if necessary (**see pages 8 and 34**). Suggest also using another family planning method and review protection strategies (**see page 7**).

Next step: If client wants to choose a new method, go to **6**

Discuss: If problems, listen to the client's concerns.

- **Take all comments seriously**. Answer questions respectfully.
- Reassure a woman that she can switch family planning methods at any time.
- If you suspect a serious underlying condition, diagnose and treat or refer.

Family planning after childbirth

- **Best to wait at least 2 years before becoming pregnant again**
- **If not breastfeeding, you could get pregnant again soon**
- **If breastfeeding, exclusive breastfeeding is safest for your baby**



Family planning after childbirth

- **Best to wait at least 2 years before becoming pregnant again**



- Discuss with woman if she has had infant feeding counselling and her decision.
- If not, counsel or refer for counselling.

- **If not breastfeeding, you could get pregnant again soon**



- Waiting at least 2 years after the last birth to become pregnant again is healthiest for mother and child.

- **If breastfeeding, exclusive breastfeeding is safest for your baby**



- If she is not fully breastfeeding, she may be at risk of pregnancy again as soon as 4 weeks after childbirth.

- Breastfeeding exclusively is safer than mixed feeding.
- Exclusive breastfeeding also can prevent pregnancy. **See LAM, page 29.**
- Discuss other methods in case she stops LAM or wants additional protection.
- Other good methods while breastfeeding are nonhormonal methods such as condoms or IUD. The IUD can be inserted within 2 days after childbirth, or after 4 weeks.
- Progestogen-only methods can also be used while breastfeeding, starting 6 weeks after childbirth (the mini-pill, long-acting injectables, implants).

- **If not breastfeeding**



- If not breastfeeding, she can use any method. She can start any progestogen-only methods immediately (the mini-pill, long-acting injectables, implants), or the Pill after 3 weeks. See above for starting the IUD.

- **Whether breastfeeding or not**



- Listen carefully to the client's views.
- Discuss her thoughts about having more children. Ask what her partner thinks.
- If they have decided that they want no more children, discuss vasectomy and female sterilization.
- All women with new babies should be advised to use condoms correctly and consistently to avoid infection and pregnancy.

Next step: For more information about LAM, go to **29**
or, for choosing a method, go to **6**

Talking with your partner

- **Where, when and how**



- **Being prepared**



Tips for talking with your partner

Where

- Choose a place that is comfortable for both of you.
- Suggest a quiet place, but close to safety if needed.
- Find a neutral ground.

When

- Talk at a time when you are both relaxed and comfortable.
- Avoid distractions or rushing.
- Can be discussed over a period of time, not just at one sitting.
- Discuss before sex starts.

How

- Stress the good things.
- Emphasize partner's caring, your concern.
- Start with what you both agree on.
- Focus on safety and good health, not mistrust.
- Talk about good examples, such as people that your partner respects.
- Try to reach agreement.

Being prepared

Stay safe

- Don't risk your safety.
- Consider having another trusted person there.
- Start with general facts and watch reactions.

Get the facts right

- Provider can answer your questions.

Plan

- Decide where, when, and how to start.
- What if discussion goes badly? Turns violent?
- Counselling as a couple?

Practice

- Rehearse with provider or with friends.

How to use this page:

- Offer suggestions but let client decide what can work.
- Discuss doubts and fears. Don't dismiss them.
- Reassure clients that they can succeed. With permission, tell the stories of others who have succeeded.
- Suggest that seeing a health care provider together as a couple is sometimes very helpful.
- **ARRANGE** a follow-up visit to discuss what happened.

You can start the method now if ANY ONE of these is true



1. Menstrual period started in the past 7 days



or 2. Gave birth in the past 4 weeks



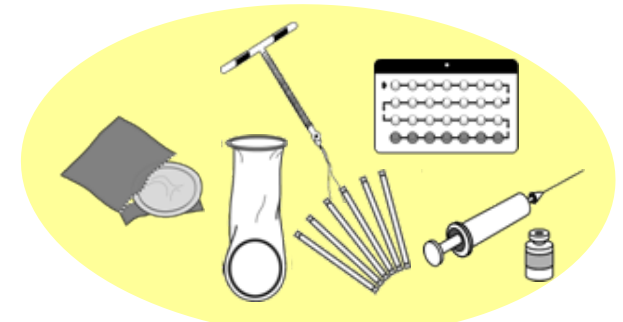
or 3. Fully or nearly fully breastfeeding AND gave birth less than 6 months ago AND periods have not returned



or 4. Miscarriage or abortion in the past 7 days



or 5. No sex since last menstrual period or delivery



or 6. Been using another method correctly

Making reasonably sure a woman is not pregnant (so she can start hormonal methods, IUD, or female sterilization)

Women who are not currently menstruating may still be able to start **hormonal methods (pills, injectables, implants), the IUD or have sterilization NOW**. (All other methods can be started at any time.) Ask if ANY of these statements is true.

If a woman answers **NO to ALL of these statements**, pregnancy cannot be ruled out. She should wait until next menstrual period (and avoid sex or use condoms until then) or else take pregnancy test.

If a woman answers **YES to AT LEAST ONE of these statements** and she has no signs or symptoms of pregnancy,* provide her with the method.

| No | | Yes |
|----|---|-----|
| | 1. Last menstrual period started within the past 7 days (12 days for the IUD) | |
| | 2. Gave birth in the last 4 weeks | |
| | 3. Fully (or nearly fully) breastfeeding AND gave birth less than 6 months ago AND has had no menstrual period since then | |
| | 4. Miscarriage or abortion in the past 7 days | |
| | 5. NO sexual intercourse since last menstrual period or delivery | |
| | 6. Using a reliable contraceptive method consistently and correctly | |

*Signs of Pregnancy

If a woman has a late menstrual period or several other signs, she may be pregnant. Try to confirm by pregnancy test or physical examination.

Late menstrual period
Breast tenderness
Nausea
Vomiting

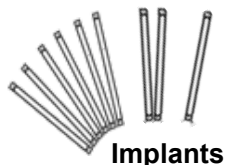
Weight change
Always tired
Mood changes

Changed eating habits
Urinating more often
Larger breasts
Darker nipples

Comparing effectiveness of methods

More effective

Less than 1 pregnancy per 100 women in one year



Implants



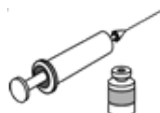
Vasectomy



Female Sterilization



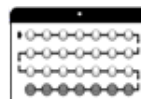
IUD



Injectables



LAM



Pills



Male Condoms



Female Condoms



Diaphragm



Fertility-Awareness Based Methods



Withdrawal



Spermicide

How to make your method most effective

After procedure, little or nothing to do or remember

Vasectomy: Use another method for first 3 months

Injectables: Get repeat injections on time

LAM (for 6 months): Breastfeed often, day and night

Pills: Take a pill each day

Condoms, diaphragm: Use correctly every time you have sex

Fertility-awareness based methods:
Abstain or use condoms when fertile.
Newest methods (Standard Days Method and TwoDay Method) may be easier to use.

Withdrawal, spermicide: Use correctly every time you have sex

Less effective

About 30 pregnancies per 100 women in one year

**APPLICATION FOR AMENDMENT OF PROTOCOL REFERENCE NUMBER:
HSS/0772/09D**

PROJECT TITLE: Development of HIV/AIDS self-management education conceptual framework for people living with HIV/AIDS Semi-rural KwaZulu-Natal, South Africa.

I hereby apply for amendment of my previously approved protocol (HSS/0772/09D) due to some problems encountered.

Problems

1. Access to research settings denied due to a claim that the settings presently have no facilities needed for the conduct of my study and that students are not allowed to conduct research in the premise at the time. I was faced with the problem of having to look for another setting using the criteria in the approved protocol of the research setting being semi-rural in KwaZulu-Natal, ARVs roll out centre with adequate facilities and participants for the study.
2. Instrument/participant's health status- participants are too ill to complete the 16 pages questionnaire that took them 45 minutes to complete excluding the break period. There arise needs to undergo further search for a more concise instrument that will capture the variables of interest to the study.

How the problems were resolved

Firstly, the investigator after series of phone calls, applications and visits was accepted to conduct the study at Danganya Clinic.

Danganya Clinic

Danganya clinic is a comprehensive health centre under the Department of Health situated on the outskirts of Durban in Danganya between Umugababa and Infracombe, located along south coast road about 40 km south of Durban. Danganya is more of a rural situation, underdeveloped but with improvement in terms of infrastructure. The main means of transportation is Metrorail and commercial taxi drivers plying the south coast road. The clinic serves a catchment area of more than 850000, mostly Zulu-speaking, and catered primarily to the healthcare needs of the "poorest of the poor", living in rural and semi-rural areas. The clinic is one of the Charles James Hospital

ARVs down-referral clinics also serve as down-referral for Prince Mshiyeni Hospital and Addington Hospital. Supplies of ARVs for all the down-referred patients are from Charles James Hospital and other hospitals mentioned above. Patients from the areas served by the clinic are down-referred for ARVs provided: viral load is less than 25; and there is no sign of clinical deterioration. Blood monitoring and evaluation of the down-referred patients are done at the clinic and if there is deterioration in their clinical status at anytime before the six month period, CD4 count and viral load are repeated on the motivation of the doctor at the clinic. For viral load greater than 1000, or a fall/decrease in CD4 count: make sure the patient is adherent and re-enforce adherence; repeat viral load and CD4 count. If viral load is still greater than 1000, refer patient back to Charles James Hospital for further management. For any acute or chronic illness that needs referral to a tertiary health institute, the normal referral pattern is followed. The clinic keeps statistics of patients who exit the program for any reason and inform Charles James Hospital pharmacy on time. Patients that are diagnosed with TB whilst on ARVs and are to be started on anti-TB therapy have their LFT done before anti-TB therapy and EFV sopped for NVP if possible.

Services offered

- Clinical management of HIV, AIDS, STIs and TB (HAST)
- A laboratory service for screening of blood for HIV and sputum smears for AFB.
- Voluntary counseling and testing services.
- Offered antiretroviral treatment.
- Provide health education for People living with HIV/AIDS and TB patients, families, staff and communities.
- Provide primary health care services including immunization, treatment for sick infants and adults.
- Administer prescribed treatment for chronic conditions that are down-referred from Charles James Hospital and other tertiary health institutes.

Charles James Hospital is situated at Ezimbokodweni reserve, near Amanzimtoti, south of Durban. The nearest township is KwaMakhutha-about 5 km. The hospital was established in 1966 as SANTA centre. In July 2005, the centre was incorporated into the Department of Health as this was the process taken up for all SANTA centres. The hospital admits male and female TB

adult patients and is down referral site for TB that has been accredited as an ARV site in 2008 and it does not offer emergency services of any kind.

Secondly, the investigator have now resolved to use instrument I (HIV/AIDS Self-Management Education Needs Survey) in the approved protocol with one open ended question added “What one thing would be most helpful in meeting your current self-management needs?” for qualitative data collection on self-management needs of the participants prior intervention. A new instrument was introduced to capture health-related quality of life of the participants at baseline. The instruments II to VII in the approved protocol were dropped. SF-36 questionnaire will be used for data collection during the assessment phase in addition to HIV/AIDS Self-Management Education Needs Survey. SF-36 questionnaire will also be used during evaluation plus in-depth interview (using the previously approved interview guide) and consultation. The instruments are briefly described below.

1. HIV/AIDS Self-management Education Needs Survey (HASMENS) was adapted from Health and Self-Care Learning Needs Survey developed by Mendias & Paar (2007) for assessing self-care learning needs of outpatients with HIV/AIDS. A pilot study was conducted to identify possible problems, suitability for South African participants and estimate internal consistency of the instruments. Content validity was addressed through literature review on HIV-positive patient’s health concerns and needs. In addition, expert clinicians suggested items for inclusion and clinic patients informally queried, prior to survey development, for patient interest in self-management education programs, as well as topics of interest. Once the survey is developed, expert clinicians reviewed items for content and clarity and in lieu of formal assessment of readability, for appropriateness of terminology, based on words commonly used with and by patients in the clinic. The investigator obtained permission for the use of the instruments from the appropriate authorities.
2. SF-36 Questionnaire considered to be one of the best instruments, proved to be very useful for measuring the health-related quality of life (HRQOL) of general and specific populations, patients with acute and chronic diseases in clinical practice in various situations and under different circumstances (Joshi et al. 2001:136; Ware, 2001:1). The SF-36 questionnaire, is directed towards the respondent’s experiences, feelings, beliefs

and convictions about their health-related quality of life, consists of eight scales and two summary measures (physical and mental health). The eight multi-item scales that were used, are: (a) limitations in physical activities because of health problems; (b) limitations in social activities because of physical or emotional problems; (c) limitations in role activities because of physical health problems; (d) bodily pain; (e) general mental health; (f) limitations in role because of emotional problems; (g) vitality; and (h) general health perceptions (Ware & Sherbourne, 1992:473-483). The content validity of the SF-36 questionnaire is confirmed by systematic comparisons that indicate that this questionnaire includes eight of the most frequently represented health concepts in the measurement of health-related quality of life (Ware, 2001:3). Both the internal and construct validity of SF-36 instrument have also been confirmed through various studies (Petr, 2001; Moller & Petr, 2002; Strassnig, Brar & Ganguli, 2003).

Conclusion

The new setting is directly under the Department of Health which makes it a more representative of health care delivery to this group of people in South Africa, unlike the previous settings that are privately owned of which services might be available to those who can afford it. The new instruments consist of 9 pages taking the participants 20-25 minutes to complete. Copies of the instruments are hereby attached. The changes are in line with the previously approved protocol. Thank you so much for the previous full approval of my protocol and for your usual cooperation.

I look forward to your reply.

Yours sincerely,

Omisakin Folorunso Dipo (Mr.)

Student number: 209506889