

*An Investigation into Home-Based Care  
as a Continuum of the  
Comprehensive Health Care Provision  
for People Living with AIDS at Umlazi  
and its Informal Settlements in  
Health Region "F" of KwaZulu-Natal Province*

By

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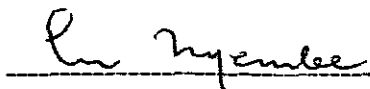
in the Department of Nursing Science at  
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## DECLARATION

I declare that the production of this dissertation on *Home-Based Care as a Continuum of the Comprehensive Health Care Provision for people living with HIV/AIDS at Umlazi and its informal settlements in Health Region "F" of KwaZulu-Natal Province* is purely my own work. All sources that I have quoted have been indicated by means of full references.



L.N. NYEMBE  
DURBAN  
JANUARY 2001

## DEDICATION

This work is dedicated to my husband, Artwell, my children Julian, Anita, Portia, Zamaswazi, Emmanuel and grandchildren Samukelisiwe and Boitumelo (Tumi)

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## ABSTRACT

The study was an exploratory descriptive one to investigate Home-Based Care as a continuum of the health care provision with specific reference to People Living with HIV/AIDS in the Umlazi metro area of KwaZulu-Natal and its informal settlements. A critical analysis of literature on perspectives on HIV/AIDS and home-based care was done to provide in-depth understanding of these phenomena.

Purposive sampling complemented with snowball sampling was done to select participants from a population of people living with HIV/AIDS, home-based caregivers, social workers and traditional healers. Questionnaires comprising open-ended and close-ended questions were used.

The study revealed that a holistic approach to care is provided to sick individuals and family members through home-based care. In spite of limited resources in the home environment, those cared for at home by loving, caring family members expressed satisfaction. It was found that the Department of Health and various organizations were involved in different initiatives in the fight against HIV/AIDS and support of home-based care, but it was difficult to cope with the psycho-social problems and the frequent episodes of severe AIDS-related illnesses.

Recommendations made were directed at coordination of strategies to strengthen home-based care and support for the sick individuals and their families. Teamwork and participation of the various stakeholders were emphasised through construction of the model entitled "*AIDS-PETAL Home-Based Care Model*". The model highlights the specific role that each category should play. The joined tips of the petals symbolise the synergic effects of the combined efforts in home-based care.

## OPSOMMING

Hierdie ondersoek is as 'n deskriptiewe studie onderneem om insae te verkry in tuistesorg as 'n voortsetting van die voorsiening van gesondheidsorg, met spesifieke verwysing na mense met VIGS in die Umlazi Metropolitaanse Gebied van KwaZulu-Natal en sy informele nedersettings. 'n Kritiese ontleding van literatuur met perspektiewe oor HIV/VIGS en tuistesorg is onderneem ten einde begrip vir die fenomeen te bevorder.

Doelbewuste steekproewe is gekomplementeer met sneeubal-steekproewe om deelnemers te selekteer uit 'n populasie van mense wat aan VIGS ly, wat tuistesorg verskaf, sosiale werkers en tradisionele helers. Vraelyste met ope en geslote vrae is gebruik.

Die studie het aan die lig gebring dat 'n holistiese benadering tot sorg aan siek individue en familieledede verleen word deur middel van tuistesorg. Ten spyte van beperkte hulpbronne in die huisomgewing, het diegene wat tuis deur liefdevolle, toegewyde familieledede versorg word, met dankbaarheid daarvan getuig. Daar is gevind dat die Departement van Gesondheid en verskeie ander organisasies betrokke is by verskillende inisiatiewe in die stryd teen HIV/VIGS en dat hulle tuistesorg ondersteun, maar dat dit moeilik is om die psigo-sosiale probleme en die frekwente episodes van gevorderde VIGS-verwante siektes aan te spreek.

Aanbevelings is gemaak vir die koördinasie van strategieë ten opsigte van tuistesorg en vir die ondersteuning van die siek individue en hul families. Spanwerk en deelname deur die verskillende rolspelers is beklemtoon deur die daarstelling van 'n model, wat grafies deur 'n blom voorgestel word, met die titel "VIGS-PETAL Tuistesorg Model". Hierdie model belig die spesifieke rol van elke kategorie, terwyl die middelpunt wat gevorm word deur die samekoms van die afsonderlike kroonblare die sinergiese effek van die gekombineerde pogings simboliseer.

**TABLE OF CONTENTS**

<b>CONTENTS</b>	<b>PAGE</b>
DECLARATION .....	ii
DEDICATION .....	iii
ACKNOWLEDGEMENTS .....	iv
ABSTRACT .....	vi
OPSOMMING .....	vii

**CHAPTER 1: OUTLINE OF THE STUDY**

1.1	INTRODUCTION .....	1
1.2	BACKGROUND OF THE PROBLEM .....	1
1.3	STATEMENT OF THE PROBLEM .....	6
1.4	SIGNIFICANCE OF THE STUDY .....	7
1.5	MOTIVATION FOR THE STUDY .....	7
1.6	OBJECTIVES OF THE STUDY .....	8
1.7	ASSUMPTION .....	9
1.8	THEORETICAL FRAMEWORK OF THE STUDY .....	9
1.9	RESEARCH METHODS .....	10

CHAPTER 1 (continued)	PAGE
1.10 DEFINITION OF TERMS .....	10
1.11 ORGANIZING THE REPORT .....	16
1.12 CONCLUSION .....	17

**CHAPTER 2:**

<b>CONTENTS</b>	<b>PAGE</b>
2.1 INTRODUCTION .....	18
2.2 EXTENT OF HIV/AIDS INFECTION .....	18
2.3 CLASSIFICATION OF PEOPLE LIVING WITH AIDS .....	29
2.4 RIGHTS OF PEOPLE LIVING WITH AIDS .....	29
2.5 COMMON PROBLEMS ENCOUNTERED BY PEOPLE LIVING WITH AIDS .....	31
2.6 STAGES OF HIV/AIDS INFECTION AND THE LIFE-SPAN OF THE SICK INDIVIDUAL .....	33
2.7 FEATURES OF THE CHRONICITY OF AIDS .....	37
2.8 THE IMPACT OF AIDS .....	39
2.8.1 Impact on Government .....	41
2.8.2 Impact on households (families) .....	41
2.8.3 Impact on the community .....	42
2.8.4 Impact on hospitals .....	42
2.8.5 Individual-psycho-social impact .....	43
2.8.6 Impact on care-givers .....	43
2.8.7 Impact on Medical Aid Schemes .....	44
2.8.8 Impact on women .....	45

CHAPTER 2 (continued)	PAGE
2.8.9	<i>Economic impact of HIV/AIDS on the Public Health Sector</i> . . . . . 46
2.8.10	<i>Impact on the Private Sector</i> . . . . . 46
2.8.11	<i>Impact of HIV/AIDS on special organizations e.g. the AIDS Foundation</i> . . . . . 46
2.8.12	<i>Cost comparison between private and public sector</i> . . . . . 47
2.9	<b>THE NEED FOR A JOINT EFFORT BY ALL SECTORS AND SPECIFIC GROUPS TO OVERCOME THE SPREAD OF HIV-INFECTION</b> . . . . . 47
2.9.1	<i>The HIV/AIDS/STD Strategic Plan for South Africa 2000-2005</i> . . . . . 47
2.9.2	<i>Contributions of certain prominent individuals to better understanding of AIDS</i> . . . . . 51
2.9.3	<i>The Youth Friendly centre as means to curb the rapid spread of HIV/AIDS and sexually-transmitted diseases among the youth</i> . . . . . 52
2.10	<b>TREATMENT OF AIDS</b> . . . . . 54
2.10.1	<i>Use of Anti-Retroviral therapy</i> . . . . . 54
2.10.2	<i>Benefits of using an anti-retroviral therapy</i> . . . . . 54
2.10.3	<i>Promoting optimal health, wellbeing and safer sex practices</i> . . . . . 55
2.11	<b>POWER RESOURCES OF AN HIV/AIDS CLIENT ON IMMUNO-SUPPRESSIVE DRUGS AND COPING STRATEGIES OF A PERSON WITH AIDS AND ITS CHRONICITY</b> . . . . . 56

CHAPTER 2 (continued)

2.12	HOPE FOR AN AIDS VACCINE BY YEAR 2004 . . . . .	60
2.13	INDIGENOUS OR TRADITIONAL TREATMENT OF AIDS AND ASSUMPTIONS ABOUT CURATIVE EFFECTS . . . . .	60
2.14	CONCLUSION . . . . .	62

**CHAPTER 3: HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS**

<b>CONTENTS</b>	<b>PAGE</b>
3.1 INTRODUCTION .....	63
3.2 HISTORICAL BACKGROUND OF HOME-BASED CARE .....	63
3.3 NEED FOR HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS .....	64
3.4 ADVANTAGES OF HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS .....	65
3.5 PSYCHO-SOCIAL STRESSORS ASSOCIATED WITH HOME-BASED CARE .....	66
3.6 EXPLORING HOW CONTINUITY OF CARE FOR PEOPLE LIVING WITH AIDS IS MAINTAINED THROUGH HOME-BASED CARE .....	67
3.7 DIFFERENT AUTHORS' VIEWS ON THE PROVISION OF HOME-BASED CARE PROGRAMMES .....	68
3.8 THE UMLAZI HOME-BASED CARE PROGRAMMES .....	69
3.8.1 The Umlazi home-based care Pilot project from April 1998 to March 2000 .....	69
3.8.2 The Umlazi home-based care programme from July 2000 to date .....	73

CHAPTER 3 (continued)	PAGE
3.9 HOME-BASED CARE PROVISION IN ONE OF THE NEIGHBOURING LOCATIONS OF UMLAZI .....	74
3.10 HOME HEALTH CARE PROVIDED BY ONE OF THE PRIVATE TEAMS OF HEALTH CARE SERVICES IN THE DURBAN AREA .....	77
3.11 COPING STRATEGIES OF FAMILY MEMBERS AND OTHER CARE-GIVERS WHEN CARING FOR A SICK INDIVIDUAL, WITH PARTICULAR REFERENCE TO PEOPLE LIVING WITH AIDS .....	79
3.12 TRAINING OF FAMILY MEMBERS ON HOW TO TAKE CARE OF A SICK INDIVIDUAL WITH HIV/AIDS .....	81
3.13 ASSESSING THE NEEDS OF THE SICK INDIVIDUAL NURSED AT HOME USING THE FUNCTIONAL, INSTRUMENTAL AND 'PULSES' PROFILE ASSESSMENT TOOLS .....	82
3.13.1 Functional assessment .....	82
3.13.2 Instrumental assessment .....	83
3.14 PAIN ASSESSMENT AT HOME FOR PEOPLE LIVING WITH AIDS USING THE PAIN ASSESSMENT RULES .....	84

CHAPTER 3 (continued)	PAGE
3.15 HOME-BASED CARE MODEL ACCORDING TO THE WORLD HEALTH ORGANIZATION (WHO) . . . . .	85
3.16 QUALITIES OF FAMILY OR NON-FAMILY CARE-GIVER OF PEOPLE LIVING WITH AIDS . . . . .	86
3.17 HOPE AS THE MOTIVATING FORCE FOR SURVIVAL OF PEOPLE LIVING WITH AIDS . . . . .	88
3.18 DESPERATION OF AIDS ORPHANS AND THE IMPACT ON FAMILIES AND SPECIFIC ORGANIZATIONS . . . . .	90
3.19 CARE OF AIDS ORPHANS IN CHILDREN'S HOME 'X' OF DURBAN . . . . .	96
3.20 HOSPICE CARE FOR THE TERMINALLY ILL AIDS PATIENTS . . . . .	97
3.20.1 Home care services . . . . .	98
3.20.2 Available services to sick individuals . . . . .	98
3.20.3 Extended hospice facilities . . . . .	99
3.21 DISCLOSURES AND NARRATIVES OF PEOPLE LIVING WITH AIDS . . . . .	100
3.22 CONCLUSION . . . . .	101

**CHAPTER 4: THEORETICAL FRAMEWORK**

<b>CONTENTS</b>	<b>PAGE</b>
4.1 INTRODUCTION .....	102
4.2 THE OVERVIEW OF ALBRECHT'S NURSING MODEL FOR HOME HEALTH CARE .....	102
4.2.1 The structural elements .....	104
4.2.2 The process elements .....	104
4.2.3 Outcome elements .....	105
4.3 OREM'S GENERAL THEORY OF NURSING .....	106
4.3.1 The Theory of Self-care .....	107
4.3.2 The Theory of Self-care deficit .....	108
4.3.3 The Theory of Nursing Systems .....	110
4.4 ADAM'S CONCEPTUAL MODEL FOR NURSING .....	112
4.5 APPLICATION OF THE ALBRECHT NURSING MODEL FOR HOME HEALTH CARE, OREM'S GENERAL THEORY OF NURSING AND ADAM'S CONCEPTUAL MODEL FOR NURSING IN HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS .....	115
5 CONCLUSION .....	117

**CHAPTER 5: RESEARCH METHODS**

<b>CONTENTS</b>	<b>PAGE</b>
5.1 INTRODUCTION . . . . .	119
5.2 RESEARCH DESIGN . . . . .	119
5.3 AREA OF STUDY . . . . .	119
5.3.1 Size and population of Umlazi . . . . .	120
5.3.2 The informal settlements . . . . .	120
5.3.3 Type of formal housing . . . . .	121
5.3.4 Infrastructure . . . . .	121
5.3.5 Health services . . . . .	123
5.3.6 The AIDS clinic . . . . .	124
5.3.7 Staffing of the AIDS clinic . . . . .	125
5.4 ETHICAL CONSIDERATIONS . . . . .	126
5.4.1 Permission to conduct the study . . . . .	126
5.4.2 Anonymity and confidentiality . . . . .	126
5.4.3 Informed consent . . . . .	126
5.5 POPULATION . . . . .	127
5.6 SAMPLE AND SAMPLING METHOD . . . . .	127
5.6.1 Sample of people living with AIDS . . . . .	127
5.6.2 Sample of care-givers . . . . .	128
5.6.3 Sample of social workers . . . . .	128
5.6.4 Sample of traditional healers . . . . .	128
5.7 THE RESEARCH INSTRUMENT . . . . .	129
5.7.1 Designing the instrument . . . . .	129

CHAPTER 5 (continued)	PAGE
5.8        VALIDITY OF THE INSTRUMENT . . . . .	135
5.9        PRE-TESTING THE INSTRUMENTS . . . . .	135
5.10       DISTRIBUTION OF THE QUESTIONNAIRES . . . . .	136
5.11       CONCLUSION . . . . .	136

**CHAPTER 6: DATA ANALYSIS, PRESENTATION, INTERPRETATION  
AND DISCUSSION OF FINDINGS**

<b>CONTENTS</b>	<b>PAGE</b>
6.1 INTRODUCTION .....	137
6.2 SECTION 1: PERSONAL PARTICULARS .....	137
Item 1 Gender .....	137
Item 2 Age of participants in years .....	138
Item 3 Marital status .....	139
Item 4 Number of children .....	140
Item 5 Age range of children .....	141
Item 6 parents with sick children due to AIDS-related illnesses .....	142
Item 7 Educational level .....	143
Item 8 Post Standard 10 certificate/diploma or degree .....	144
6.3 SECTION 2: PARTICIPANTS' KNOWLEDGE ON HIV/AIDS .....	144
Item 9 Reaction to HIV/AIDS diagnosis .....	144
Item 10 Family's knowledge on individual's HIV-positive status .....	146
Item 11 Informing children of the HIV-positive status of their parents .....	148
Item 12 participants' employment status .....	149
Item 13 transmission of HIV/AIDS infection to others .....	151
Item 14 Methods of preventing HIV/AIDS infection .....	152
Item 15 AIDS-related illness that may affect individuals .....	153
Item 16 Occurrence of illness in regard to time and space .....	154

CHAPTER 6 (continued)	PAGE
6.4	SECTION 3: PAIN, type of pain and pain control . . . . . 155
Item 17	Assessing presence of pain experienced by individuals . . . . . 155
Item 18	Description of pain with regard to part of the body affected . . . . . 156
Item 19	Assessment of severity of pain using the pain assessment ruler . . . . . 157
Item 20	Pain control in the home environment . . . . . 158
Item 21	Effects of pain on people living with AIDS who are employees . . . . . 160
6.5	SECTION 4: MEDICATION AND OTHER TREATMENT . . . . . 161
Item 22	Establishing if participants were on long-term medication . . . . . 161
Item 23	Types of medication currently taken by participants . . . . . 162
Item 24	Source of medication . . . . . 163
Item 25	Use of other forms of healing . . . . . 164
6.6	SECTION 5: CARE AND SUPPORT SYSTEM . . . . . 165
Item 26	Perceptions on how the participants were cared for at home . . . . . 166
Item 27	Rating of care received at home . . . . . 166
Item 28	Ways of improving home-based care . . . . . 167
Item 29	Availability of pension or disability grant for people living with AIDS . . . . . 169
Item 30	Providers of support to clients . . . . . 170

CHAPTER 6 (continued)	PAGE
6.7 SECTION 6: COUNSELLING SERVICES . . . . .	171
Item 31 Counselling sessions . . . . .	171
Item 32 Availability of AIDS counsellors . . . . .	172
Item 33 HIV/AIDS counselling helped individuals with HIV/AIDS-infection . . . . .	173
Item 34 Counselling officers/members . . . . .	174
Item 35 Place for conducting counselling sessions . . . . .	175
6.8 CONCLUSION . . . . .	176

**CHAPTER 7: DATA ANALYSIS AND INTERPRETATION OF FINDINGS  
FOR CARE-GIVERS, SOCIAL WORKERS AND  
TRADITIONAL HEALERS**

7.1	INTRODUCTION .....	177
7.2	HOME CARE-GIVERS .....	177
SECTION 1	PERSONAL PARTICULARS .....	177
Item 1	Gender of participants .....	177
Item 2	Age group in years .....	178
Item 3	Relationship with client/s .....	179
Item 4	Educational level .....	181
Item 5	Post standard 10 certificate, Diploma or degree .....	182
SECTION 2:	BASIC NURSING PREPARATION FOR HOME- BASED CARE .....	182
Item 6	Basic nursing preparation of participants .....	182
Item 7	Other qualifications / certificates relevant to nursing .....	183
Item 8	Counselling skills .....	184
Item 9	Place where counselling courses were obtained by care-givers .....	185
SECTION 3:	EXPERIENCE IN THE CARE OF PEOPLE LIVING WITH HIV/AIDS INFECTION .....	186
Item 10	Previous experience in care of AIDS clients .....	186
Item 11	Participants' opinion of their clients' rating of home- based care .....	187



CHAPTER 7 (continued)	PAGE
Item 21      Period of hours with regard to availability of local community health services and referral system between hospital and hospice care . . . . .	198
SECTION 9: COPING WITH STRESS . . . . .	200
Item 22      Experience of stressful situations . . . . .	200
SECTION 10: BENEFITS OF HOME BASED CARE FOR THE HIV/AIDS INDIVIDUAL . . . . .	201
Item 23      Participants' perceptions on the benefits of home- based care . . . . .	202
SECTION 11: PROBLEMS EXPERIENCED BY CARE- GIVERS IN HOME-BASED CARE . . . . .	204
Item 24      Problems experienced by care-givers in home-based care . . . . .	204
7.3            DATA ANALYSIS FROM SOCIAL WORKERS . . . . .	205
SECTION 1: DEALING WITH CLIENTS WITH AIDS- RELATED PROBLEMS . . . . .	206
Item 1      Attending to clients with AIDS-related problems . . . . .	206
Item 2      The Psycho-social problems dealt with by the social workers . . . . .	206
Item 3      Intervention strategies applied to people living with AIDS by the social workers . . . . .	208

CHAPTER 7 (continued)		PAGE
Item 4	Clients' compliance with advice given by the social workers .....	208
SECTION 2: PROBLEMS RELATED TO RELATIVES OF SICK INDIVIDUALS .....		209
Item 5	Problems experienced by the social workers in relation to relatives of their clients .....	209
SECTION 3: REFERRAL SYSTEM FOR PEOPLE LIVING WITH AIDS .....		211
Item 6	Assessing the perceptions of participants on the referral system .....	211
Item 7	Type of clients referred to other professionals for further management .....	211
Item 8	perceptions of Social Workers on the possible ill-effects on non-referred clients to them .....	213
SECTION 4: THE INTERVENTION IN REGARD TO AIDS ORPHANS .....		214
Item 9	Participants' perceptions of the intervention in regard to the AIDS orphans .....	214
Item 10	Common problems experienced by AIDS orphans .....	215
7.4	ANALYSIS OF DATA FROM TRADITIONAL HEALERS .....	216

CHAPTER 7 (continued)

SECTION 1:

7.4.1	Personal particulars . . . . .	216
Item 1	Gender of participants . . . . .	217
Item 2	Age group in years . . . . .	217
7.4.2	Educational level and registration as traditional healers . . . . .	218
Item 3	Educational level of participants . . . . .	218
Item 4	Registration with <i>Inyanga</i> or Traditional Healers Association . . . . .	219

SECTION 2:

7.4.3	Experience in traditional healing practice . . . . .	220
Item 5	Length of period in traditional healing practice . . . . .	220
Item 6	Signs and symptoms that clients treated by traditional healers presented with . . . . .	221
Item 7	How participants made the diagnosis of HIV/AIDS . . . . .	221
Item 8	Participants' perceptions on the success of their treatment . . . . .	222
Item 9	Beliefs of participants in combining Western medicine with traditional medicine . . . . .	222
Item 10	Action on non-response to treatment . . . . .	222

SECTION 3:

7.4.4	Knowledge on HIV/AIDS-infection . . . . .	223
Item 11	Knowledge on AIDS as a curable disease or not . . . . .	223
Item 12	Transmission of infection from one person to another . . . . .	223
Item 13	Methods used in treating clients with AIDS . . . . .	224
7.5	CONCLUSION . . . . .	225

**CHAPTER 8: SUMMARY, LIMITATIONS, DISCUSSIONS OF FINDINGS,  
CONCLUSIONS AND RECOMMENDATIONS**

<b>CONTENTS</b>	<b>PAGE</b>
8.1 INTRODUCTION .....	226
8.2 SUMMARY .....	226
8.3 LIMITATION OF THE STUDY .....	228
8.4 DISCUSSION OF FINDINGS AND CONCLUSIONS .....	230
8.4.1 Objective One: To determine the type of nursing care provided for people living with AIDS at home .....	230
8.4.1.1 Reaction to HIV/AIDS diagnosis and its impact on care of the sick individual .....	231
8.4.1.2 AIDS-related illnesses that oaffected individual's management of the disease .....	231
8.4.1.3 perceptions on type of pain and pain controlling measures .....	232
8.4.1.4 Type of medication used by people living with AIDS .....	232
8.4.1.5 Use of other forms of healing .....	233
8.4.2 Objective Two: To elicit participants' views on the quality of care provided .....	233
8.4.3 Objective Three: To determine the type of support given to people living with AIDS, their families and non-family care-givers .....	234
8.4.4 Objective Four: To determine strategies implemented to prevent the spread of HIV/AIDS- infection .....	234

CHAPTER 8 (continued)	PAGE
8.4.5 objective Five: To develop a model that can be adopted in providing high quality care to people living with AIDS in a home setting . . . . .	237
8.5 RECOMMENDATIONS . . . . .	237
8.6 PRESENTATION OF THE PROPOSED MODEL . . . . .	240
8.6.1 The client . . . . .	242
8.6.2 The family . . . . .	242
8.6.3 Other members of the multidisciplinary team e.g. Independent Practitioners, The Dependent Practitioners and Support Staff . . . . .	243
8.7 CONCLUSION . . . . .	245
BIBLIOGRAPHY . . . . .	246

**ANNEXURES**

1.	QUESTIONNAIRES FOR PEOPLE WITH AIDS, CARE-GIVERS, SOCIAL WORKERS .....	254
2.	QUESTIONNAIRES FOR HOME CARE-GIVERS .....	265
3.	QUESTIONNAIRES FOR SOCIAL WORKERS .....	277
4.	QUESTIONNAIRES FOR TRADITIONAL HEALERS .....	282
5.	MAP OF KWAZULU-NATAL HEALTH REGIONS AND DISTRICTS .....	288
6.	MAP OF UMLAZI .....	289
7.	MAP OF INFORMAL SETTLEMENTS OF UMLAZI .....	290
8.	MAP OF DURBAN METRO AREA .....	291
9.	APPLICATION LETTERS FOR THE STUDY .....	292
10.	LETTER FROM MAYOR OF UMLAZI .....	295
11.	LETTER FROM MEDICAL SUPERINTENDENT AND DEPUTY DIRECTOR OF NURSING SERVICES .....	296
12.	ZULU VERSION OF QUESTIONNAIRE FOR TRADITIONAL HEALERS .....	297

**LIST OF TABLES**

	PAGE
Table 2.1    Global estimates of HIV/AIDS epidemic as at end of 1999 . . . . .	19
Table 2.2    People living with AIDS, AIDS orphans and AIDS deaths in South Africa as compared with other Sub- Saharan countries as at the end of 1999 . . . . .	21
Table 2.3    Further projections of the National Department of Health on the increase of HIV/AIDS is in South Africa . . . . .	22
Table 2.4    HIV/AIDS in South Africa compared with the rest of the Sub-Saharan Africa and the World . . . . .	23
Table 2.5    Average cost of care per infected person per year by stage and sector . . . . .	47
Table 3.1    Age group distribution of HIV/AIDS clients in Umlazi as from April 1998 to March 1999 . . . . .	71
Table 3.2    Number of people who had HIV-positive results . . . . .	76
Table 3.3    AIDS orphans in Sub-Saharan countries as at the end of 1999 . . . . .	89
Table 3.4    The number of AIDS orphans as at the end of 1999 worldwide . . . . .	90

Table 3.5	The continuum of community care for orphaned children in South Africa . . . . .	92
Table 6.1	Gender of people living with AIDS . . . . .	138
Table 6.2	Age distribution . . . . .	138
Table 6.3	Marital status of participants . . . . .	139
Table 6.4	participants with children . . . . .	140
Table 6.5	Number of children per participant with children . . . . .	141
Table 6.6	Age range of children in years . . . . .	142
Table 6.7	Educational level of participants . . . . .	143
Table 6.8	Participants with post-standard 10 certificate / Diploma / Degree . . . . .	144
Table 6.9	Reactions to HIV-positive status . . . . .	145
Table 6.10	Family's reaction to Individual's HIV-positive status . . . . .	147
Table 6.11	Transmission of infection . . . . .	151
Table 6.12	Methods of preventing HIV/AIDS infection as indicated by participants . . . . .	152

Table 6.13	Illnesses that affect individuals . . . . .	153
Table 6.14	Frequency of occurrence of illness in individuals . . . . .	155
Table 6.15	Individual's part of the body affected by pain . . . . .	157
Table 6.16	Pain assessment according to colour-coded ruler . . . . .	158
Table 6.17	Participants on long-term medication . . . . .	161
Table 6.18	Type of medication used by participants . . . . .	162
Table 6.19	Sources of medication for participants . . . . .	163
Table 6.20	Use of other forms of healing . . . . .	165
Table 6.21	Perceptions on how the participants were cared for at home . . . . .	166
Table 6.22	Rating of care received at home . . . . .	167
Table 6.23	Providers of support to clients . . . . .	170
Table 6.24	Counselling officers /members . . . . .	174
Table 7.1	Gender of participants . . . . .	178
Table 7.2	Age distribution of care-givers . . . . .	179
Table 7.3	Educational level of participants . . . . .	181

Table 7.4	Participants with post-standard 10 certificate / diploma or degree . . . . .	182
Table 7.5	Qualifications certificates relevant to nursing . . . . .	183
Table 7.6	Place where counselling courses were attended . . . . .	185
Table 7.7	Participants' opinions of their clients' rating of home-based care . . . . .	187
Table 7.8	Participants' likelihood of being infected with HIV-infection drug caring roles . . . . .	188
Table 7.9	Preference on working alone or with others . . . . .	189
Table 7.10	Groups that provide support to care-givers . . . . .	190
Table 7.11	Transmission of HIV-infection from one person to another . . . . .	191
Table 7.12	practices for preventing transmission of HIV-infection . . . . .	192
Table 7.13	Extent to which the following factors negatively influence provision of care . . . . .	194
Table 7.14	Frequency in assessing clients' needs . . . . .	196
Table 7.15	People who assess clients regularly . . . . .	197

Table 7.16	Period of hours with regard to availability of local community health services . . . . .	198
Table 7.17	Referral system between home, hospital and hospice care . . . . .	199
Table 7.18	Participants perceptions on benefits of home-based care . . . . .	202
Table 7.19	Problems experienced by care-givers in home-based care . . . . .	204
Table 7.20	The psycho-social problems of people living with AIDS that the social workers dealt with . . . . .	207
Table 7.21	Participants' perceptions of the intervention in regard to AIDS orphans . . . . .	214
Table 7.22	Participants age group in years . . . . .	218
Table 7.23	Educational level of participants . . . . .	219
Table 7.24	Length of period in traditional healing practice . . . . .	220
Table 7.25	Methods used in healing clients with AIDS . . . . .	224

**LIST OF FIGURES**

	PAGE
Figure 2.1	Extent of Global HIV/AIDS epidemic . . . . . 20
Figure 2.2	National HIV survey of women attending ante-natal clinics of Public Health Services in South Africa . . . . . 24
Figure 2.3	HIV prevalence amongst pregnant women attending ante-natal clinics by Province in South Africa (1998) . . . . . 25
Figure 2.4	HIV prevalence in Umlazi / KwaDabeka / KwaMashu Locations . . . . . 27
Figure 2.5	HIV prevalence reported at King Edward VIII Hospital antenatal clinic (KaZulu-Natal) as from 1992-1999 . . . . . 28
Figure 2.6	The diagnostic representation of the lifespan of an HIV/AIDS person . . . . . 36
Figure 2.7	Coping strategies of a person living with AIDS and its chronicity . . . . . 57
Figure 3.1	The Pain Assessment Ruler by Roxane Laboratories, Inc. for Palliative Care and Cancer pain . . . . . 84
Figure 3.2	WHO's Home-Based Care Holistic Assessment and Care plan model . . . . . 85

Figure 4.1	Diagrammatic representation of Albrecht's Nursing Model for Home Health Care . . . . .	103
Figure 4.2	Diagrammatic representation of Orem's Theory of Nursing Systems . . . . .	111
Figure 6.1	Family's knowledge of individual's HIV-positive status . . . . .	146
Figure 6.2	Informing children of parents' HIV-positive status . . . . .	148
Figure 6.3	Employment Status of Participants . . . . .	149
Figure 6.4	Informing Employer and Colleagues on HIV-positive status of the individual . . . . .	150
Figure 6.5	Pain experienced with illness . . . . .	156
Figure 6.6	Effectiveness of pain control at home . . . . .	159
Figure 6.7	Effect of pain on affected individuals . . . . .	160
Figure 6.8	Availability of pension or disability grant . . . . .	169
Figure 6.9	Pre- and post-HIV-test counselling . . . . .	171
Figure 6.10	Availability of AIDS counsellors . . . . .	172
Figure 6.11	Place for counselling sessions . . . . .	175

Figure 7.1	Participants' relationship with clients . . . . .	180
Figure 7.2	Basic nursing preparation of participants . . . . .	183
Figure 7.3	Participants' attendance to a counselling course . . . . .	184
Figure 7.4	Participants' experiences according to number of clients nursed . . . . .	186
Figure 7.5	Participants' experience of stressful situations . . . . .	200
Figure 7.6	Problems experienced by social workers in respect of relatives of their clients . . . . .	210
Figure 7.7	Perceptions of social workers on possible ill-effects of failure to refer clients to them . . . . .	213
Figure 8.1	The AIDS Petal Home-Based Care Model . . . . .	241

## **CHAPTER 1**

### **OUTLINE OF THE STUDY**

#### **1.1 INTRODUCTION**

The subject of this study is Home-Based Care as a continuum of the comprehensive health care provision for People Living with AIDS, in Health Region "F" or Ilembe Region of KwaZulu-Natal Province. Home-based care is the component of community-based care which includes community participation in decisions about health services. The focus is on health promotion and prevention of spread of the disease. It is based on the understanding that the hospital is no longer the exclusive provider of care to the community. The impact of AIDS on individuals, families, communities and health care services has changed the modalities in the health care provision.

#### **1.2 BACKGROUND TO THE PROBLEM**

The HIV/AIDS prevalence in South Africa was 4 200 000 out of a population of 39 796 000 as at the end of year 1999, that is 11%. There is an estimated increase of 1 600 new HIV-infections occurring in each day. This epidemic has become a worldwide pandemic, with Sub-Saharan Africa having the highest incidence of 24,5 million people with HIV/AIDS infection as compared to Australia and New Zealand with the lowest incidence of 15 000 HIV-infections as at the end of year 1999 (UNAIDS Report on Global HIV/AIDS Epidemic, June 2000). Bed occupancy in hospitals has increased by 50% due to acute illnesses that are associated with HIV-related opportunistic diseases (Kunene, 2000:9).

In many developing countries, 60-70% of hospital beds are occupied by people with AIDS. As the pandemic grows, Home-Based Care of People living with

AIDS has been found to be better than long-term hospitalization. Clients feel loved and secure in familiar surroundings with objects of value to them (Pritchard & Collard, 1990:46). Family members as care-givers experience many problems, including psychological, physical, social, economic and spiritual stresses. They are mainly stressed about the precautionary measures to take in regard to the disease with limited or scarce resources.

The cost containment issues have limited the hospitalization time, where the individual is admitted for acute intervention only such as assistance with ventilation in cases of acute respiratory distress and then discharged earlier than expected. This has made it essential that home-care assumes a great role in the nursing care of the recuperating individuals at home.

The continuum of care includes care between hospital and home during the course of the illness. Care provided should incorporate clinical management, direct patient care, education, prevention of infection, ongoing counselling, palliative care and social support. Home-based care is a client and family centred approach. Clients with the help of their family members decide on clinical management of symptoms of the disease with regard to how they want to be nursed, by whom and where. They also decide on the type of medication they want e.g. Western or Traditional medicine or a combination of these two types when opportunistic infections and other conditions occur. Ongoing education of the sick individuals, their families, volunteering care-givers and others is important to equip them with basic nursing skills and ways of preventing spread of infection or auto-infection.

The majority of clients prefer to be nursed at home where they feel comforted and secured with familiar people and their valuable assets around them. This is in line with South Africa's Primary Health Care Approach to the provision of care, which emphasises self-help and empowerment of people, to regain control over their own lives, make genuine choices and effectively utilize the available resources in their communities.

The continuum of care needs adequate resources in order to be effective. These include the following:

- ▶ Community services like clinics to be available and accessible for 24 hours.
- ▶ Good transport facilities with reasonable transport fees.
- ▶ Enough funds for purchasing equipment and supplies as well as medications, food, and shelter where necessary.

Good clinical management of acute, infections and minor ailments, and direct physical care on those who are confined to bed, helpless and dependent on others for assistance with Activities of Daily Living.

- ▶ Ongoing counselling to provide social, spiritual and emotional support to the sick individuals and their families or other care-givers.
- ▶ Implementation of approved strategies that promote acceptance of People Living with AIDS, and reduce the stigma and isolation at home.
- ▶ Observing that the rights of People Living with AIDS are known and respected always.

The good coordination of home-based care, hospital outpatient care, in-patient hospital care and Hospice care reduce recurrence of opportunistic infections and re-hospitalization of clients with AIDS (UNAIDS Fact Sheet, 2000:3-1, 3-8).

The Department of Health's response to HIV/AIDS pandemic according to Department of Health (June, 2000:15) is as follows:

- ▶ The Department of Health has formulated strategies to fight HIV/AIDS, encompassing all sectors of the South African nation.
  
- ▶ The HIV/AIDS/STD Strategic Plan for South Africa 2000-2005 was drawn up by representatives from all sectors of society. The plan focuses on four main priority areas namely:
  - Prevention of spread of the disease.
  
  - Treatment, care and support of infected individuals.
  
  - Ongoing research on the curative treatment and vaccine for HIV/AIDS.
  
  - Human and legal rights surveillance at all times.

Some strategies implemented include improvement, management and control of sexually-transmitted diseases, reduction of mother-to-child transmission, improvement of access to voluntary HIV counselling and testing and improvement of care and treatment of HIV-positive persons and people living with AIDS. These strategies are underpinned by the principle of ongoing research monitoring and evaluation.

Some highlights of achievements of the National AIDS Programme formulated in 1999 include the following:

- ▶ The primary-school life-skills and HIV/AIDS education programme was developed and is currently being expanded for implementation throughout the country.

- ▶ The nationwide implementation of a life-skills and HIV/AIDS education programme is being expanded at secondary schools.
- ▶ The National Department of Health continues to support provinces by providing barrier methods of contraception - mainly male condoms, freely in health facilities, and use of non-traditional outlets like truck-stops, shebeens and local shops.
- ▶ Provision of an Essential Drug List which has guidelines on management of opportunistic infections like tuberculosis which is the most common opportunistic infection that kills many people living with AIDS. About 40-50 percent of people living with AIDS have tuberculosis (Department of Health, 2000:15).

The HIV/AIDS/STD Strategic plan also caters for the provision of home-based care services, training workshops with traditional healers and training of lay counsellors - especially in counselling children, as well as integrated strategies for children with AIDS or AIDS orphans. The skills development projects are part of home-based care aimed at preventing boredom and providing some sources of income to many unemployed people living with AIDS. A network of relationships is developed and it includes a teaching function as people living with AIDS are taught sewing, cooking, literacy classes and handicrafts like bead-work.

The available support system, palliative care throughout the stages of illness, ongoing counselling sessions of clients and their families facilitate acceptance of the disease, issues of disclosure of the diagnosis to others and coping with impending death (Sims & Moss, 1991:31-36).

### 1.3 STATEMENT OF THE PROBLEM

KwaZulu-Natal is reported to have the highest numbers of HIV/AIDS infected people. According to statistics, in 1995, 43 508 people were HIV-positive, of which 32 614 were people of 16 years to 40 years. These numbers are increasing yearly. In 1996 it is reported that approximately 729 069 people were diagnosed HIV-positive (AIDS Analysis, South Africa Edition 8 (1) June/July, 1992:12). In South Africa approximately 3-million people are living with AIDS, with 1 600 infected each day. It is estimated that by year 2005 about 6-million South Africans will be infected with HIV (HIV/AIDS/STD Strategic plan for South Africa 2000-2005:9).

Health care for HIV/AIDS people is on top of the agenda for policy-makers, a major concern for health care professionals, clients, affected families and the community at large. Very little is known of the type and mode of delivery of health care in the households, and the coping abilities of affected families to match the increasing levels of responsibilities when severe physical and neurological complications of the disease occur (Sims & Moss, 1991:33). The Department of Health has drawn a programme which is being implemented on the training of home-based care-givers. The Non-Governmental Organizations like the AIDS Foundation, facilitate with funding of most projects related to home-based care. According to Nzimakwe (1997), home-based care restores the essence of nursing which seems to have been lost. This is evidence of the Government's and the Non-Governmental Organizations' commitment to deal with the effects of the disease and facilitate community involvement in health-related matters regarding HIV/AIDS.

Home-based care is not a new concept. It is a traditional way of caring for the chronic sick individuals dating back to the primitive times as outlined by Dolan, Fitzpatrick and Hermann (1983:1) in discussion of the genesis of nursing. Family members and non-family care-givers in most cases need empowerment on home-

based care skills, hence they are presently trained on home-based care nursing programmes in various training centres. Since there is no cure for AIDS, health education is the most important method used to educate people on the precautionary measures against prevention of spread of the infection to others.

The changing demographic patterns which have resulted in an expanding young population of between the ages of 15-39 years with HIV/AIDS infection, and other age groups like the elderly with chronic illness, have increased the demand for home-based care.

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

The study is significant in that it creates an awareness to all health-care providers, community members and different sectors of the need of joining hands in supporting home-based care projects, to meet the demands of increasing numbers of clients with AIDS who are discharged early from hospital to recover at home. This study contributes to the identification of coping strategies of clients with stressful situations as the disease progresses, as well as assessment tools for care-givers to use as they assess their clients' needs and problems at regular intervals. A pain assessment ruler has been provided which facilitates pain assessment by care-givers when attending to their clients. This is to ensure a better understanding of the severity of pain experienced by people living with AIDS and referral of those with severe pain that cannot be managed at home.

The narrative stories included in chapter two of this report, written by some people living with AIDS, highlight how the support by friends and the family members, employers and co-workers as well as love, and acceptance by others improves one's self-esteem and changes the state of helplessness to that of hope for delayed onset of opportunistic infections, and staying alive longer for at least five to ten years.

## **1.5 MOTIVATION FOR THE STUDY**

The researcher, being a nurse in the district hospital that serves the community of the study area, and a resident of the Umlazi District, has observed problems encountered in families of HIV/AIDS clients being discharged early from hospital as a result of the great demand for hospital bed occupancy for acute illnesses. The researcher gets involved in the provision of home-based nursing care to some of the people living with AIDS after working hours. This is done voluntarily, and as requested by family members when clients have problems with feeding, severe oral thrush and generalised body pains.

Studies on home-based care of HIV/AIDS clients have not been documented yet in the Durban Functional Region "F" or Ilembe Region with its informal settlements. The prevalence of HIV-infection in Umlazi is high. It has increased from 22% in 1996 to 36% in 1999 (Report - University of Natal - Durban Medical School: Department of Virology, 1999).

## **1.6 OBJECTIVES OF THE STUDY**

The study aimed at achieving the following objectives:

- ▶ To determine the type and appropriateness of nursing care provided for people living with AIDS at home.
- ▶ To detect the views of people living with AIDS and care-givers on the quality of care provided at home.
- ▶ To determine the type and extent of the support given to people living with AIDS, their families and the non-family care-givers.

- ▶ To determine the strategies implemented to prevent the spread of HIV/AIDS infections.
- ▶ To develop a model that can be adopted to ensure co-ordinated effort in providing high quality care to people living with AIDS in a home setting.

### **1.7 ASSUMPTION**

This study is based on the assumption that HIV/AIDS infection is a chronic disease affecting all body systems. Early discharge from hospital has increased the demand for home-based care to help the sick individuals with the Activities of Daily Living, through basic nursing care, administration of medication and prevention of complications.

### **1.8 THEORETICAL FRAMEWORK OF THE STUDY**

The theoretical framework on which the study is based is the modified Albrecht's Nursing Model for Home Health care. This model reflects the interaction between nurses, clients, and their families. The three major elements are used to measure the quality of home health care client outcomes namely, the structural elements, the process elements and the outcome elements.

This model links well with Dorothea Orem's General Theory of Nursing, with its three interrelated components namely, The Theory of Self-Care, The Theory of Self-Care Deficits and the Theory of Nursing Systems. In the context of this study Orem's Theory of Nursing Systems which includes wholly Compensatory System, partly Compensatory System and the Supportive-Educative System, link well with home-based care for HIV/AIDS clients.

Adams' Conceptual Model for Nursing is also used in this study and complements well the other two theorists' models. This model emphasises the provision of a

helping relationship between clients and care-givers in a home environment that provides warmth, mutual respect, empathy and acceptance without discrimination. This theory stresses the importance of a coordinated effort with clients and their families with multidisciplinary team to cope with psycho-social, physical, economic and spiritual needs and problems.

The application of these three models, shows the effectiveness of the coordinated effort of the multidisciplinary team, clients, and their families in the provision of comprehensive health care to people living with AIDS in a home setting. Detailed descriptions and application of the theories are dealt with in chapter four of this report.

## **1.9 RESEARCH METHODS**

A descriptive survey was selected for this study. An in-depth study on people living with AIDS, their families or care-givers, social workers and traditional healers was done. Questionnaires were used to collect data from the aforementioned categories with regard to provision of home-based care.

The purposive sampling complimented with snowball sampling method was used since it was not easy to identify all individuals with AIDS and their families. A Pilot Study was done to test the validity of the research tool before the major study. Permission to conduct the study was obtained from key figures or counsellors of the areas to be covered, and the health care institutions. Informed consent was obtained from people living with AIDS, their families and other care-givers. Quantitative data analysis was done followed by interpretation of findings based on the responses to the open-ended questions which were summarised. Conclusions and recommendations are dealt with in chapter eight of this report.

## **1.10 DEFINITION OF TERMS**

Conceptual and operational definitions are given in this section. They include the concepts family, home-based care, AIDS, support system, social support, stress, coping, network support, counselling, palliative care, comprehensive care, continuity of care, epidemic, pandemic, and communicable disease. Operational definitions are used to define the terms as they are used in the study.

### **1.10.1 Family**

Family refers to a primary group of people living in a household, in consistent proximity and intimate relationships (Swanson & Nies, 1997:301). In the context of this study it is restricted to those family members who share the same household with people living with AIDS.

### **1.10.2 Home-Based Care**

It is that component of the continuum of the comprehensive health care, whereby health services are provided to individuals and their families in their places of residence, for the purpose of promoting, maintaining or restoring health and maximising their level of independence while minimising illness (Stanhope & Lancaster, 1992:748). In this study it refers to care provided for AIDS clients in their homes at Umlazi and its informal settlements.

### **1.10.3 AIDS**

AIDS refers to Acquired Immuno-deficiency Syndrome, which is a deadly viral disease, occurring in human beings as a result of HIV infection. The severely compromised immune status of those infected characteristically leads to unusual opportunistic infections, indignancies, neurological disorders, wasting syndrome and other conditions (Green, 1996:80).

#### 1.10.4 Support System

The concept refers to a resource pool, comprising of members of a reliable caring work, family or social group such as church members. A common bond holds together members with a specific goal to support and encourage affected people to talk about stress-producing situations without fear of rejection or retaliation (Stanhope & Lancaster, 1992:617). In the context of this study the support system refers to family members, voluntary care-givers, social and health care representatives. People living with AIDS are guided and assisted in coping with stressful situations, learning and practising new responses to overcome the challenges of the disease. Sarafino (1994:102-103) differentiate between the two types of support namely:

##### 1.10.4.1 Social support

The concept refers to perceived comfort, caring, esteem or help a person receives from other people or groups e.g. spouse, family or lover (Sarafino, 1994:102).

##### 1.10.4.2 Network Support

It is the support that provides a feeling of membership in a group of people who share some interests and social activities (Sarafino, 1994:103).

#### 1.10.5 Counselling

This concept refers to the mechanism for providing psycho-social support which includes provision of information, support for identifying and resolving issues of integration, care and social needs (UNAIDS Fact Sheet, 2000:7,1-7,5). In the context of this study, counselling refers to ongoing support given to people living with AIDS throughout the course of the disease to help them cope with psycho-

social, physical, economic and spiritual problems, as well as pre- and post-test counselling of individuals.

#### 1.10.6 Vaccine

This concept refers to a preparation made either from dead, living attenuated, or living fully virulent organisms which is introduced into the body to produce or artificially increase immunity to a specific disease by causing the formation of antibodies (Spradley & Allender, 1996:670). In the context of this study, the vaccine referred to is the HIV/AIDS vaccine that is still being developed by scientists for vaccination of the non-infected members of the community.

#### 1.10.7 Palliative Care

The term "palliative care" refers to the active comprehensive care, providing for physical, spiritual, psycho-social and emotional needs of the patient and the family. It starts at the moment of the diagnosis of any illness, continues throughout the life-threatening illness and bereavement. It is the type of care that remains sensitive to the personal, cultural and religious values, beliefs and practices of clients and their families. It is a very important intervention at the terminal stages of illness in AIDS clients (Fröhlich, 1997:17).

#### 1.10.8 Comprehensive Care

This is care directed towards meeting the physical, psychological, social and spiritual expectations and needs of the patient and the family with sensitivity to their personal, cultural, religious beliefs and practices (Fröhlich, 1997:199).

#### 1.10.9 Continuity of Care

It refers to coordinated continuous plan of care that is maintained across all settings from the time of admission to support of the family during bereavement (Fröhlich, 1997:20).

1.10.10 **Epidemic**

This term refers to a disease occurrence that clearly exceeds the normal or expected frequency in a community or region (Spradley & Allender, 1996:506).

1.10.11 **Pandemic**

The concept pandemic refers to an epidemic that is worldwide in distribution (Spradley & Allender, 1996:506). AIDS is a pandemic because no country has escaped it.

1.10.2 **Communicable disease**

This term refers to a disease that can be transmitted from one person to another and is caused by an infectious agent that is transmitted from the source or reservoir to a susceptible host (Spradley & Allender, 1996:506), (Nzimande, 1993:10).

1.10.13 **Stress**

Stress is defined by Sarafino (1994:74) as a condition that results when the person or environment transactions had the individual to perceive a discrepancy, whether real, or not. This occurs between the person's demands of the situation and the resources of the person's biological, psychological or social systems.

1.10.14 **Coping**

Coping is defined as the process by which people try to manage the perceived discrepancy between the demands and resources they appraise in a stressful situation (Sarafino, 1994:139).

1.10.15 **Orphan**

This term refers to a child with both parents dead or a child abandoned by his or her parents (Brown, 1993:2024). In the context of this study, an orphan is a child whose parents have died as a result of AIDS.

1.10.16 **Specialist**

There are specialists in many professions. In the context of this study a specialist refers to a medical practitioner with advanced training in and dealing exclusively with the study or treatment of a particular part of a system of the body or a particular group of people, as supported by Brown (1993:2971).

1.10.17 **Hospice Care**

This term refers to the group of holistic services provided to the dying persons in their home or in a facility which provides a more dignified and comfortable death (Spradley & Allender, 1996:671).

1.10.18 **Umlazi District**

The term "Umlazi District" refers to the magisterial area of land which is a Black residential area, about 24 kilometres from the city of Durban. It is about 4 500 to 4 800 hectares with informal settlements within and around its periphery (Townsend, 1991:34-35). In the context of this study, it is the area within which the home-based care under study is conducted.

1.10.19 **Primary Health Care**

Primary Health Care is defined as an essential health care based on scientifically sound and socially acceptable methods and technology made universally accessible

to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms the integral part both of South Africans' health systems, of which it is the central function and the main focus of the overall social and economic development of the community. It is the first level of contact of individuals, the family and the community within the national health system, bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process (Dreyer, Hattingh & Lock, 1997:131).

The provision of home-based care is based on the Primary Health Care approach which emphasises community participation, developing people's skills and knowledge. This is important when dealing with HIV/AIDS so as to help the individuals cope with illnesses and be self-care agents at home.

### **1.11 ORGANIZING THE REPORT**

The report of this study is organized in chapters as follows:

Chapter one, gives an outline of the study. The discussion gives the background to the study and statement of the problem, objectives to be achieved, research methods, conceptual and operational definitions of terms used in the study.

Chapter two, presents an overview of literature viewed for the study in which the perspectives on HIV/AIDS infection are discussed in-depth.

Chapter three, presents detailed general information from literature on provision of home-based care for people living with AIDS in a comprehensive way to meet the needs and problems of sick individuals in a home setting.

Chapter four, presents the theoretical framework on which the study is based, namely: Albrecht's Nursing Model for Home Health Care, Orem's General Theory of Nursing and Adams' conceptual Model for Nursing.

Chapter five, presents a description of the research methods. It includes the explanation of the research design, sample and sampling methods, research instruments and ethical implications.

Chapter six, provides the analysis and interpretation of data collected from people with AIDS. Data is presented in the form of tables and graphs followed by the necessary discussions and interpretations.

Chapter seven, deals with the analysis and interpretation of data collected from care-givers, social workers and traditional healers. The same approach as used in chapter six is followed.

Chapter eight, presents a summary of the research, conclusions drawn from findings, limitations and recommendations made for practice and for future research. The proposed model of home-based care is also presented in this chapter.

## **1.12 CONCLUSION**

This chapter has outlined the orientation to the study, giving an indication of the problem under investigation and the objectives to be achieved. The next chapter gives a critical analysis of literature about the perspectives on HIV/AIDS infections

## **CHAPTER 2**

### **PERSPECTIVES ON HIV/AIDS**

#### **2.1 INTRODUCTION**

This chapter presents a critical review of literature pertaining to perspectives of HIV/AIDS infection as a global catastrophe which impacts on the lives of all nations in the world, some to a lesser, and others notably the developing nations, to a greater extent. Africa, particularly Sub-Saharan Africa, is the hardest hit since approximately 29 900 000 people were living with HIV/AIDS as at the end of 1999 (UNAIDS Report on global HIV/AIDS epidemic - June 2000:125). This chapter presents a foundation for a better understanding of home-based care for people living with AIDS, which is the subject of this research.

No country in Africa has escaped the HIV/AIDS infection. In South Africa HIV/AIDS, like tuberculosis, was declared a National Priority in 1998. AIDS is a chronic disease that makes demands on a variety of services and on families and communities who can barely fend for themselves, let alone take care of orphans. AIDS has no cure, only palliative treatment is provided to affected individuals. The affected individuals prefer to remain anonymous for fear of discrimination with resultant inaccessibility to needed services. This has severe physical and psycho-social effects.

#### **2.2 THE EXTENT OF HIV AIDS INFECTION**

According to the UNAIDS report (June 2000:6), the global extent of HIV/AIDS epidemic as at the end of 1999 is as presented in table 2.1 of this chapter.

It should be noted that these figures are mere estimates which do not reflect reality, because many cases remain unknown due to the "silence" imposed on the AIDS status of clients.

**Table 2.1 Global estimates of HIV/AIDS epidemic as at end of 1999**

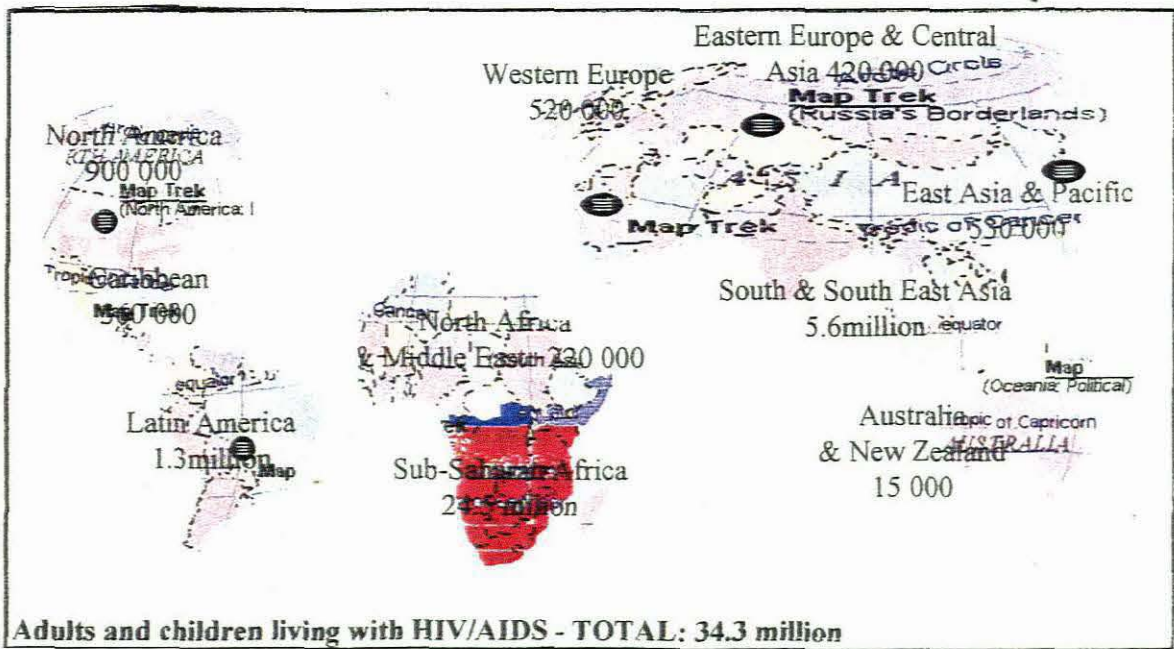
People infected with HIV in 1999	Total Adults Women Children below 15 years	5,4 million 4,7 million 2,3 million 620 000
Number of people living with HIV/AIDS	Total Adults Women Children below 15 years	34,3 million 33,0 million 15,7 million 1,3 million
AIDS deaths in 1999	Total Adults Women Children below 15 years	2,8 million 2,3 million 1,2 million 500 000
Total number of AIDS deaths since the beginning of the epidemic	Total Adults Women Children below 15 years	18,8 million 15,0 million 7,7 million 3,8 million
Total number of AIDS orphans since the beginning of the epidemic . . . . .		13,2 million

(Source: UNAIDS Report on the global HIV/AIDS Epidemic - June 2000:6)

Africa faces enormous challenges in a long-lasting epidemic. Sub-Saharan Africa has forty-five countries that show evidence of varying HIV infection rates. In Senegal and Uganda HIV infection rates have been reduced. In most Sub-Saharan countries, adults and children are acquiring HIV infection at a high rate with new infections in 1999 reported to be four-million.

Sub-Saharan Africa has the largest number of people living with AIDS in the world. The average incidence of adults living with HIV is 1:5. Figure 2.1 confirms the high incidence of HIV/AIDS in Sub-Saharan African countries.

Figure 2.1: Extent of Global HIV/AIDS Epidemic



(Source: UNAIDS Report on global HIV/AIDS Epidemic, June 2000:6).

Figure 2.1 confirms that Sub-Saharan Africa has the highest figures of HIV/AIDS-infected people viz. 24,5-million, South and South-East Asia 5,6-million, Latin America 1,3-million North America 900 000, East Asian and Pacific 530 000, Western europe 520 000, Eastern Europe and Central Asia 420 000, Caribbean 360 000, North Africa and Middle East 220 000, and Australia and New Zealand, 15 000.

Figure 2.1 confirms that there is a high incidence of HIV/AIDS infection in Sub-Saharan Africa.

Table 2.2      People living with AIDS, AIDS Orphans and AIDS deaths in South Africa as compared with other Sub-Saharan countries as at the end of 1999

Countries	People living with AIDS	AIDS Orphans	AIDS deaths
South Africa	4 200 000	420 000	250 000
Ethiopia	3 000 000	1 200 000	280 000
Nigeria	2 700 000	1 400 000	250 000
Kenya	2 100 000	730 000	180 000
Zimbabwe	1 500 000	900 000	160 000
Mozambique	1 200 000	310 000	98 000
Zambia	870 000	650 000	99 000
Uganda	820 000	1 700 000	110 000
Rwanda	400 000	270 000	40 000
Botswana	290 000	66 000	24 000
Namibia	160 000	67 000	18 000
Senegal	79 000	42 000	7 800

(Source:      UNAIDS Report on Global HIV/AIDS Epidemic, June 2000:124)

Table 2.2 reflects that South Africa has the highest number of HIV/AIDS infection viz: 4 200 000 which appears to be increasing rapidly, as is the number of AIDS orphans. Other Sub-Saharan countries like Uganda, Nigeria, Ethiopia, were the first countries to be hit by HIV/AIDS infection. Therefore they reflect the highest number of orphans. Senegal had the lowest numbers of HIV/AIDS infection viz: 79 000 which corresponds with the low number of deaths viz. 7 800.

**Table 2.3** Further projections of the National Department of Health on the increase of HIV/AIDS in South Africa

	1999	-	2004	Percentage increase
HIV Infections	3,75-million		5,5- million	31,8%
AIDS deaths	175 000		400 000	56,2%
AIDS orphans	250 000		750 000	66,6%
Hospital Bed occupancy (in Gauteng alone)	2 000		8 000	75 %

(Source: (Kunene, 2000:6)

The future projections in Table 2.3 as indicated by the Health Sector Strategies Framework from 1999 - 2004, shows an alarming increase of 75% bed occupancy in Gauteng's hospitals only. There is also a projected increase in AIDS orphans by 66,6% and in the AIDS death rate by 56,2%, with a progressive increase in HIV/AIDS infections of 31,8%. It is evident that, if no cure or vaccine is found, South Africa will be faced with a crisis situation of increasing numbers of HIV/AIDS infections, deaths and orphans with a marked decline of the total population.

Mzobe (2000:16) stated that the AIDS epidemic in South Africa had gone unchecked for the last ten years. Almost four-million South Africans are HIV-positive, with 1 600 infected people reported each day. The disease has silently worked its way into an epidemic as it gained advantage from people's fears, confusion and plain indifference. 'Shame' was the adjective used to describe HIV infection. Stories of who died, how and why, were told over township fences in hushed tones. Lifestyle implications were discussed, yet no change of behaviour has been noted. The author further urged all South Africans to live safely, for the benefit of the new generation that deserves an equal opportunity to regenerate.

Table 2.4 HIV/AIDS in South Africa compared with the rest of the Sub-Saharan Africa and the World

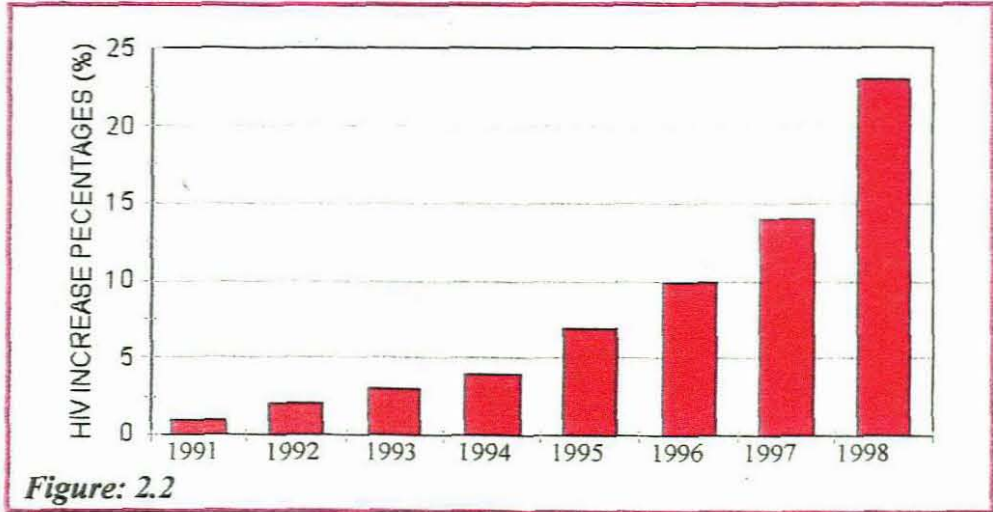
	People living with AIDS	AIDS deaths	AIDS orphans
Global total	34 300 000	2 800 000	13 200 000
Sub-Saharan Africa (45 countries)	24 500 000	2 200 000	12 100 000
South Africa alone	4 200 000	250 000	420 000

(Source: Adapted from UNAIDS Report on the Global HIV/AIDS Epidemic, June 2000:124)

Table 2.4 reflects the high incidence of HIV/AIDS infection in the Sub-Saharan Africa as compared with the global total. It also reflects that HIV infection in South Africa appears to follow the future projections of the National Department of Health. AIDS is currently not a notifiable disease in South Africa though this is under review. Voluntary reporting seriously diminishes estimates of the incidence of people with AIDS.

Data from the Department of Health's Annual National HIV sero-prevalence surveys of women attending antenatal clinics for the past nine years provides a good estimate of HIV prevalence and trends in South Africa, as reflected in figure 2.2.

Figure 2.2    National HIV survey of women attending antenatal clinics of Public Health Services in South Africa

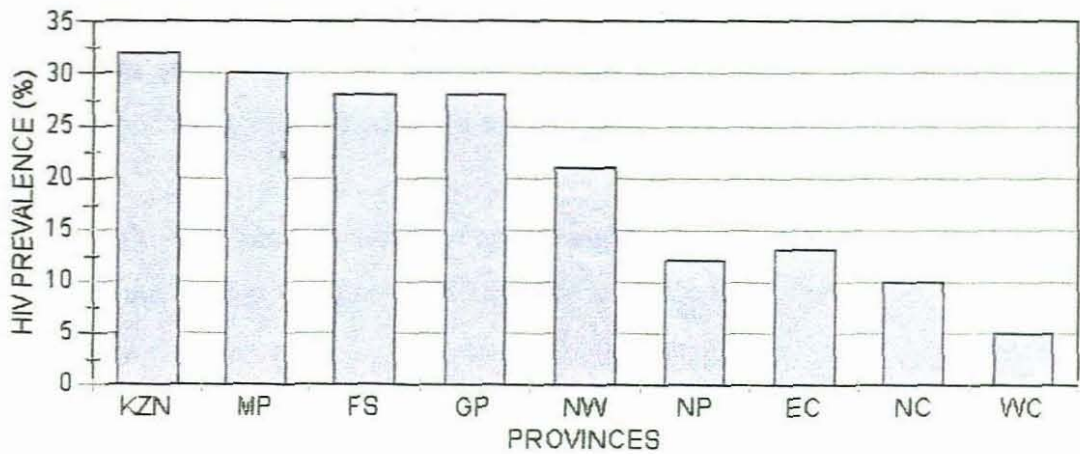


(Source: HIV/AIDS/STD Strategic Plan for South Africa 2000-2005, January 2000:8)

Figure 2.2 reflects the progressively increasing incidence of HIV infection in pregnant women who attended the antenatal clinics of public services. This increase excludes those who attended private services and non-clinic cases. It is evident that HIV/AIDS infection is both a regional and a national priority.

The HIV prevalence amongst pregnant women attending public antenatal clinics in all provinces of South Africa is shown in figure 2.3.

Figure 2.3 HIV prevalence amongst pregnant women attending antenatal clinics by Province in South Africa (1998)



Provinces

Key

KZN =	KwaZulu-Natal	NW =	North West Province
MP =	Mpumalanga Province	NP =	Northern Province
FS =	Free State Province	EC =	Eastern Cape Province
GP =	Gauteng Province	NC =	Northern Cape Province
WC =	Western Cape Province		

(Source: HIV/AIDS/STD Strategic Plan for South Africa 2000-2005, January 2000:9).

Figure 2.3 reflects that KwaZulu-Natal and Mpumalanga provinces are at the forefront of the AIDS epidemic in South Africa. The Western Cape Province has the lowest incidence of HIV/AIDS infection. Smith (2000) cited in Kunene (2000:5) expressed his views on this phenomenon in KwaZulu-Natal as due to the following:

- ▶ Two seaports, i.e. Durban and Richards Bay, linked by road, forming major truck routes associated with high rates of commercial sex.
- ▶ Highly populated province of approximately 8.4-million, representing 20% of the total population in South Africa while it comprises 7,6% of land area.
- ▶ 64% of the population is under 25 years of age.
- ▶ Migrant labour, men away from home for long periods which leads to exposure to casual and/or commercial sex as well as dysfunctional families.

The factors that contribute to the high rate of HIV/AIDS infection in Mpumalanga are not stated. The researcher believes that a possible reason is the high number of immigrants coming into South Africa from surrounding countries. Mpumalanga is near the border. It is a point of entry into South Africa, and also has the major truck routes for exports.

The Western Cape province has the lowest numbers of HIV/AIDS infection. This may be an indication of a positive attitude to sexuality education which forms part of the socialisation process and the school education programme. There is also less unauthorised immigrants in this province whereas KwaZulu-Natal has many entry points from neighbouring countries like Mozambique, Zimbabwe, Swaziland and the seaports already stated in this chapter.

The increasing HIV prevalence in the Durban townships of Umlazi, KwaMashu and KwaDabeka as from 1996-1999 is reflected in figure 2.4

Figure 2.4 HIV Prevalence in Umlazi/KwaMashu/KwaDabeka Locations

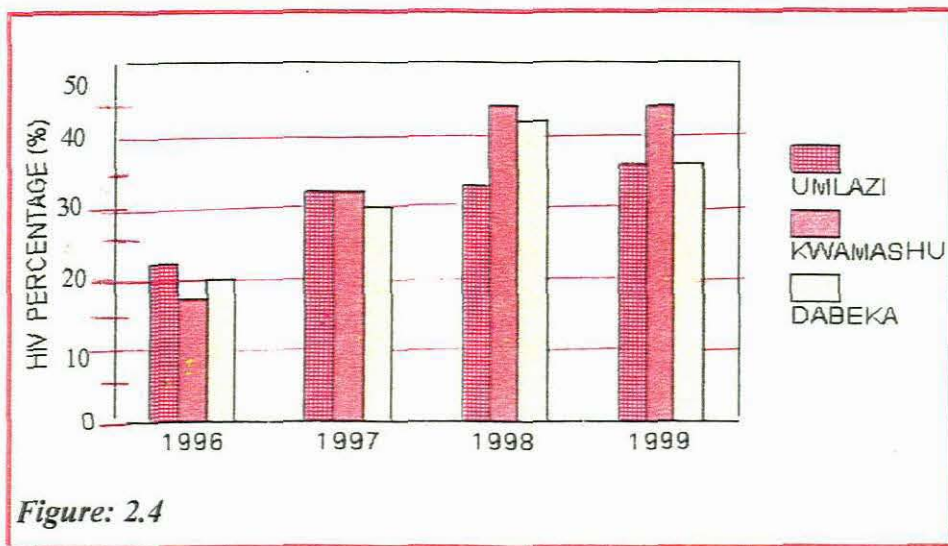
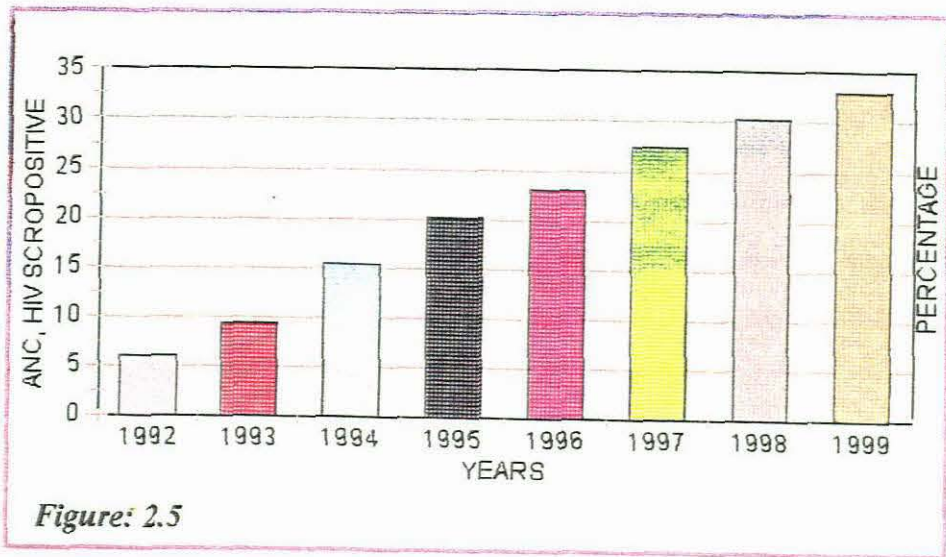


Figure: 2.4

(Source: Report: University of Natal Durban Medical School, Dept of Virology)

Figure 2.4 reflects a steady rise in HIV infections in Umlazi from 22% in 1996 to 36% in 1999, 17% in 1996 to 44% in 1999 in KwaMashu and 20% in 1996 to 36% in 1999 in KwaDabeka which reflects a decline of 6% from 42% in 1998.

Figure 2.5 HIV Prevalence reported at King Edward VIII Hospital antenatal clinic (KwaZulu-Natal) as from 1992-1999



(Source: Adapted from Smith, (1998) Virology Department University of Natal Medical School)

Figure 2.5 reflects a progressive rise in HIV infections amongst pregnant women in spite of all the strategies that are implemented by the government and other organizations to control the spread of the infection. This increase is from 6,05 % in 1992 to 33,05 % in 1999.

### **2.3 CLASSIFICATION OF PEOPLE LIVING WITH AIDS**

HIV/AIDS does not kill instantly. It works its complex dynamics in two phases called HIV/AIDS Cycle. According to Mzobe (2000:13) there are two groups of people living with AIDS.

**Group 1 refers to people who test HIV-positive but show no signs and symptoms of the disease**

During this period the sick individual feels healthy, with a healthy life, lasting an average of seven years. This period is a dangerous one, full of myths and misconceptions about the existence of the disease. It is associated with a lack of safe sex practice and spreading of the HIV infection to others.

**Group 2 refers to people in the second phase of the HIV/AIDS Cycle known as Full Blown AIDS**

In this group, the disease shows the clinical manifestations of various opportunistic infections, which usually cause death. These people have rights that must be respected (Draft Policy Statement on HIV/AIDS Annexure A, 1997:4).

### **2.4 RIGHTS OF PEOPLE LIVING WITH AIDS**

People living with AIDS have the right to:

- compassionate care in an institutional or home setting.
- ongoing high quality care to maintain their quality of life and express emotions and wishes on approaching death.

- gain independence in the caring roles.
- non-discrimination at work, home, school and in the community since this may affect the individual's self-esteem and morale.
- refuse services, to accept or reject health teaching or treatments.
- be informed of the consequences of refusing treatment and not to be deceived.
- be informed of available services.
- be informed of therapeutic interventions and procedures regarding complaints and have their questions answered honestly.
- be re-assured of confidentiality regarding their health status as this has an important ethical value especially when dealing with HIV/AIDS infection associated with stigmatisation of affected individuals.
- participate fully in the identification of their needs, planning, implementation, monitoring and evaluation process.
- disclosure of HIV status and acceptance by the public.
- ongoing counselling, education and support even though the goal of "cure" changes to one of comfort.
- share the results of HIV-positive status with those he/she is comfortable to inform.
- be given dignity and respect always.

- privacy and psycho-social safety.
- good infection control and information to protect himself/herself against opportunistic diseases.
- access to traditional practitioners as part of their cultural heritage and belief system, since some clients do not believe in the existence of AIDS. They regard this illness as punishment from the Ancestors that can be calmed by traditional healers.
- maintain a sense of hopefulness however changing its focus may be.
- discuss and enlarge religious and spiritual experiences, whatever these may mean to others (Draft Policy Statement Annexure A 1997:4) and (HIV/AIDS/STD Strategic Plan for South Africa 2000-2005:16-17).

## **2.5 COMMON PROBLEMS ENCOUNTERED BY PEOPLE LIVING WITH AIDS**

### **2.5.1 Physical problems**

- Fever which may be continuous or intermittent.
- Anorexia, nausea and vomiting.
- Dysphagia (pain or difficulty in swallowing).
- Dyspnoea (air hunger or shortness of breath).
- Oedema (due to kaposi sarcoma in the lymph nodes and skin).
- Skin or mucous membrane lesions, which may be mild at first but gradually chronic skin rashes occur.

- Herpes Zoster and Herpes Simplex are common.
- Nutritional deficiency due to inability to swallow, anorexia or malabsorption in the intestinal tract. This can lead to profound weight loss often called 'wasting syndrome' and death.
- Neurological impairment which may cause cognitive impairment leading to memory loss, clouded thinking, confusion, personality changes, dementia and speech problems.
- Visual impairment and blindness if the optic nerve becomes affected.
- Loss of hearing and paralysis of one part of the body, possibly lower extremities and respiratory muscles.
- Severe headaches.
- Unbearable pain with stiffness of joints.
- Development of pressure sores due to lack of active and passive exercises when confined to bed.
- Inability to perform Activities of Daily Living like bathing, dressing, feeding, grooming.
- Severe reactions to medications used like alopecia.

#### 2.5.2 Psycho-social problems

- Dependency on others for maintaining most of the Activities of Daily Living. This is against one's values.

- Restrictions on long-term organization and planning of activities.
- The guilt of hiding the HIV-positive status to family members and friends in fear of rejection or stigmatisation.
- Fear to open up and talk about the disease, which tends to prolong the stage of denial.
- The danger of being victimised by neighbours and the community.
- The Problem of being refused medical aid scheme policies, insurance policies, housing subsidies if one's HIV-positive status is publicised.
- Fear of being neglected at home or abandonment in hospital by family members.
- Lifestyle changes causing restrictions and reduced social and sexual outlets (Alexander, Fawcet & Runciman, 1994:908).

The researcher has observed the use of multi drug therapy as a problem, especially when complemented with traditional or herbal medicines. Clients tend to concentrate on the use of herbal medicines with the excuse that the other medicines are the cause of nausea and vomiting and other complications. This confirms the statement on page 31, that sick individuals consult with traditional healers first which is their cultural heritage and belief system.

## **2.6 STAGES OF HIV/AIDS INFECTION AND THE LIFE-SPAN OF THE SICK INDIVIDUAL**

### **2.6.1 The four stages of HIV infection**

Van Dyk (1992:9-11) described the four stages of HIV/AIDS infection as follows:

Stage 1: The Acute Stage

This stage begins a week after infection and produces sero-conversion or changing over from HIV-negative to HIV-positive. The symptoms of HIV infection are fever, swollen glands, night sweats, skin rashes, headaches and coughing. Blaikie and Barnett (1992:52) described this stage as frightening. The affected individual becomes physically and psychologically traumatised once sero-positivity is confirmed.

The individual and his/her family have to learn to cope with HIV/AIDS-related symptoms. Family boundaries become more rigid, the family learns to perform its own counsel, out of fear of being stigmatised at work, at school or by friends and the community. Van Dyk argued that AIDS is a 'Robber disease'. It deprives people of sexual fulfilment and marriage, some people die childless, being robbed of producing their own children. Mothers are deprived of parenting their children, children are deprived of parental love and protection, become orphans or die early in life as a result of AIDS.

Stage II: The Asymptomatic Carrier Stage

The infected individual develops antibodies, becomes the carrier of the virus for life, but displays no symptoms of the disease. Sometimes the infected individuals are not aware that they are carrying the deadly virus. Some people remain HIV-positive for as long as fifteen years without showing clinical manifestations of the disease. Others deteriorate rapidly and develop full-blown AIDS and die within months.

Stage III: The AIDS-related Complex or (ARC) Stage

This stage starts when people have antibodies of HIV and display one or more of the following symptoms:

- Fever
- Night sweats
- Diarrhoea and vomiting
- Weight loss
- Fatigue
- Lethargy
- Genital lesions
- Oral hairy leucoplakia
- Skin rashes
- Herpes-zoster
- Headaches
- Lymphadenopathy
- Splenomegaly
- Memory loss
- Confusion

This stage may be long or short and is sometimes referred to as the time of "Living in Limbo".

The affected person is at a loss. The family and the affected individual often come to grips, psychologically and organisationally, with permanent changes resulting from the AIDS-related illness. They jointly devise ongoing *modus-operandi*.

Sometimes children are thrust into the caring role, exposed to stressful situations of witnessing a parent slowly dying of AIDS. Van Loon (2000:154) supports Van Dyk's views of the traumatic experiences of children as care-givers. She argues that some children leave school and develop school phobia because of the stigma of having a dying parent due to AIDS. The children's involvement in the caring roles appears to influence their parents' response to illness.

Most mothers become motivated to make changes in their lives, like recovering from drug abuse and seeking out resources that would provide support, comfort and assistance to their children even after their death.

#### Stage IV: The Full-Blown AIDS Stage

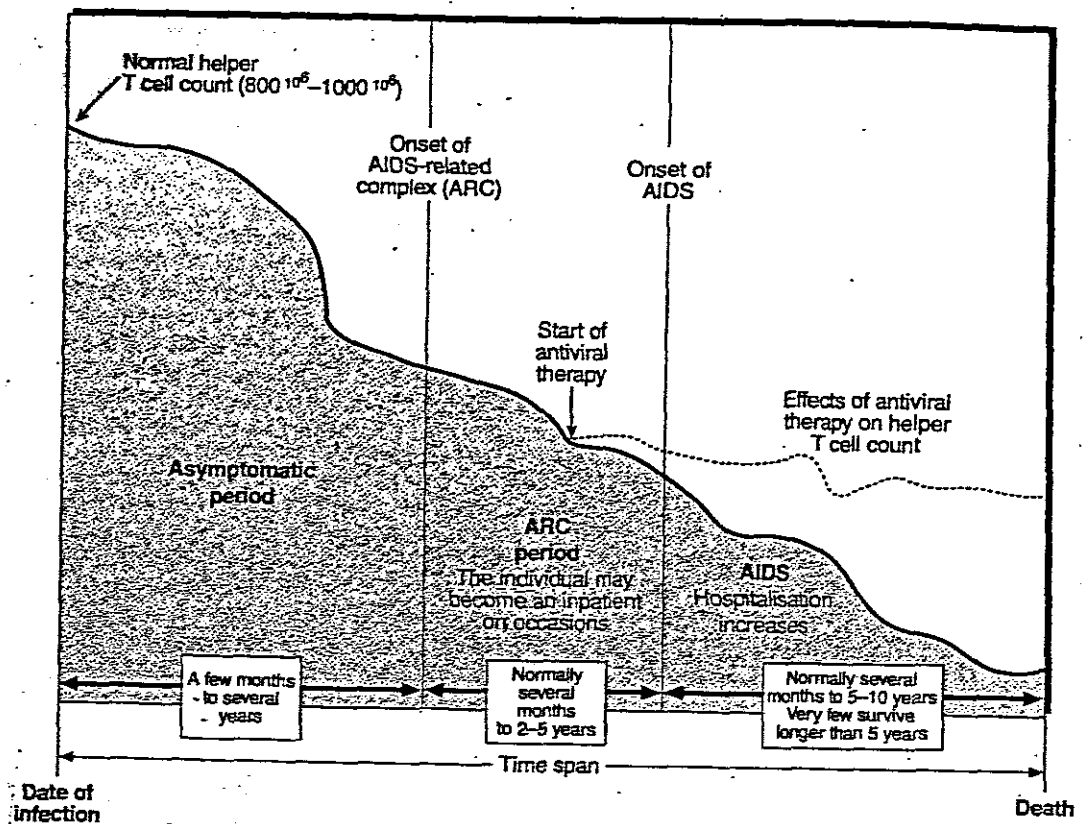
This is the terminal stage of the disease. The immune system deteriorates increasingly. More opportunistic infections appear frequently. The sick individual

at this stage becomes aware of imminent death. He/she may express wishes as to where to die or what should happen to his/her children and assets. The sick individual may request to be nursed at home, and die in the presence of the family members in familiar surroundings. At this stage the sick individual is completely dependent on health care personnel and others. Orem, in George (1990:96-97), describes this stage as the wholly compensatory system which means assisting the sick person with all the activities of daily living which includes breathing, hygiene, elimination, feeding and even changing position.

### 2.6.2 The lifespan of the sick individual

Alexander *et al.* (1994:898-910) described the life-span of an individual with HIV/AIDS infection, which may be a few months, two to five years or five to ten years, as presented in figure 2.6.

Figure 2.6 The Diagrammatic representation of the lifespan of an HIV/AIDS person



(Source: Adapted from Alexander *et al.*, 1994:1004)

Table 10 shows the lifespan of a person infected by the HIV virus and the stages of infection until death. The normal T4 lymphocyte cell count is  $800^{\text{mm}^3}$  -  $1\ 000^{\text{mm}^3}$ . The infected individual remains asymptomatic for a few months to several years before the virus begins to use the resources of the cell to multiply. The virus starts to destroy the helper cells thereby reducing the T4 cell count to about  $500/\text{mm}^3$  or less in severe cases. This stage is the onset of AIDS-Related Complex (ARC) period. The infected person with the HIV antibodies displays clinical manifestations of the disease such as fever, diarrhoea, weight loss, oral thrush and others. At this stage the sick individual becomes very ill, starts anti-viral therapy and supplementary nutrient medications to boost the declining immune system.

The AIDS-Related Complex period (ARC) takes several months, to two to five years, with a marked increase of expenditure on drugs. When the T4 cell drops to  $200/\text{mm}^3$  or less, the sick individual becomes more seriously ill. The immune system deteriorates fast and untreatable opportunistic infections occur. Repeated hospitalisations for onset of acute symptoms of diarrhoea, oral thrush, anorexia, and vomiting with signs of dehydration occur. This is the last stage of the infection known as AIDS which may last several months or five to ten years before death occurs. Few survive beyond five years.

Albrecht, in Stanhope and Lancaster (1992:807) described the case of an individual nursed at home in the terminal stages of illness as one of coordinated effort, to ensure a comprehensive continuum which involves the client, family or care-giver and other disciplines. The individual's self-care capabilities, health status and cost-effectiveness of the treatment given are continuously evaluated. Treatment and nursing care are modified to meet the client's needs and shrinking resources.

## 2.7 FEATURES OF THE CHRONICITY OF AIDS

- ▶ Alexander, Fawcet and Runciman (1994:908-910) state that all patients with AIDS have a number of co-existing diagnoses, many of which will be

opportunistic infections. Repeated interactions with health care workers become frequent, to receive active treatment for relief from their symptoms of the disease.

- ▶ A chronic illness is uncertain, and it is difficult to establish the prognosis. The sick individuals, their families and other care-givers are exposed to stressful situations. Pain and discomfort restrict the individuals' movements which may lead to confinement to bed. As the disease progresses, the individual may be forced to forego the achievement of socially and culturally specified tasks, like getting married and having a family. A person with AIDS may decide not to have children for fear of the danger of vertical transmission to children born to sero-positive mothers.

Libman and Witzburg (1993:472-3) state that during pregnancy, the immune status of an HIV-positive mother changes in the lymphocyte count in response to HIV infection. The T4 cell count drops to below  $500\text{mm}^3$ . This results in rapid progression of HIV infection with resultant early maternal death. The newly-born child may suffer from paediatric AIDS.

Sims and Moss (1991:1) argue that multiple problems, sudden dramatic changes in condition and the lengthy dying process cause total dependency on others. This causes psychological trauma and uncertainty to the sick individual who may value self-reliance and economic and physical independence. Adam, in Marriner-Tomey (1994:494-5), argued that the nurse and the client must both establish what is perceived as the helping relationship, since the client at this stage is helpless and dependent on others. She proposed a climate of empathy, warmth, mutual respect, caring and acceptance of the prognosis of the disease for the of nursing care to be effective.

Lambert and Lambert (1987), quoted in Alexander *et al.* (1994:910) describe the intrusive nature of AIDS. AIDS disrupts happy families' lives, in some cases couples either separate or divorce. Recurrent crisis episodes of clinical manifestations of the disease impinge on the domestic, work-related and recreational activities of the family, or other care-givers, leading to isolation and stress.

## **2.8 THE IMPACT OF AIDS**

The impact of HIV/AIDS cannot be overestimated. It takes its toll on all the sectors of the fabric of society. This has a direct and indirect impact on the health of the nation and on the health care system. The impact of AIDS is best described in terms of the following aspects.

### **2.8.1 Impact on Government**

The citizens expect the government to provide funding for the purchase of anti-retro-viral therapy, aimed at inhibiting and suppressing HIV activity and replication in infected individuals, especially Nevirapine believed to prevent mother-to-child HIV transmission.

- ▶ The government is expected to take a lead in initiating HIV/AIDS programmes aimed at prevention, reducing the spread of HIV infection and caring for those already infected and ill with HIV/AIDS-related conditions.
- ▶ Ongoing funding is needed to support non-governmental organizations (NGOs) and community-based organizations (CBOs) in the fight against AIDS through intensive education, counselling and care programmes.

- ▶ Effective coordination and control of all initiatives to prevent competition and enhance the benefit for all those affected by HIV/AIDS is required.
- ▶ There should be support for the business plans of HIV/AIDS/STD programmes which deal with voluntary counselling and testing, treatment of opportunistic infections, prevention of mother-to-child transmission, blood transfusion, human rights and sexually-transmitted diseases management.
- ▶ Funding must be provided, for training and development of AIDS counsellors, home-based care providers, protection material and ongoing research.
- ▶ The orphans left by young parents who died of AIDS-related illnesses exert a big strain on the welfare service and on the government's budget.
- ▶ Human resource development which is supported by the government becomes severely affected as professionals of all disciplines get infected with the HIV virus.
- ▶ The government has a crucial responsibility for providing for the education, care and welfare of all South Africans, regardless of their HIV status.
- ▶ There should be ongoing monitoring and evaluation of all AIDS intervention strategies, observing the rights of all people in relation to AIDS.
- ▶ Other costs incurred are related to drug trials. Since these are for research purposes, patients who volunteer to participate in research get the drugs free of charge at a great cost to the State. Toxic effects are managed free

of charge (Strategic and operational Plan (Business Plan) for 1999-2000: 1-3) and (Kunene, 2000:17).

### 2.8.2 The impact on households (Families)

- ▶ The burden created by an HIV/AIDS infection on families is enormous. The poor urban and rural families become more severely affected. When a family member is affected the whole family has to deal with the effects of the disease. The impact of the epidemic is felt through the increasing mortality of family members, human suffering and poverty, particularly in female-headed or child-headed families.
- ▶ Medical expenses incurred by the sick individual may cause severe depletion of financial resources, leading to unpaid accounts, for example service charges or rates, with possible loss of land or housing.
- ▶ The home-based care, which is a cheaper alternative to hospital care, is an ordeal for many families because of inadequate amenities like latrines, safe water supply and protective material. The death of a mother also leads to an increased risk of infant and child mortality. Many children leave school either to care for a sick parent or to enter the children's labour market to alleviate the family's financial burden.
- ▶ After the death of a breadwinner the health status of the remaining family members deteriorates, especially that of children who develop various diseases that occur as a result of a decline in nutritional levels, or because of their own HIV-positive status with the onset of opportunistic infections like pulmonary tuberculosis, diarrhoea and other infections. Children born after parents have been diagnosed HIV-positive may contract HIV-infection and suffer from paediatric AIDS, with a high death rate, thereby increasing

financial expenses for the affected family. Members of the family who would be able to earn or perform household and family maintenance activities may be compelled to spend their time caring for the sick person with AIDS (Whiteside, 1998:110) and (Lovelife, 2000:10).

### 2.8.3 Impact on the community

- ▶ The increasing numbers of people affected with HIV/AIDS result in a greater demand for additional community resources which are already lacking, for example adequate medical and surgical supplies and more health personnel. The high costs prohibit access to health care e.g. if no transport is available. Community members experience problems in areas where clinics do not provide 24-hour services due to lack of security for staff members. Clients with AIDS suffer the most since many of them are jobless because of ill-health and cannot afford to pay hospital bills or travel to clinics if these are more than 5 km from where they live.

### 2.8.4 Impact on hospitals

- ▶ Bed occupancy has increased by an average of 50% due to prolonged illnesses caused by HIV-related opportunistic diseases as stated in Chapter 1 (page 1) of this report..
- ▶ Health care institutions cannot keep sick individuals for long periods, resulting in early discharge to recuperate at home.
- ▶ The AIDS epidemic has changed the nature of hospital wards/units. Medical wards which used to be regarded as "light" wards with patients less dependent on nurses, have now taken the category of "critical care wards" with patients wholly dependent on nursing personnel. This places an extra burden on the already over-burdened and burnt-out staff, since shortages are a typical feature of many health services in South Africa (Kunene, 200:9).

### 2.8.5 Individual-psycho-social impact

- ▶ The diagnosis and disclosure of HIV status itself is a major source of stress for the individual.
- ▶ The prospect of death is an emotional, psychological and social trauma to the individual and the family, and the thought of leaving orphans with no-one responsible for their well-being, leads to severe depression, especially when both parents are terminally ill.
- ▶ A lack of commitment by some family members and refusal to perform some care-giving activities i.e. mouth cleaning, dressing of wounds, giving of injections, for fear of contracting the infection, lead to severe stress for the sick individual.
- ▶ The individual fights for wellness in the face of severe viral infections and the poor-functioning immune system. This causes physical and mental strain.
- ▶ Unpleasant physical symptoms develop as a result of opportunistic infections, like severe diarrhoea, skin lesions, weight loss and fatigue, alopecia and loss of memory or confusion.
- ▶ The inaccessibility of AIDS treatment to many people living with AIDS and who are not covered by medical aid schemes, is a major source of stress.

### 2.8.6 Impact on care-givers (community volunteers)

- ▶ The uncertainty that results from silence or secrecy surrounding HIV/AIDS diagnosis is very unsettling to the care-givers.

- ▶ The fear of contracting the HIV infection makes care-givers spend most of their time in efforts to protect themselves, especially if they lack knowledge and experience of preventive measures against AIDS.
- ▶ The physical strain of working hard, long hours day and night and being emotionally close to the sick individual results in enormous stress.

#### 2.8.7 Impact on Medical Aid Schemes

- ▶ Increasing members of policy holders die due to AIDS-related illnesses. The Medical Aid does not pay if there is confirmation that the cause of death is AIDS.
- ▶ Long-term illness requiring long-term prescription of expensive medications of 6-12 months or 1-7 years leads to rapid utilization of funds credited for medication and payment of hospitalisation.
- ▶ Challenges on medical aid schemes regarding non-discrimination against members with AIDS have adversely affected the medical aid schemes but thrown a lifeline to the health Industry. Lifeline is Life-sense (Peters, 1999:5) stated that Life-Sense The Lifeline referred to in the preceding paragraph is Life-Sense. Peters (1999:5) stated that Life-sense is a project initiated by the Durban Chamber of Commerce and Industry. It has eight large medical aid schemes which provide their clients with complete means to manage AIDS and ongoing research on how care could be best provided to reduce hospitalisation, absenteeism from work and increase the clients' projected lifespan.

#### 2.8.8 Impact on women

- ▶ When husbands die as a result of AIDS-related illnesses their wives too may have started to show the symptoms of the HIV/AIDS infection.
- ▶ Women-headed households tend to be poorer, especially if the woman is unemployed.
- ▶ Many women face the risk of abandonment and abuse if they disclose their HIV-positive status.
- ▶ Women traditionally provide care to the sick and terminally ill individuals at home, but become over-burdened if more than one member of the family becomes ill due to HIV/AIDS-related illnesses which are chronic in nature.
- ▶ Widows may become dependent on a husband's male heir for support under some customary arrangement, which may make them more vulnerable (Love-Life, 2000:11). According to Customary Marriages Act (Act 120 of 1998) assets of the deceased may be awarded to the spouse or spouses (Government Gazette No. 19539 of 2 December 1998:12).

#### 2.8.9 Economic impact of HIV/AIDS on the Public Health Sector

- ▶ The public sector is under stress. In the mid-90s, 66% of public health spending was on AIDS. Tuberculosis as the leading cause of death among people living with HIV infection, accounting for about a third of AIDS deaths worldwide. Each new tuberculosis infection is reported to create a further cost to the health sector.
- ▶ In 1997 public health spending for AIDS alone exceeded 2% of the gross domestic product (GDP) when the total health spending was 3-5% of the gross domestic product (GDP). Up to 50% of hospital beds are utilised for

HIV/AIDS. The increased mortality and health care expenditure is exacerbated by the exploding tuberculosis epidemic (UNAIDS Report on the global HIV/AIDS epidemic, June, 2000:31).

- ▶ Anti-retroviral therapy is available at a very high cost, ranging from R2 000–R3 000 per month for a three-drug combination. It is estimated that one tablet of this combination might cost as much as R160,00. This makes AIDS treatment expensive and inaccessible to many people living with AIDS who do not have Medical Aid Schemes (Kunene, 2000:11-12).

#### 2.8.10 Impact on the Private Sector

The economic consequences of the HIV/AIDS epidemic result from the increasing need for resources for caring for AIDS sick persons. In South Africa, private health care is funded mainly via employment-related medical schemes, covering about 20% of the population. The private and public sectors' HIV/AIDS expenditure projections by year 2010 are expected to be 9% and 13% respectively.

#### 2.8.11 The impact of HIV/AIDS on special organizations e.g. the AIDS Foundation

The AIDS Foundation is responsible for the funding of approved initiatives. The training of personnel as AIDS counsellors or community health workers. It gives assistance to community home-based care models for chronic illnesses that have the full support of community members.

A lack of funds to maintain all projects that are AIDS-related is still a problem, as well as the sustained commitment of all sectors and individuals in the fight against AIDS.

## 2.8.12 Cost comparison between private and public sector

Table 2.5 Average cost of care per infected person per year by stage and sector

	Public Sector			Private Sector		
	In patient (R)	Out patient (R)	Total (R)	In patient (R)	Out patient (R)	Total (R)
Stage 1 and 2	700	600	1 300	1 600	1 400	3 000
Stage 3	5 200	1 100	6 300	11 800	2 400	14 200
Stage 4	15 500	1 400	16 900	35 100	3 200	38 300

(Source: Love-Life, 2000:16)

Table 2.5 reflects that private sector charges for medication and treatments are far higher than those of the public sector in all the stages of illness. The fourth stage of HIV/AIDS infection, which is the critical stage of illness requiring intermittent admissions to hospital, is the most expensive one. The difference of financial cost at the fourth stage of illness between the private and public sector is R21 400. This is proof that only those people with medical aid schemes have access to expensive treatments for HIV/AIDS.

## **2.9 THE NEED FOR A JOINT EFFORT BY ALL SECTORS AND SPECIFIC GROUPS TO OVERCOME THE SPREAD OF HIV INFECTION**

### **2.9.1 The HIV/AIDS/STD Strategic Plan for South Africa 2000-2005**

The HIV/AIDS/STD Strategic Plan for South Africa 2000-2005 was initiated by the Minister of Health, Doctor Manto Tshabalala-Msimang in July 1999. This was

in response to President Thabo Mbeki's challenge of an AIDS Partnership to all sectors of society to become actively involved in initiatives designed to address the HIV/AIDS epidemic. The goal of the plan is to provide the following:

- ▶ Collaboration initiated by the Department of Health at various levels to ensure an interdepartmental and inter-sectoral response.
- ▶ Highly motivated and active non-Governmental Organizations (NGOs) and Community-Based Organizations (CBOs), both operating with limited resources, promoting safer sex practices, fighting prostitution, drug abuse, rape, etc.
- ▶ Adequate drug supply and accessibility to the management of sexually-transmitted diseases at most clinics.
- ▶ Improvements in pulmonary tuberculosis services.
- ▶ A high level of commitment from the Minister of Health in supporting the initiatives.
- ▶ Reduce the impact of HIV/AIDS on individuals, families and communities.
- ▶ Improve the treatment of HIV-positive people and people living with AIDS by promoting a better quality of life whilst limiting the need for hospital care.
- ▶ Provide HIV/AIDS/STD education to increase public awareness, using an effective communication strategy that will facilitate behavioural change and openness.

- ▶ Improve condom use to reduce sexually-transmitted diseases and HIV incidence and prevalence.

The Strategic Framework for the South African Youth programme as well as the HIV/AIDS/STDs and tuberculosis programmes were aimed at better coordination and a harmonised response to prevent the spread of these diseases and improve people's quality of life. These programmes are listed below:

- Development of policy and legislation relating to HIV/AIDS/STDs and sexual assault. This aims at preventing the spread of HIV/AIDS and providing syndromic management of sexually-transmitted diseases.
- Development and provision of life skills material for the provinces.
- Ensuring that the necessary drugs are included in the revised essential drug list.
- Collaborating with existing poverty alleviation strategies and incorporating HIV/AIDS issues.
- Encouraging voluntary HIV testing and counselling, and providing a policy through which HIV testing may be a necessity even without the individual's consent.
- Increasing collaboration with traditional healers on HIV/AIDS/STDs and tuberculosis prevention and treatment.
- Assisting and supporting different sectors to develop HIV/AIDS/STD programmes and policies.

- Facilitation and support of the trucking industry's AIDS High Transmission project to prevent the spread of HIV/AIDS infection.
- Developing and implementing counselling and care programmes for all national government departments.
- Improving family planning services to known HIV-positive women.
- Ensuring safe blood transfusion services through recruitment of low risk blood donors and monitoring guidelines with regard to blood transfusion.
- Investigating options to reduce HIV and STD Transmission and pregnancies resulting from sexual assault.
- Building the capacity of health professionals to provide comprehensive HIV/AIDS/STD and tuberculosis treatment, care and support.
- Provision of youth friendly services where the youth could express their concerns without fear.
- Improvement of access to male and female condoms through non-traditional outlets, e.g. in truck stops, at the borders of provinces, mines, brothels, village shops and clinics.
- Increase of initiatives that involve youth in activities geared towards increasing development of acceptance of condoms and other safe sex practices.
- Establishment of strong referral networks at all levels, from health facilities to the community.

- Conducting annual assessment on the impact of HIV/AIDS/STDs and Tuberculosis on health services and the state (HIV/AIDS/STD Strategic Plan for South Africa, 2000-2005:11-43).

### 2.9.2 Contributions of certain prominent individuals to better understanding of AIDs

The Bank Policy Research Report (1997:278-9) provided information on some courageous individuals who made the difference, by changing the way society thinks about AIDS. These individuals, not infected themselves by the HIV virus, joined hands in the fight against the community's patterns of discrimination and persecution of those affected by HIV/AIDS as follows:

- ▶ Actress Elizabeth Taylor, devoted most of her life raising funds for AIDS-related projects or programmes.
- ▶ The late Princess Diana of Britain reduced fear and prejudices by simply allowing herself to be photographed embracing a child with HIV/AIDS.
- ▶ There were those who were affected by the disease but came forward and made their HIV-positive status known. They raised funds towards AIDS projects and through singing they raised community awareness on AIDS as a killer disease. These individuals were the late Philly Lutaoya, a Ugandan singer, others were Arthur Ashe, the late tennis star and the late Duduzile Dlamini of Durban who was killed when she publicised her HIV-positive status. The above information confirms the importance of the need for a good support system of any nature to people living with HIV/AIDS.

**2.9.3 The Youth Friendly Centre as means to curb the rapid spread of HIV/AIDS and sexually-transmitted diseases among the youth**

Since the youth are more vulnerable to HIV infection, a youth-friendly centre that is in line with the requirements outlined in the Strategic Framework for the Youth programme is described in this section. An example of such a centre as described by Heunis, Van Rensburg and Ngwenya (2000:58) is the proposed Thabong/Welkom Youth Multi-function Centre in the Free State Province. These authors argue that the centre should be seen as an independent and locally "owned" establishment that permits a variety of role-players, including active youth involvement, in the identification of their needs and preferred strategies to meet them. Its intended purpose is to encourage effective utilization by the youth, in order to curb the rapid spread of HIV/AIDS and sexually-transmitted diseases. The following youth programmes are seen as necessary for youth development and attendance at the centre viz.:

- Computer literacy training as well as the Internet.
- An information and referral service on training and employment opportunities for youths.
- Entertainment such as drama, debates, dancing, music, shows and beauty contests.
- A youth rape crisis service.
- An out-of-school youth literacy programme.
- Programmes that create awareness of risk-taking behaviour with messages about sexual relationships and of protection from pregnancy and disease.

- Student-lead programmes for peer-group instruction and outreach activities in the identified areas.

Heunis *et al.* (2000:60) further describe the benefits of the youth multi-function centre as follows:

- The youth do not feel threatened or self-conscious as the centre is exclusively for youths.
- There is enough time to socialise with peers, receive essential health care without the embarrassment that comes with actually visiting a clinic.
- Youths can make contacts, get information and engage in certificate skills-development programmes.
- Adolescents feel more secure in obtaining information from health care providers who are youthful, with a genuine interest in youths, and who handle their unique reproductive problems well.

According to these authors, the vast age differences of youth necessitate a variety of programmes to suit specific age categories for specific purposes. The programmes can be classified as for:

- ▶ Pre-teens (younger than 10 years)
- ▶ Young teenagers (10-14 years)
- ▶ Teenagers/young people (15-19 years or 15-24 years)
- ▶ Young people/young adults (25-35 years) (Heunis, Van Rensburg & Ngwenya, 2000:58-60).

Categorising these programmes according to age groups will facilitate use of appropriate teaching material and content that will actually convey the message on HIV/AIDS awareness.

## **2.10 TREATMENT OF AIDS**

### **2.10.1 Use of Anti-Retroviral therapy**

AIDS has no cure. The use of anti-retroviral therapy only eases suffering, slows down the multiplication of the virus and prolongs life. In individuals who have not yet developed immune deficiency, anti-retroviral therapy may indirectly help to maintain adequate immune function without disease progression.

The complexity of drug regimens, potential side effects and drug toxicity may preclude the use of anti-retroviral therapy. The possibility of HIV resistance to these drugs is likely and is a common cause of treatment failure. Clients on anti-retroviral therapy must comply and adhere to treatment regimens which are given under supervision. Currently anti-retroviral therapy is a life-long commitment requiring regular follow-up care to detect side effects early (Evian, 1988:55-57) and (Evian, Miller & Steinburg, 1993:66-81).

### **2.10.2 Benefits of using an anti-retroviral therapy**

Libman and Witzburg (1993:380), supported by Evian *et al.* (1993:199) and the Policy Document on HIV/AIDS Clinical Care Guideline for Adults (1998:36-7), provide the following benefits of using anti-retroviral therapy:

- ▶ The general condition of the clients with AIDS or AIDS-related conditions is improved.
- ▶ There is positive HIV viral suppression, which in turn results in less damage and slower decline of the clients' health status.
- ▶ The T4 cell count which had dropped to below 500/mm<sup>3</sup> steadily rises to acceptable levels of 500/mm<sup>3</sup> and above.

- ▶ The onset of opportunistic infections is reversed.
- ▶ The cost of repeated hospitalization is reduced.
- ▶ In patients who are asymptomatic, there is a delay in the onset of symptoms of the disease.
- ▶ Anti-retroviral therapy is used to protect health workers who have been accidentally exposed to HIV infection via a needle prick or other sharp instruments.
- ▶ It has been used in pregnant women by some countries to reduce HIV transmission from pregnant mother to the foetus.
- ▶ The safety of an individual while on anti-retroviral therapy is still under investigation.

### 2.10.3 Promoting optimal health, well-being and safer sexual practices

A positive mental attitude and adopting and maintaining a healthy lifestyle has significant benefits to people living with AIDS. In addition to the use of anti-retroviral therapy the following contribute towards improving of health status:

#### Nutrition

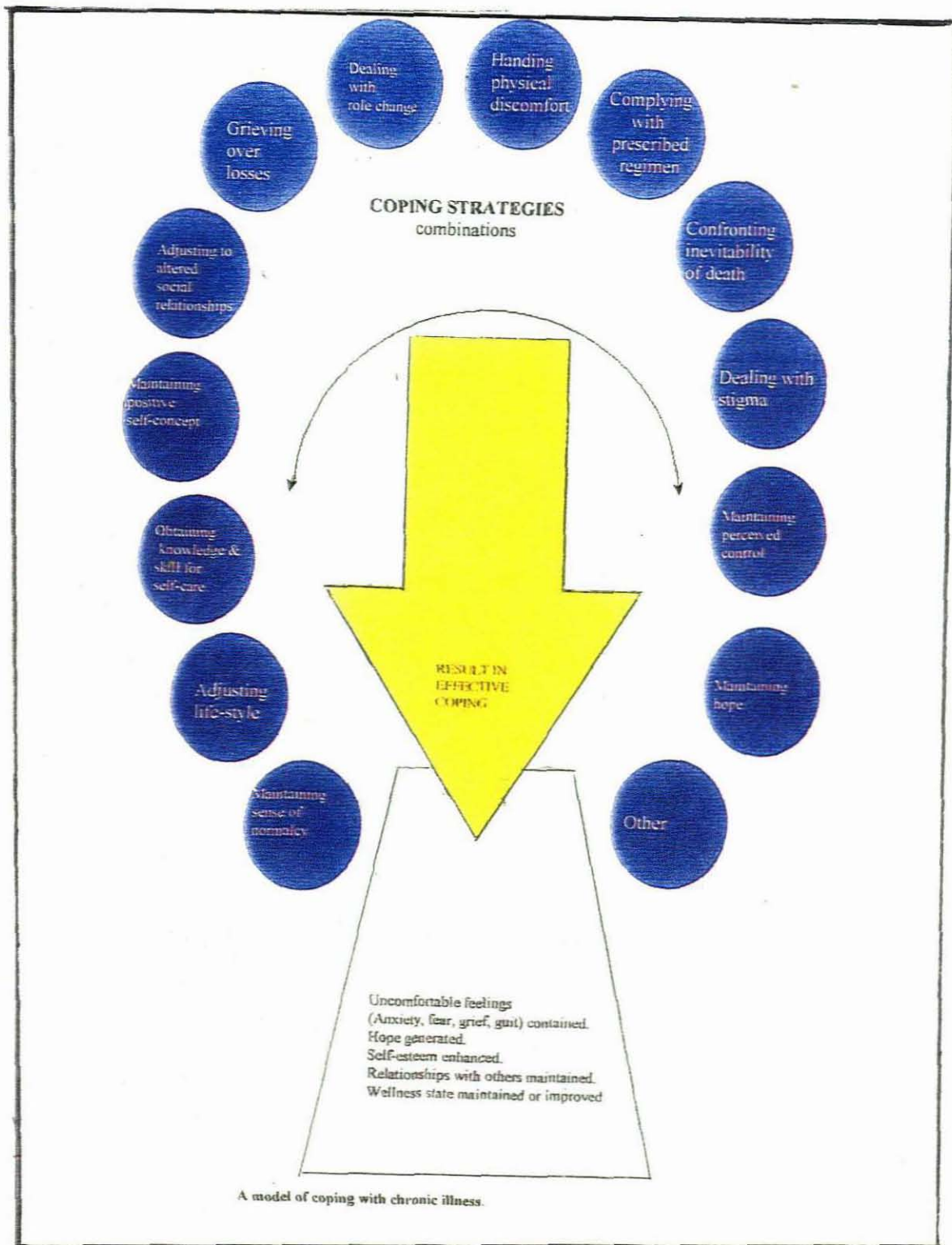
- People living with AIDS are encouraged to eat well-balanced diets as much as possible.
- Water should be boiled before use for drinking or with foods.

- Fruit and vegetables peeled before eating also reduce the likelihood of bowel infection which may lead to diarrhoea.
- Vitamin and nutritional supplementation is necessary.
- In pregnancy vitamin E supplementation may have some effect on reducing mother-to-child transmission.
- Avoidance of abuse of substances like tobacco, alcohol, dagga and hallucinogenic drugs which contribute to deterioration of health in people living with AIDS.

## **2.11 POWER RESOURCES OF AN HIV/AIDS CLIENT ON IMMUNO-SUPPRESSIVE DRUGS**

Alexander *et al.* (1994:1002-3) describe AIDS as a chronic illness which causes rapid deterioration of energy reserve, poor self-concept and a feeling of unworthiness of previous social contacts. The sick individual on long-term therapy with immuno-suppressive drugs has less strength in fighting infection. The power and energy to strive for longer life are stimulated by the clients' power resources. The individual's unique coping strategies are utilised when resources are compromised. These coping strategies are discussed with a diagrammatic representation in figure 2.7.

Figure 2.7 Coping strategies of a person living with AIDS and its chronicity



(Source: Adapted from Miller, 1983:32)

Figure 2.7 reflects the coping strategies of a person living with AIDS and its chronic condition, as illustrated in the model by Miller (1983:32) as follows:

- ▶ The person living with AIDS maintains a sense of living a normal life in spite of living under stressful situations of physical psychological trauma and stigmatisation.
- ▶ Adjust lifestyle like stopping drug abuse, to prolong life and reduce onset of opportunistic infections.
- ▶ Obtains knowledge and skills for self-care to prevent infection and to be an independent self-care agent.
- ▶ Maintains a positive self-concept to boost the self-esteem.
- ▶ Adjusts to altered social relationships, since the individual may experience loss of close friends, or family members or good relations with neighbours and co-workers.
- ▶ Grieving over losses, for example a job, friends, reduction of income or the chance of having his/her own children.
- ▶ Dealing with role change, for example, not being able to provide parental care to children under five years.
- ▶ Handling physical discomfort which becomes more severe as the disease progresses.
- ▶ Complying with a prescribed regimen which has many prescriptions that are costly, and produce severe side effects in certain individuals.

- ▶ Dealing with the stigma which is often associated with isolation and depression.
- ▶ Confronting the inevitable death which is a frightening experience.
- ▶ Maintaining hope and other coping tasks.

Miller believes that a combination of all these coping strategies result in effective coping with good outcomes. Effective coping has the following characteristics:

- Containment of uncomfortable feelings, anxiety, fear, grief and guilt feelings.
- Achievement of self-esteem and maintaining of relationships with others.
- Improved state of wellness state and hope to live longer and as normally as possible.

Van Dyk (1995:5) described how people living with AIDS express their feelings about the disease. They see the disease as a death sentence, a nightmare which triggers many deepest fears especially the inevitable death. The disease evokes severe emotional reactions such as shock, anger, feelings of guilt, anxiety, depression, suicidal thoughts, denial, obsessiveness and loss of autonomy and control.

The feelings of fear and anger become more pronounced as the disease progresses. There is bleakness and uncertainty about what the future holds for them, since there is no cure for AIDS. Periods of denial in most cases become prolonged. Fear and prejudice make AIDS the loneliest illness in the world.

## **2.12 HOPE FOR AN AIDS VACCINE BY YEAR 2004**

Makgoba (2000:7) promised that a South African Vaccine initiative would be starting a trial of the developed vaccine against HIV infection by August 2000, and hopes to have an effective vaccine by year 2004. So far no further information has been obtained as to whether the trial vaccine was implemented or not. The author further stated that, despite the search for a possible vaccine, the public has the responsibility to guard itself against HIV/AIDS infection. The researcher believes that if people are vaccinated against HIV infection, the number of infections will be reduced as well as people nursed at home with HIV/AIDS related illnesses.

## **2.13 INDIGENOUS OR TRADITIONAL TREATMENT OF AIDS AND ASSUMPTIONS ABOUT CURATIVE EFFECTS**

Mchunu (2000:4) argued that the issue of traditional healers warrants attention. Traditional healers are consulted first by a majority of people, particularly Blacks, before approaching the modern health services, since traditional medicine is part of their cultural heritage and belief system. According to Kunene (2000:11) many traditional healers have "moved away from the cure" claims, but play a significant role in improving the patient's condition, boosting the immune system through use of indigenous herbs. Homeopathy also plays a role. The formal health sector is now very accommodating in terms of alternative medicine.

Berer and Ray (1993:29) agree with Mchunu (2000) that traditional medicine is the first line of treatment for African communities. It is the most accessible, affordable and culturally appropriate treatment available to them. Complimenting western medicine is common practice in home-based care for people living with AIDS.

Traditional healing does not cure AIDS or prevent AIDS-related illnesses, but it helps people to come to terms with illness by giving spiritual comfort. The rituals to appease ancestral spirits, do not cure AIDS, but satisfy the clients and their families that the correct measures have been taken, allowing acceptance and support for the client by the family.

These authors recommend involvement of traditional healers in the caring roles of people living with AIDS for the following reasons:

- ▶ Traditional healers can give health and hygiene education.
- ▶ They can encourage anyone with symptoms of HIV infection to see a doctor.
- ▶ They may give preparations that may help patients feel better psychologically.
- ▶ Traditional healers can prevent spread of infection by emphasizing the dangers of needle-sharing by drug users, comparing this with their own methods of preventing the spread of infection through using a single blade once for making cuts into one's skin for medicinal purposes.
- ▶ They are a valuable resource for the distribution of condoms in rural areas.
- ▶ HIV/AIDS literate traditional healers are able to challenge those who still claim to have a cure for HIV/AIDS infection and giving people false hopes.

## **2.14 CONCLUSION**

This chapter dealt with a critical review of literature pertaining to perspectives of HIV/AIDS infection, and the extent of the epidemic worldwide. The impact of HIV/AIDS infection on the health of the nation and health system is highlighted, especially the impact on the person living with HIV/AIDS infection and on home-based care, which is discussed in the next chapter.

## **CHAPTER 3**

### **HOME-BASED CARE FOR PEOPLE LIVING WITH HIV/AIDS**

#### **3.1 INTRODUCTION**

The impact of the HIV/AIDS epidemic is already apparent. The health care system is adversely affected and over-burdened, with the resultant inability of the established health facilities to admit and treat those with AIDS-related illnesses because of the chronic nature of this disease. Home-based care has become a priority, in view of the large-scale epidemic which is rapidly spreading. This chapter deals with the provision of individualised, comprehensive, holistic care providing nursing at home for the sick individuals with AIDS.

#### **3.2 HISTORICAL BACKGROUND OF HOME-BASED CARE**

Home-based Care is not a new concept. It is a traditional way of caring for chronic and terminally sick individuals at home. Since ancient times, women have been performing the caring roles, and still do, even when not at all well themselves. The changing demographic patterns which have resulted from: the rapidly expanding number of young people between the ages of 15-36 years who have contracted HIV/AIDS infection, and the increasing numbers of the elderly with chronic illnesses, have increased the demand for home-based care.

Home-based care continued to be part of nursing practice as the profession developed. Historically, home care services have been provided primarily by public health nurses who combined illness care in the home with comprehensive family care and health promotion. Many forces influence the current and future state of home health services. Among them are cost containment pressures and incurable diseases like AIDS.

### **3.3 NEED FOR HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS**

The impending impact of AIDS on individuals, communities and health care services has changed the modalities in the provision of health care. Bed occupancy has increased by an average of 50% due to prolonged illnesses caused by HIV-related opportunistic diseases. Sick individuals are admitted to hospital for acute intervention only, such as the intravenous drips and respiratory support. Clients are discharged with not much improvement in their helpless state, because of a shortage of hospital beds and medical staff. Hence there is greater demand for home-based care as a continuum of care. Some clients just prefer to be nursed at home (Kunene, 2000:9).

Ill people often feel comforted in their own surroundings, with familiar people around them. Community involvement as well as the involvement of professionals and formal organizations, is important for the effectiveness of home care programmes. Home-based care not only deals with meeting the person's basic medical needs, but provides holistic care, physically, socially, emotionally and spiritually at times convenient to the sick individual. Home-based care aims at helping an ill person in such a way that he/she maintains his/her dignity and continues to do as much as he/she can for himself/herself. Orem, in George (1990:94), emphasises the importance of client and family involvement in nursing activities, in order to become independent of nursing staff and become excellent self-care agents. This is possible in home-based care programmes, especially when the family and other care-givers have been trained in basic nursing skills and referral skills to ensure continued medical care. (Policy Documents on HIV/AIDS: Clinical Care Guidelines for Adults, 1998:159-162)

### **3.4 ADVANTAGES OF HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS**

- ▶ If the sick person is at home, family members can discharge their other responsibilities more easily, and the expense of frequent visits to hospital is reduced.
- ▶ With home-based care prevents the sense of isolation experienced by many people living with AIDS is avoided.
- ▶ Terminally ill persons spend their remaining days in familiar surroundings.
- ▶ Family members and other care-givers gain access to counselling support for themselves, which they need to reduce or overcome the stressful conditions under which they work.
- ▶ Home-based care provides opportunity for a proactive approach, rather than waiting for health or other problems to occur.
- ▶ It allows for targeted education of the client, the family and the community to ensure that people have access to care and follow-up.
- ▶ Ongoing assessment of clients' needs includes assessment of family and various community resources that may be drawn upon to provide care and support for people living with AIDS and their families in their homes.
- ▶ The culture and values of the client, the family and the community are taken into account and AIDS-awareness is created within the community.
- ▶ Care-givers have access to widows, orphans and others who may need psycho-social care.

- ▶ The sick individual gets individualistic and person-centred care with common diseases and conditions effectively managed at home.
- ▶ Home-based care is beneficial to the family and friends, allowing them to spend time with the sick individual and to be involved in home care.
- ▶ It is cost-effective for both the health care system and the patient, the community can provide manpower and other resources and the cost of care is shared between various systems.
- ▶ The client has access to comprehensive, multi-disciplinary care on all levels such as preventative, promotive, curative, rehabilitative and palliative care. (Policy Document on HIV/AIDS: Clinical Care Guidelines for Adults, 1998:159-165)

### **3.5 PSYCHO-SOCIAL STRESSORS ASSOCIATED WITH HOME-BASED CARE**

A person cared for at home may present with a variety of personal and relationship problems such as the following:

- ▶ Loneliness and depression when confined to bed, unable to get out of bed or leave home for recreational activities.
- ▶ Difficulty in understanding instructions on how to take medications and the importance of compliance with a regular medication routine.
- ▶ It may be difficult to pay for the medicine or to afford the costs of travelling to obtain the medicine because of financial constraints.

- ▶ Lack of full understanding on the part of the sick individual about the illness, and the fear of telling the family about any symptoms, fearing their rejection or that the family could become infected.
- ▶ Severe weakness and fatigue which makes the person dependent on others.
- ▶ Relatives may have no time or energy to take good care of the patient and there may be no money to pay for help.
- ▶ There may be no volunteers in the community to assist sick individuals living alone.
- ▶ Uncontrollable pain causes altered sleep patterns leading to depression and anxiety.
- ▶ Intimate sexual relations deteriorate / diminish. Women face the risk of physical abuse if they disclose their HIV-positive status.
- ▶ The effects of medication used can cause alopecia and gastro-intestinal upset like diarrhoea and severe oral thrush (Van Loon, 2000:152, and Policy Document on HIV/AIDS: Clinical Care Guidelines for Adults, 1998:159-165).

### **3.6 EXPLORING HOW CONTINUITY OF CARE FOR PEOPLE LIVING WITH AIDS IS MAINTAINED THROUGH HOME-BASED CARE**

There was no evidence of any research studies done on this topic in the Ilembe Region or Region F. Most of the literature reviewed were mainly from international resources, local newspapers, relevant pamphlets, hand-outs from workshops and symposia.

Reports on the progress of home-based care programmes of the Umlazi Metro Area and other areas within the region providing supervised home-based care programmes are also reviewed and presented in this chapter.

### **3.7 DIFFERENT AUTHORS' VIEWS ON THE PROVISION OF HOME-BASED CARE PROGRAMMES**

Fröhlich (1997:4-5) describes home-based care as care given to individuals in their homes supported by their families, extended families or those carers of their choice. The multi-disciplinary team and complementary care-givers support the sick individuals and their families to meet specific needs. The team consists of all persons involved in care and support, and include the following members:

- Medical practitioners
- Nursing personnel
- Physiotherapist
- Occupational therapists
- Social worker
- Health educators
- Volunteers
- Religious leaders
- AIDS health-promotion workers

The care provided facilitates accessibility to comprehensive holistic care, which is managed and coordinated in accordance with the person's needs. Such care should be comprehensive enough to prevent the occurrence of the following problems:

- Non-compliance with treatment, related to inadequate knowledge on the part of the individual or the family.
- Social isolation related to confinement to bed and home or rejection by the family and friends.

- Diminishing in self-concept, related to withdrawal, weakness and dependency on others.
- Insomnia due to pain and worry about the prognosis of the disease.
- Inadequate knowledge of available community resources and the state of the disease.
- Dependency on others for care, related to economic constraints and care needs.

Nzimakwe (1997:23) states that home-based care is a traditional way of caring for chronic sick individuals. The care-givers are chiefly women, who are family members and health care workers. Very little is known of the type and mode of delivery of health care in the households and the coping abilities of affected families. The author maintains that, to ensure client and family satisfaction with care provided, care-givers need basic nursing education to acquire relevant knowledge and skills in basic nursing care, counselling and communication.

### **3.8 THE UMLAZI HOME-BASED CARE PROGRAMMES**

#### **3.8.1 The Umlazi Home-based Care Pilot Project from April 1998 to March 2000**

Qulo (1998:1-4) describes the Umlazi home-based care programme as a pilot project for chronic and terminally ill clients. This includes those living with HIV/AIDS infection. Initially this project was based in the local hospital 'X'. It was reviewed after eighteen months for its progress. It had the following multi-disciplinary members:

- An AIDS Foundation member supervising the funding and operation of the project.
- Two professional nurses.
- A medical practitioner.
- A social worker.
- An enrolled Nurse.
- An auxiliary Nurse.
- A nurse facilitator working hand-in-hand with fully-trained care-givers on the provision of basic nursing care and counselling.

The care-givers visited the sick individuals at their homes. Weekly, they reported to the multi-disciplinary team at the AIDS clinic of hospital "X" to discuss problems experienced in their caring roles. The statistical reports of all clients cared for were collected and analyzed for future reference. According to Qulo (1998) the number of clients nursed at home increased from 201 to 613 during the period of April 1998 to December 1999.

Qulo (1998:5) further argues that the programme had a good referral system, referring clients to the nearby hospitals, clinics and a hospice for the sick and critically ill clients who could not be managed at home. The increasing client load, as reflected in the data collected by the care-givers, demonstrated a certain degree of commitment to the programme, in spite of a lack of basic equipment for executing caring duties.

Care-givers could not function properly without adequate protective material like latex gloves, plastic aprons and surgical supplies for dressing minor wounds at home. The age group distribution of HIV/AIDS clients nursed at home is reflected in table 3.1.

Table 3.1     Age group distribution of HIV/AIDS clients in Umlazi as from April 1998 - March 1999 - N = 554

Age in years	Numbers	Percentage
15-20	16	2,88
21-26	156	28,15
27-31	128	23,12
32-36	80	14,44
37-41	39	7,05
42-46	24	4,32
47-60	10	1,81
Age not reflected	11	18,23
total	554	100%

(Source: Adapted from Qulo, 1998:4-5)

Table 3.1 reflects that the most affected age groups are between 21-31 years (51,27%) who are youths and young adults. The age group between 47-60 years (1,81%) is the least affected group. It should be noted that the ages of 101 (18,23%) clients were not provided.

During the period of April 1999 to December 1999, the statistics of HIV/AIDS clients identified and followed up through home-based care programmes were as follows:

- ▶ 613 AIDS clients were identified and followed up through home-based care.
- ▶ 30 clients were discovered to be very ill as a result of AIDS-related illnesses like diarrhoea and vomiting, tuberculosis and pneumonia, some with mental confusion.
- ▶ 2 critically ill clients were cared for by the hospice.
- ▶ 87 deaths were recorded.

These figures reflect the high numbers of clients in need of home-based care. (Qulo, 1999:1)

Qulo (1999:4-5) further argued that the home-based care project in Umlazi was terminated in March 2000, because of serious problems which is impeded its smooth functioning. The problems highlighted were as follows:

- ▶ Lack of finance to buy items for the home-based care kits of care-givers which included:
  - surgical sundries, disinfectants, pain killers like Panado tablets.
  - sorol sachets for oral rehydration.
  - protective material, for example latex gloves, plastic aprons, linen savers or disposable napkins.
- ▶ Lack of funds to pay for the care-givers. Care-givers were given only a R300,00 travelling allowance from the AIDS Foundation sponsorship, which was eventually exhausted.

- ▶ Ineffective coordination of the palliative care component which depended upon adequate resources, skills, time, energy and funds.
- ▶ Lack of 24-hour health care services in the community to deal with the symptoms of the acute stages of the disease, that are manageable at primary level.
- ▶ Lack of ownership and sustainability of the programme by the Umlazi community, as the Umlazi Health Forum that managed and conducted the programme became very limited, due to the voluntary nature of the Forum's membership resulting in a high turnover (Qulo, 1999:56).

### **3.8.2 The Umlazi Home-Based Care Programme from July 2000 to date**

The Umlazi home-based care programme that was terminated in March 2000 was revived in July 2000. The AIDS Foundation and Valley Trust Group are the non-Governmental Organizations (NGOs) responsible for funding, coordination and supervision of the projects. The Valley Trust Group provides direct supervision of home-based care through its trained group of community health workers in the entire area of Umlazi. Meetings and workshops are held regularly at the Umlazi Community hall, V-Section by the Valley Trust Group representatives and the community health workers, with the assistance of members from the AIDS Training and Information centre (ATIC).

Discussions with the AIDS Foundation revealed that it is responsible for the funding of the Zimisele Health Group of care-givers at Umlazi. The Umlazi Health Forum has ownership of and is able to sustain its programmes. Membership is still voluntary. The group works in close association with the AIDS clinic staff of the local hospital 'X'. The AIDS Unit clinic staff assist in client identification, and solving the problems of clients and care-givers. There is hope that the Umlazi

community will benefit from the programmes of home-based care presently provided to chronic sick individuals suffering from different illnesses, including HIV/AIDS infection.

### **3.9 HOME-BASED CARE PROVISION IN ONE OF THE NEIGHBOURING LOCATIONS OF UMLAZI**

The researcher made contact with a leader of the community outreach programmes in a hospital outside of Umlazi. This project is reported to provide excellent home-based care programmes in its area. According to the project's leader, the outreach programmes started in March 2000. It is hospital-based comprising of the following team members:

- ▶ Nine (9) trained care-givers who are volunteers.
- ▶ A professional nurse who acts as a mentor and palliative nurse.
- ▶ A doctor who monitors the provision of home-based care and refers clients to the professional nurse of the outreach programme on discharge for follow-up through home-based care programmes.
- ▶ A management committee responsible for drawing up training programmes for care-givers and all managerial duties.
- ▶ An accountant responsible for all financial affairs, like control of any funds donated for the provision of home-based care.

The team workers jointly with the staff members of the outreach centre which provides the following:

- Training in home-based care and counselling.
- Management and administrative skills.
- Coordinates and supports community-based projects including HIV/AIDS awareness projects.
- Encourages orphan-care through extended family care.

Care-givers in this community outreach programme provide care to everyone who is sick and nursed at home. Very sick clients with problems are referred to hospital and clinics for further management.

At present, care-givers in this community outreach programme do not receive any incentives. Reports on clients seen are written by care-givers using prepared formats. Formats are written in English and Zulu. They are forwarded to the hospital's home-based care team for statistical analysis and record keeping for future reference. Clients on the Directly Observed Treatment for treating tuberculosis are also supervised by care-givers and their family members. Some clients nursed at home have extensive sores. Care-givers assist clients and their families in the cleaning and dressing of sores aseptically.

Care-givers are provided with kits donated by donors like the Catholic Medical Board. Each kit bag has the following items.

- Disposable gloves and towels
- Plastic Aprons x 3
- Kleenex tissues
- Bubble washing soap
- Lanoline cream

- Packets of sterile gauze swabs
- Band-Aids and adhesive tape
- A pair of Scissors
- Pansenet combined sterline compressa bandage for extensive wounds
- Jik
- Bandages of different sizes
- Mini-wound bandages
- Woodeh spatulae
- Betadine cream
- Plastic forcep

The kit allows the care-givers to perform their caring roles effectively and guarantees their protection from being infected.

Kitbags are replenished using the top-up system, in Hospital 'Y's' department responsible for that function. Care-givers are taught to use Jik 100 mls to 400 mls of water as a disinfectant for the cleaning of bandages and the environment.

According to hospital 'Y's' statistical report, the figures of HIV-positive people from April to September 2000 were as depicted in table 3.2

**Table 3.2**      Number of people who had HIV-Positive results

Month	No. of people tested	No. Positive	Percentage
April	235	167	71,06%
May	259	188	72,58%
June	251	172	68,52%
July	265	198	74,71%
August	309	202	65,37
September	249	180	72,28%
<b>TOTAL</b>	<b>1 568</b>	<b>1 107</b>	

(Hospital 'Y's' handout on HIV/AIDS tests - April to September 2000)

Table 3.2 reflects that large numbers of people are HIV-positive. In spite of the high numbers of people who tested HIV-positive from April to September 2000, according to the statistical report on people nursed at home by care-givers, none of the clients have openly revealed their HIV-positive status to care-givers. The secrecy surrounding HIV-positive status had an impact on data collection for this study. Very few people freely agreed to participate in this study in the Umlazi area.

In its activities the home-based care team of hospital 'Y' is guided by its institution's admission and discharge policy which aims at early identification of clients admitted who are suitable for discharge and home-based care in its activities. Hospital beds are created for acutely ill clients in need of oxygen therapy, nebulisation, parenteral therapy, naso-gastric feeding and other complicated diseases like milliary tuberculosis. Medically stable clients with access to home-based care are discharged early via the leader of home-based care outreach programmes (HIV/AIDS Admission/Discharge Draft II 2000 Policy of Hospital 'Y').

### **3.10 HOME HEALTH CARE PROVIDED BY ONE OF THE PRIVATE TEAMS OF HEALTH CARE SERVICES IN THE DURBAN AREA**

The term "Home Health Care" describes a system in which health care and social services are provided to home-based or disabled people in their homes rather than in medical facilities (Brochure of Quality Health Care Services - June 2000).

Swanson and Nies (1995:798) define home health care as a component of the continuum of comprehensive health care. Health services are provided to individuals and families in their place of residence for the purpose of promoting, maintaining or restoring health, or maximizing the level of independence while minimizing the effects of disability and illness, including terminal illness. Services

appropriate to the needs of an individual patient and family are planned, coordinated and made available by home health care providers. Home health care utilises full-time staff, contractual arrangements or a combination of the two.

Home health care provided by Quality Health Care Services aims at creating an environment where the patient and the family can manage chronic illness and move towards recovery or stabilisation, thus avoiding or reducing the need for hospitalisation. These services are provided by a team of registered nurses, physical therapists, occupational therapists, home-care aides and social workers. Services provided to meet clients' needs are as follows:

- Medication supervision and instruction
- Diabetes education
- Catheter care and paediatric care
- Cancer care
- Maternal and newborn care
- Hospital assessments before discharge
- Assistance with activities of daily living
- Tuberculosis management / family instruction and follow-up
- Wound care and dressings
- Psycho-social support to the family and the client
- Physiotherapy and occupational therapy
- Home-based care for people with AIDS.

The normal working hours are from 07:00-17:00. After-hours services are provided whenever there is a need through a call system. However, the researcher however, could not get any information from this agency on follow-up on HIV/AIDS clients cared for in their homes as stated in the brochure. In the researcher's opinion, this may be related to the secrecy surrounding AIDS issues (Brochure on Quality Health Care Services - June 2000).

According to Swanson and Nies (1995:798-9), providing home care services contributes to cost containment in a managed environment. This is accomplished through timely hospital discharges, with nursing services provided in the home setting. Home care is popular to consumers of health services who prefer to receive care in their homes rather than in hospital. These authors further argue that home health nurses visit acutely ill clients, people living with AIDS, elderly people, the terminally ill clients, ill infants and children as well as high risk pregnant women and others. Home visiting is a specific nursing intervention which is an ongoing process.

### **3.11 COPING STRATEGIES OF FAMILY MEMBERS AND OTHER CARE-GIVERS WHEN CARING FOR A SICK INDIVIDUAL, WITH PARTICULAR REFERENCE TO PEOPLE LIVING WITH AIDS**

According to Alexander *et al.* (1994:898-910) the relatives of a person with HIV/AIDS infection become perplexed. They react in different ways with different coping strategies.

- ▶ Some family members distance themselves from the sick individual especially if there is a history of homosexuality or prostitution on the part of the individual.
- ▶ A complete breakdown of relationships occurs in some instances, which often results in desertion.
- ▶ Most families keep silent and manage conflict among themselves for fear of victimisation.
- ▶ There is usually a shift in family roles to overcome the disruptions in family lives and interpersonal interactions.

- ▶ Planning for the future is based on short-term objectives because of the disruptive nature of the disease.
- ▶ The individual and the family try hard to adapt themselves to the uncertainty of the course of the disease which often result in physical and psychological pain and stress.
- ▶ Where more than one member of the family is affected, the remaining members experience a severe strain on household savings. This usually results in children leaving school and being exposed to labour exploitation.
- ▶ Older children, especially those with single parents, may be left to run their households and take care of their sick parent/s as she/they slowly approach death.
- ▶ A family member may be forced to take up a very low-paying job, or become involved in crime, so as to obtain funds to pay for the sick individual's rent or bills, anti-retroviral and other drugs as well as food.
- ▶ In some families, when the husband dies of AIDS-related illnesses, the widow and her younger children become dependent on a husband's male heir for support under customary arrangements.
- ▶ Families, with their extended family members and relatives, often come together and assist each other in complying with the social norms regarding burial ceremonies, which entail large financial outlays and strict attendance requirements.
- ▶ Some family members have to give up their jobs to take care of the sick family members.

### **3.12 TRAINING OF FAMILY MEMBERS ON HOW TO TAKE CARE OF A SICK INDIVIDUAL WITH HIV/AIDS**

According to the Policy Document on HIV/AIDS (1998:183) family members need to be trained to take care of the sick client. They should know when to call upon the assisting home care-giver if problems arise. The benefits of training the family members are listed below:

- ▶ Family members acquire the information they need with regard to the prevention of anti-infection or cross-infection.
- ▶ They learn about the type of diet and nutritious foods to prepare, as well as maintenance of good personal hygiene and that of the environment.
- ▶ The family becomes less afraid of being infected and assists the sick person as much as possible.
- ▶ They feel more confident because they are able to help themselves and their family members.
- ▶ They recognise danger signs and learn when and how to seek more help.
- ▶ The sick individuals receive better care and love.
- ▶ The family members willingly organize their own resources and those available to them in the community.
- ▶ Family members encourage the sick individuals to lead as normal and satisfying a life as possible.

### **3.13 ASSESSING THE NEEDS OF THE SICK INDIVIDUAL NURSED AT HOME USING THE FUNCTIONAL, INSTRUMENTAL AND 'PULSES' PROFILE ASSESSMENT TOOLS**

Robert and Rakel (1990:342-343) describe the daily assessment of any terminally ill client nursed at home, using the Functional, Instrumental and 'Pulses' profile guide. The acronym 'Pulses' stands for assessing the following aspects:

- P - Physical and general health status of the sick individual.
- U - Upper limbs functioning, with ability to perform self-care activities like feeding and bathing.
- L - Lower limbs functioning, for example the ability to walk or move from the bed to a chair.
- S - Sensory functioning, assessing sight, hearing and the ability to communicate.
- E - Excretory functioning assessment for incontinence of urine or diarrhoea, and provision of appropriate care.
- S - Support system available to help the sick individual and the family, for example social workers, volunteers and nursing personnel.

#### **3.13.1 Functional Assessment**

Functional assessment, according to these authors, considers Activities of Daily Living. The sick individual is assessed on the ability to perform the following:

- Ambulate with or without support.
- Toilet needs with regard to normal bowel action, constipation, diarrhoea and ability to go to the toilet.
- Grooming: with regard to combing hair, brushing teeth, cutting nails, dressing and undressing properly.
- Feeding: ability to eat unassisted or a need to be fed, and type of food tolerated by the sick individual and also catering for clients' requests for preferred food.
- Bathing and changing of position in bed, to ensure good personal hygiene and prevent the development of pressure sores.

### 3.13.2 Instrumental Assessment

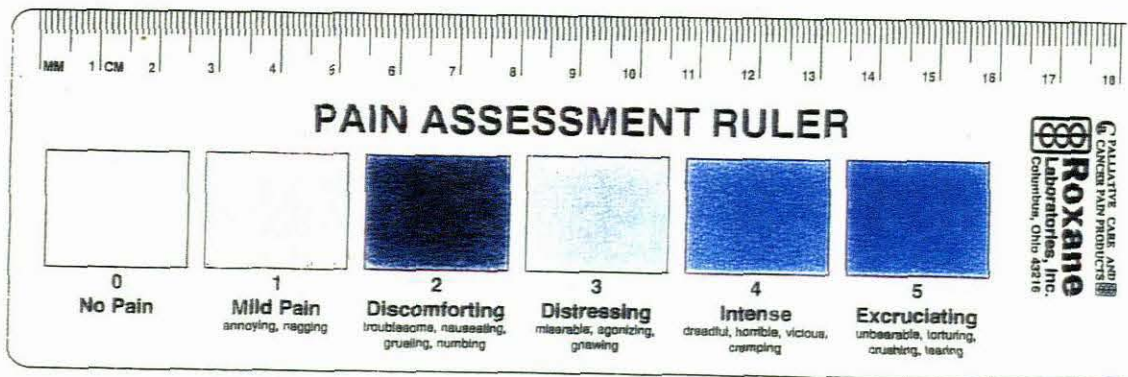
Assessment of this aspect considers the sick individual's ability to perform the following activities:

- Continue with household chores like cooking.
- Manage financial aspects like paying rent bills, school fees, food, stores' accounts.
- Writing, with regard to responding to personal letters and official documents.
- Ability to travel outside home without a companion.
- Ability to read and communicate telephonically.

Robert and Rakel (1990:344) commented that assessment of clients' needs is important even at home. Problems are identified early and prompt action taken to relieve symptoms of the disease. Clients in need of assisted breathing through oxygen therapy may be rushed to hospital on time. Critically ill ones who cannot be nursed at home, may be transferred to a hospice if available and affordable, to ensure that they die a dignified death.

### 3.14 PAIN ASSESSMENT AT HOME FOR PEOPLE LIVING WITH AIDS USING THE PAIN ASSESSMENT RULER

Figure 3.1 The Pain Assessment Ruler: by Roxane Laboratories, Inc. for Palliative Care and Cancer Pain



(Source: Swanson & Nies, 1995)

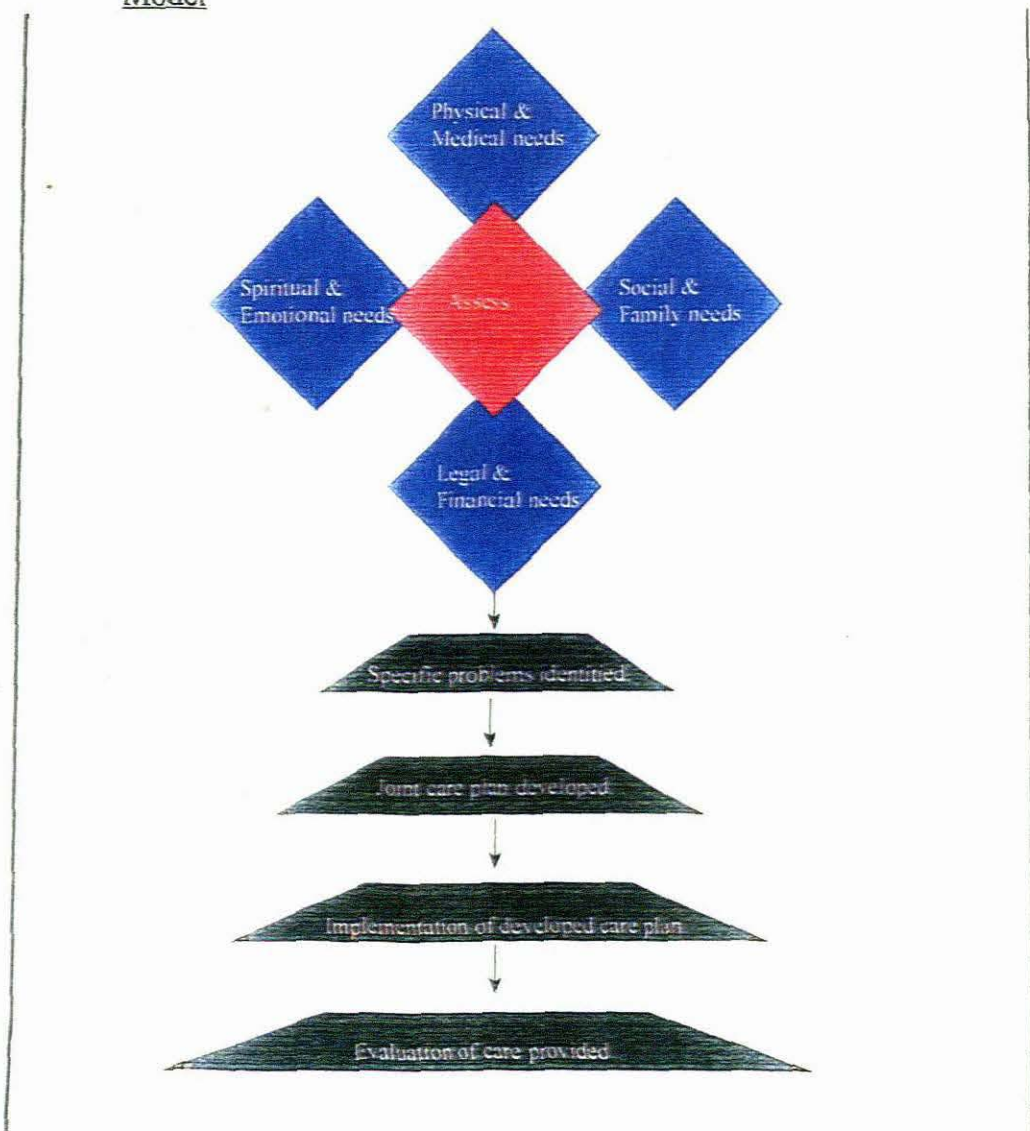
Key to coding:

- 0 - White or no pain
- 1 - Light grey indicating mild pain
- 2 - Dark grey indicates discomforting pain
- 3 - Light blue indicates distressing pain
- 4 - Blue indicates intense pain
- 5 - Deep blue indicates excruciating pain

Pain is subjective and very difficult to assess. Figure 3.1 is the scale for pain assessment which uses both colours and words. This scale is appropriate for use with very ill HIV/AIDS clients who cannot read, or have difficulty to verbalise the experienced type of pain. The care-giver must understand and be able to explain clearly to the client how this ruler operates.

### 3.15 HOME-BASED CARE MODEL ACCORDING TO THE WORLD HEALTH ORGANIZATION (WHO)

Figure 3.2 WHO's Home-Based Care Holistic Assessment and Care Plan Model



(Adapted from WHO, 1993:9 in AIDS Home Care Hand Book)

WHO (1993:9) produced a home-based care model presented in a modified form in figure 3.2. According to WHO (1993:9) a home-based care model should consist of trained volunteers who form the frontline of care for the terminally ill clients who prefer to be nursed at home. This model involves community empowerment with knowledge and skills in basic nursing of the terminally ill people at home.

AIDS clients are prone to sudden onset of opportunistic infections and intense pain which require ongoing assessment of needs and proactive action to relieve symptoms of the disease and other associated problems. The care-givers should be observant of their clients' physical and medical needs, spiritual and emotional needs, social and family needs, legal and financial needs. Through the joint effort of the clients concerned, their families and multi-disciplinary team, identified problems are analyzed, and plan of action taken to resolve them. All levels of care i.e. preventative, promotive, curative, rehabilitative and palliative care should be made available to people living with AIDS and those already ill (WHO, 1993:9 and Policy Document on HIV/AIDS, 1998:165-6).

### **3.16 QUALITIES OF FAMILY OR NON-FAMILY CARE-GIVER OF PEOPLE LIVING WITH AIDS**

Ewan (1993:193) describes care-giver's qualities as follows:

- ▶ Care-givers should be easily and readily approachable regarding any problems or concerns.
- ▶ A care-giver must be a person who is always available, confident and competent in her work.
- ▶ She should show empathy and sympathy towards sick individuals and the family.

- ▶ She should be a good listener, always attentive to the sick individual's needs and concerns.
- ▶ A person who shows genuine interest towards her clients and would "pop in" at regular intervals to give assistance whenever necessary.
- ▶ A person respected in the community who is accepted by the sick individual and the family.
- ▶ A trustworthy person who is capable of maintaining confidentiality where necessary under pressure with greater understanding of the feelings of a person living with AIDS.
- ▶ A person who is able to dispel fears and misconceptions about the disease amongst family members and the client.
- ▶ A person who facilitates behaviour change through sensitizing the individual and family.
- ▶ She/he is able to conduct ongoing assessment of the client's needs and act promptly to overcome problems.
- ▶ She/he provides relief from pain and other disturbing symptoms.
- ▶ She/he integrates the psychological and spiritual aspects of care.
- ▶ A care-giver assists the family and the sick individual to cope with illness, through the dying process and in bereavement.

### **3.17 HOPE AS THE MOTIVATING FORCE FOR SURVIVAL OF PEOPLE LIVING WITH AIDS**

WHO (1993:11) describes hope as a belief of living a longer time, sustained through:

- dealing with sickness as it comes.
- continued acceptance and love by family members and friends.
- the assurance that the sick individual's children will be cared for by the family, friends and the state after death.
- the hope of scientists eventually finding a cure for AIDS and a vaccine for the non-infected individuals.
- the hope of life after death.

Hope gives the individual power, motivation and a positive self-concept in spite of knowledge of approaching death. Effective application of coping strategies and power resources already discussed in chapter two of this report adequately help the individual to achieve the following:

- Enhanced self-esteem.
- Further generation of hope.
- Relationships with others are maintained.
- Wellness state is maintained or improved thereby prolonging one's life-span through God's help.

**Table 3.3** AIDS Orphans in Sub-Saharan countries as at the end of 1999

Country	No. of AIDS Orphans
Uganda	1 700 000
Nigeria	1 400 000
Ethiopia	1 200 000
Tanzania	1 100 000
Zimbabwe	900 000
Kenya	730 000
Democratic Republic of Congo	680 000
Zambia	650 000
Cote d'Ivoire	420 000
South Africa	420 000
Malawi	390 000
Mozambique	310000
Swaziland	12 000
Equatorial Guinea	860

(Source: Report on Global HIV/AIDS epidemic - June, 2000:124)

Table 3.3 reflects that Sub-Saharan countries have high numbers of AIDS orphans, especially those countries which were hard-hit by AIDS in the early years (the 1980s), like Uganda, Nigeria, Ethiopia, Tanzania, Zimbabwe and others.

The number of AIDS orphans in South Africa appears to be increasing and the country is faced with the challenge of providing a continuum of care to meet all the orphaned children's developmental needs as described in table 3.3.

**3.18 DESPERATION OF AIDS ORPHANS AND THE IMPACT ON FAMILIES AND SPECIFIC ORGANIZATIONS**

According to UNAIDS (1995:5) Africa is experiencing a growing tide of children living in AIDS-affected households. Some are struggling to survive after the death of their mother or both parents. Often, the extended family itself, reduced by AIDS-related deaths, fails to cope with the demand to care for the orphans. The grieving children struggle hard without parental care to survive.

Specific organizations like the Durban Children’s Society provide help for the orphaned children through linking with resources, such as Family Preservation, support groups for adults and children, People Living with AIDS groups, home-based carers, capacity building, support of child-headed households, adoption, and foster care and in many ways described in this chapter (which shows a continuum of care for AIDS orphans as recommended in the Interim Policy (of November 1996) of the South African Ministry of Welfare). The statistics of AIDS orphans are presented in table 3.4.

Table 3.4      The number of AIDS orphans as at the end of 1999 worldwide

Global total orphans accumulative	13 200 000
Sub-Saharan Africa	12 100 000
East Asia and Pacific	5 600
Australia and New Zealand	<500

(Source: Global HIV/AIDS Epidemic, June 2000:124)

According to Table 3.4 the Sub-Saharan Africa has very high numbers, approximately 13% (92) of the global total orphans accumulative.

Item 3.18:

Continuum of community care for orphaned children in South Africa is shown in item 3.18. The comprehensive continuity of care for children is clearly shown in table 3.5

Table 3.5 Continuum of community care: the orphaned children

To meet Children's Developmental Needs (i.e. Practical; Material; Emotional; Educational; Recreational; Legal; Cultural and Religious)

LEAST RESTRICTIVE		MORE RESTRICTIVE				
		←----->				
		LEVEL 2	LEVEL 3		LEVEL 4	
RAPID REFERRAL (Early Identification)	FAMILY PRESERVATION (In-home Support)	KINSHIP CARE (Extended Family)	COMMUNITY CARE (Job Creation ?)	STATUTORY PROCESS	ADOPTION (Permanent Alternative)	FOSTER CARE (Short or Long-term)
<ul style="list-style-type: none"> <li>Linking and development of Partnerships</li> <li>Home-based Carers</li> <li>Primary Health Clinics</li> <li>Hospitals</li> <li>PWA Support Groups</li> <li>Counselling Services</li> </ul>	<ul style="list-style-type: none"> <li>Psychosocial Support</li> <li>Capacity Building</li> <li>Linking with available Resources</li> <li>Day Care &amp; Schools</li> <li>Health Services</li> <li>State Grants</li> <li>I.G. Grants</li> <li>Material Assistance etc.</li> </ul>	<ul style="list-style-type: none"> <li>Identification and Assessment</li> <li>Setting-in &amp; Capacity Building</li> <li>Support of Child-headed Households</li> <li>Linking with Resources (as with Family Preservation)</li> <li>Support Groups (Adults and children)</li> </ul> <p>(May become part of the Foster Care System)</p>	<ul style="list-style-type: none"> <li>Surrogate Parents</li> <li>Peripatetic Parents</li> <li>Shared Care</li> <li>Community Children's Committees</li> <li>Coordination</li> <li>Capacity Building</li> <li>Developing Resources</li> <li>Linking with Resources (as with Family Preservation)</li> </ul>	<ul style="list-style-type: none"> <li>Including Crisis-Family Care</li> <li>pending</li> <li>Investigation</li> <li>and</li> <li>Assessment</li> </ul>	<ul style="list-style-type: none"> <li>Adoption of Babies and Children with Special Needs</li> <li>Community-based Identification/Recruitment</li> <li>Assessment and Capacity Building</li> <li>Linking with Resources</li> <li>Cross-cultural and other Minority Group Adoptions</li> <li>Undisclosed Infant Adoptions</li> </ul>	<ul style="list-style-type: none"> <li>Community-based Recruitment &amp; Assessment</li> <li>Community-Based Monitoring</li> <li>Capacity Building</li> <li>Foster Care Support Groups (Foster parents &amp; Children)</li> <li>Linking with Resources</li> <li>"Special Needs" Foster Care (e.g. AIDS infants/children)</li> <li>Community-Family Care (6 children in Community)</li> </ul>

Extended by Durban Children's Society's "Co-ordinated Orphan Response" from:  
 (Source: Interministerial Committee on Young People at Risk: "Continuum of Care for Children and Youth." Interim Policy Recommendations (Nov. 1996); S.A. Ministry for Welfare)

Table 3.5 reflects that the comprehensive continuity of care of orphans is maintained through adequate early identification of children in need of care, organizing of in-home support by involving extended family members where possible for placement of children, according to applicable laws. Children may be placed for foster care, adoption, or admitted in an orphanage according to Child Care Act 1974 (Strauss, 1987:187).

According to Stein (1998:40) traditional orphan care through extended families is under unsustainable strain in countries like Uganda, Zimbabwe, Ethiopia, as well as South Africa. Children are taken care of by relatives, some end up being domestic slaves, while others are placed in orphanage institutions. These children never get the benefits enjoyed by other children, for example good education, nutrition or proper socialisation and love.

Mathaba and McGlew (1991:1) warned that orphaned children represent a growing young community of people of 15 years and below, left alone in a cold world because of the death of parents due to AIDS.

Hilton-Barber (2000:12) reported that over three million orphans are expected in South Africa in the next decade. Some of these children are on the streets and this makes the statistical reports inaccurate. The author further argues that, without proper planning for a proper support system, accommodation and education for these children, South Africa will find itself being ruled by a generation which grew up on the streets, in youth camps or institutions. These children may become dysfunctional adults with no experience of parental love, family bonding or formal education.

According to a report on global HIV/AIDS epidemic (June, 2000:28), AIDS orphans are at a greater risk of malnutrition, illness, abuse and sexual exploitation than children orphaned by other causes. These orphans grapple with the stigma

and discrimination so often associated with AIDS which often deprives them of basic social services and education. Family structures in developing countries fail to cope as young parents die leaving their children with grandparents, or the children are left on their own in child-headed households.

In Malawi, the government decided on the support of community-based programmes and has had a National Orphan Care Task Force since 1991. Child-care centres have been developed to improve the care of children and increase their learning opportunities.

In Zambia, non-governmental organizations are working hard to fill gaps by providing food, clothing and school fees to orphans and their families.

In Uganda women started an organization known as the Uganda Women's Effort to Save Orphans (UWESO). This organization assisted orphans in the settlement camps and returned them to their extended families. UWESO has 36 branches worldwide. It has funded education and training for orphaned children, runs a micro-finance scheme to help the children's care-takers and assists interested groups with the starting of a small business and trading activities (UNAIDS, 2000:28).

In Zimbabwe, about 7% of all children under 15 years are orphaned by AIDS. A National Policy on the care and protection of orphans has been developed, which advocates that orphans should be placed in institutions as a last resort and be cared for by the community wherever possible. According to the report on Global HIV/AIDS epidemic (Jun, 2000:124) there are approximately 900 000 orphans in Zimbabwe. A survey at the beginning of 1996 estimated 2.1 orphans per farm on commercial farms. The number of orphans has increased to about ten (10) per farm in 1999. The average age of these children is ten (10) years, and they are struggling to survive without parents.

The farm owners showed concern about the welfare of their workers and their families and supported the initiatives to care for orphans on their farms. Most of these initiatives centred on finding other farm families to foster abandoned children and orphans. This has been very difficult since many people believed that orphaned children would bring bad luck in their families (WHO Fact Sheet 1999:7).

In South Africa, there is a coordinated orphan response under special organizations like the Durban Children's Society in KwaZulu-Natal, which aims at meeting the children's developmental needs, i.e. practical, material, emotional, educational, creational, legal, cultural and religious needs. This organization is in favour of linking in-house and extended family support for orphaned children as a means of family preservation, rather than the institutionalised care of orphans.

There are foster care support groups who support the foster care of children, Resources such as day care facilities, educational schools, health services and state grants are facilitated through the Durban Children's Society. The child-headed households are supported and supervised to improve capacity building of the members of these households. Crisis Family care and thorough assessment of how to meet the needs of children with special needs, i.e. AIDS infants and children, are ensured (Interim Policy Recommendations, S.A. Ministry for Welfare, November 1996).

Hilton-Barber (2000:12) stated that South Africa lacks the resources to cope with increasing AIDS orphans. The existing foster homes are just the tip of the iceberg. The author advocated a more effective joint effort in the fight against AIDS, and control of orphaned children and their relatives. The orphaned children present a serious crisis which is already starting to spiral out of control.

The information on AIDS orphans reveals the impact of HIV/AIDS infection on individuals, families and care-givers. They have to cope with the taking care of

young orphans or ill parents who have very young children dependent on others for their living in a home setting. It also highlights the role played by special organization to alleviate the problems e.g. the Durban Children's society of KwaZulu-Natal Province.

### **3.19 CARE OF AIDS ORPHANS IN CHILDREN'S HOME 'X' OF DURBAN**

According to a key person of the children's home, this children's home is registered to accommodate 200 children at any one time, from birth to eighteen years. Not all of these orphans are HIV-positive. Only 37 are HIV-positive, and 16 have developed full-blown ADS. Children mix freely but all their activities are well-supervised by dedicated staff. There are about 83 staff members, excluding members of the cleaning company.

Children are roomed according to their ages, as follows:

- 0-1 year are neonates nursed next to supervisors' offices.
- 1-2 years are nursed in nursery wards or rooms.
- 2-3 years are junior toddlers.
- 3-5 years are pre-scholars.
- A 14-bedded Special Care Unit for the terminally ill.

There is an internal preschool under the Department of Education. Children from 6-18 years attend local schools. A pass rate of 94% was achieved by the 72 children who wrote the end-of-year examinations in 1999.

On admission children are screened for Hepatitis B, Pulmonary Tuberculosis and any other infectious diseases in preparation for fast adoption procedures. The child is then sent to any of the three local hospitals they use for physical

examinations by doctors. Immunisations are done at City Health Department clinics. Ongoing counselling is provided to staff and children within the orphanage.

The HIV-positive children fall sick often and rapid recovery is dependent on individualised attention and love. They often present with feeding problems like anorexia and need to be fed slowly. The need for volunteers to help with the caring roles is great. It is reported in the Durban Children's Society annual report (2000:9) that forty volunteers helped in 1999. These children need a lot of fresh air and volunteers are encouraged to take the children for visits.

### 3.19.1 Prophylactic treatment given to children with HIV/AIDS infection

The children are given the following standardised prophylactic treatment:

- Multivitamin daily
- Bactrim 3 times a week on Monday, Wednesday and Friday
- Moducare as prescribed by doctor

The researcher believes that the members of staff in this institution are able to cope with children's needs when they are ill since there are 83 staff members, 200 children and only 37 who are HIV-positive and 16 with full-blown AIDS. Volunteering members also assist with caring roles.

### 3.20 HOSPICE CARE FOR THE TERMINALLY ILL AIDS PATIENTS

According to the Highway Hospice Association brochure, a hospice provides care for patients with a terminal illness, and support to their families. It is a medically directed, nurse coordinated programme: both the at-Home and In-care Unit. It

focuses not only on the physical aspect of an individual, but also on the psychosocial, spiritual and cultural needs of terminally ill patients.

### 3.20.1 Home-care services

Most patients are cared for in their own homes. A team of compassionate, caring, home-care nurses and volunteers look after the sick individuals. The team is coordinated by a professional nurse with a speciality in hospice care. Patients are visited in their own homes regularly and according to need, and they are offered support, pain and symptom control, encouragement and information necessary for both patients and their families.

Patients are encouraged to remain at home in the care of their own doctors and family members. The hospice compliments this care with specialised support and advice. Patients are encouraged to lead the team of carers and make their own decisions. A back-up system is provided by the Medical and Social Work departments. All services are provided free of charge, except the salaries for private nurse aids and medicines obtained for the patients' own use.

### 3.20.2 Available services to sick individuals

The following services are made available to those in the community with sick relatives:

- ▶ A 24-hour telephone service.
- ▶ Equipment is available on loan to home-care patients.
- ▶ Once or twice a week a day centre is open for recreation and fellowship which provides the following:

- It relieves the family members of the strenuous caring roles by giving them time to catch up on other tasks, run errands or just have some time to themselves.
- Hairdressing and beauty therapy is available during the day and a social luncheon is provided to encourage patients to meet and socialise.
- Patients' self-care needs are evaluated by the occupational therapist and recommended specialised equipment or techniques to help the patient remain as independent as possible, is available.
- Spiritual support ministers from different religious denominations.
- Aromatherapy massage with scented oils serves to help relieve pain and stress.
- Nutritional support in the form of a morning tea and a delicious lunch.
- Enjoying a variety of activities which include arts and crafts and other entertainment.
- Provision of meals for family members who visit at a nominal charge.

These services are not available for the Umlazi community.

### 3.20.3 Extended Hospice Facilities

Community hospices are in demand, and an outreach programme into the disadvantaged communities has been launched. Ongoing assessment and management of patients to improve their self-worth and their ability to cope with

their activities of daily living is undertaken. Social care continues after death into the bereavement stage. Recently bereaved families are supported by support groups (Highway Hospice Association of Natal Brochure).

### **3.21 DISCLOSURES AND NARRATIVES OF PEOPLE LIVING WITH AIDS**

AIDS evokes severe emotional reactions, including fear and anger, which are described in narratives by the following individuals, extracted from writings of different authors:

- Adams (1989:21) revealed his own reaction to HIV/AIDS diagnosis. He described the impact of his HIV/AIDS status as a "Mourning process with a code of Silence". This forced him to silence for months without speaking to anyone. To him, it was the beginning of a new life, with a shaky, emotional instability, marked by suicidal episodes. However, he stated that the ongoing counselling facilitated acceptance of the condition, and provided a challenge for improvement of his quality of life, with no time for arguments. He was loved and supported by family members.
- Gregg (1993:51-52) he had haemophilia. He revealed how he contracted AIDS through blood transfusion. He longed to know how long he would live, as he had experienced various chronic illnesses since birth. He lost his job because of poor health and became more dependent on family members. Eventually he accepted death as a normal end for everyone, with the support of family members and friends. He no longer felt lonely and tense but continued with college studies but he did not live to graduate.
- Cameron (1993:72) related Carlos's testimony of his suffering and loss through AIDS. Over a period of three months, Carlos wrote five letters describing how wonderful it was to be loved by people and God, in spite

of the HIV/AIDS-positive status. He described 'love' as the foundation of 'hope'. Love heals grief, gives strength, understanding and emotional release, which makes room for reassurance and awareness. Hope had been the key to the attainment of coping strategies already described in this study. Hope helped him to prepare himself for a peaceful death as the disease progressed. Carlos died a peaceful death, loved by his family and those close to him. He died still hoping that a cure for AIDS would be found that would save the nation.

These narratives and many others not included in this study, confirm the importance of support, love and acceptance of a person living with AIDS, by others. The sick individual and family members both experience stress, fear, guilt and have instincts with internal values to help and protect each other. People tend to listen to a story of someone infected versus an educator's point of view. What a person living with HIV/AIDS says, is more acceptable than what a non-infected person says.

### **3.22 CONCLUSION**

This chapter highlighted the importance of a well-supported home-care programme that meets the different needs of a patient with a chronic illness, especially AIDS-related diseases. A home environment is seen as the best place when nursing a terminally ill patient, as described in this chapter.

## **CHAPTER 4**

### **4.1 THEORETICAL FRAMEWORK**

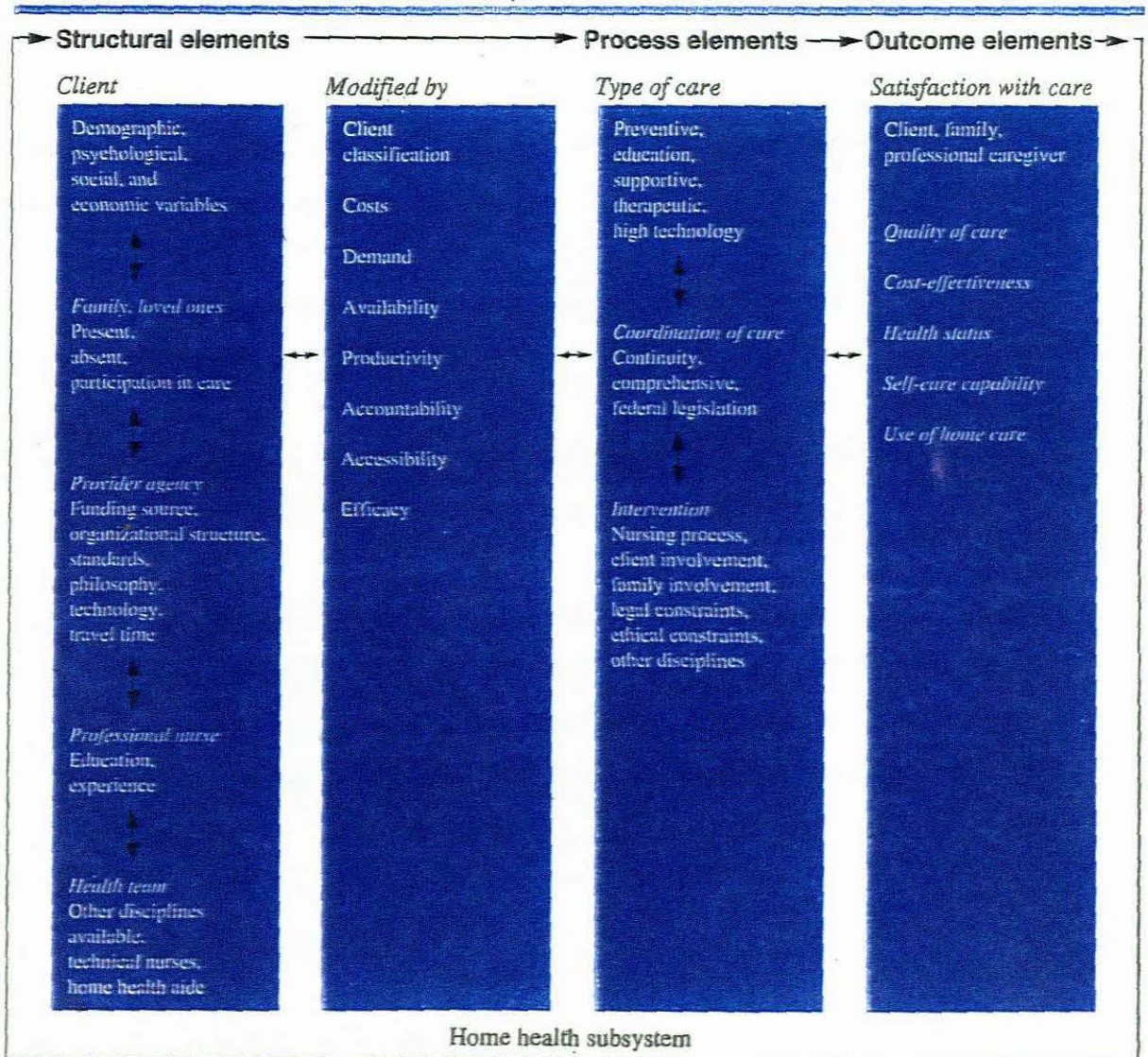
#### **4.1.1 Introduction**

In this chapter, the theoretical framework on which this study is based will be explained. The study is based on the work of three theorists namely: Albrecht's Nursing Model for Home Health Care, Orem's General Theory of Nursing and Adam's Conceptual model for Nursing. These theorists have devised workable models for planning care for all those in need of health care assistance, to achieve the desired outcomes of providing quality care and greater patient satisfaction with the care provided. The relevance of these theoretical frameworks to the study will be highlighted in this chapter.

### **4.2 AN OVERVIEW OF ALBRECHT'S NURSING MODEL FOR HOME HEALTH CARE**

Albrecht's Nursing model for Home Health care provides a framework within which nurses, patients and their families can interact to identify the mutual goals of intervention and promote the self-care capabilities of the sick individual at home.

Figure 4.1 The Diagrammatic Representation of Albrecht's Nursing Model for Home Health Care



(Source: Swanson and Nies, 1995:807)

Figure 4.1 of Albrecht's Nursing model for Home Health care describes how its three major elements affect client care at home.

According to Albrecht (1990), cited in Swanson and Nies (1995:806), three major elements are used to measure the quality of care at home. These elements are described as follows:

#### 4.2.1 The Structural Elements

Comprising the client who needs holistic care, i.e. psycho-social, physical, spiritual and economic support.

- The family members, other care-givers and special loved ones who participate in the caring roles.
- The health care provider agency which may be a hospital, clinic, hospice, non-governmental organization or community support groups.
- The availability of 24-hour health care services which are within walking distance to a greater majority of clients, which provide high standards of nursing care based on a sound philosophy, using the latest technology which meets clients' demands, is cost-effective and approved by clients as efficient.

#### 4.2.2 The Process Elements

The Process elements include three components namely:

- The type of care - which refers to preventive, educative, supportive, therapeutic and use of high technology.
- Coordination of care - this refers to the nurses' role as care-giver who coordinates care provided by other members of the health team to ensure its comprehensiveness as directed by the legislation of the country.

### The intervention

According to Albrecht (1990), in Swanson and Nies (1995:807), a nursing process approach should be used which involves:

- assessment of clients' needs/data collection
- analysis of data
- planning type of care to be implemented
- implementation of the drawn care plan
- evaluation of care provided
- recording of the process

Providers of care should observe the following when implementing intervention strategies:

- Client and family involvement in the caring roles.
- Explanation to client and family of the importance of involving other disciplines in the caring roles.
- Observation of legal and ethical constraints.

#### 4.2.3 Outcome elements

This is concerned with satisfaction with care for the client by the client, family and professional care-givers. Care provided to be accepted as of high quality and cost-effective care which improves the health status of the client and self-care capabilities through the use of home care and education.

According to this model, positive outcome elements are determined by adequate structural and process elements. The quality of care is an especially important variable, because it may reflect the elements constituting a home care agency and the care given. The agency, if any, providing home care services should give support to clients and care-givers. It should also teach them the needed skills in providing basic nursing, assessing economic and psycho-social needs of the clients which may impair the clients' ability to cope with the stresses associated with the illness.

Albrecht (1990), in Swanson and Nies (1995:907), stressed that families are a major part of home care, and need support. The right combination of structural and process variables can produce a high degree of self-care capability.

#### **4.3 OREM'S GENERAL THEORY OF NURSING**

Orem had an intuitive insight into why individuals required and could be helped through nursing. Her knowledge of nursing practice situations acquired over many years motivated her to formulate and express her concept on General Theory of Nursing (Marriner-Tomey, 1989:119).

According to Orem (1985), cited in George (1990:192), nursing has as its special concern the individual's need for self-care action, the provision and management of care provided on a continuous basis in order to sustain life and health, recovery from the disease or injury and coping with their effects. Orem developed her general theory of nursing in three related parts, namely:

- The Theory of Self-care
- The Theory of Self-care Deficit
- The Theory of Nursing Systems

#### 4.3.1 The Theory of Self-care

According to George (1990:92), Orem's theory of self-care includes self-care, self-care agency and therapeutic self-care demand and self-care requisites.

##### 4.3.1.1 Definition of concept of self-care theory

- ▶ Self-care - is the practice of activities that individuals imitate and perform on their own behalf in maintaining life, health and well-being. Self-care, when effectively performed, contributes to the regulation of human structural integrity, human functioning and human development.
- ▶ Self-care agency - refers to the individual's ability to engage in self-care. This is dependent on the age, developmental stage, life experience, socio-cultural orientation, health and available resources.
- ▶ Therapeutic self-care demand - is the measures of care required at moments in time in order to maintain life and promote health and the developmental and general well-being of the individual or group.
- ▶ Self-care requisites - are otherwise known as Activities of Daily Living. There are three types of self-care requisites described by Orem in George (1990:92) which are as follows:
  - Universal self-care requisites or Activities of Daily Living are common to all human beings and include the maintenance of air, water, food, elimination activity and rest, solitude and social interaction, prevention of hazards and promotion of human functioning.

- The developmental self-care requisites which may be specialised expressions of universal self-care requisites necessary for promotion of human functioning and development within social groups. Proper identification of one's limitations and correction of conditions that affect normal growth and development, for example adjusting to the body changes such as severe loss of body weight.

- The Health deviation self-care

The normal health status of the individual may be affected by illness, disease or injury. When the integrated functioning is seriously affected, the individual's power of agency is seriously impaired temporarily or permanently, causing partial or total dependency on others for maintaining the basic needs of living. The sick individual therefore moves from the position of being a self-care agent to that of a patient. He/she seeks medical assistance, learns to live with the effects of the disease, illness or injury. The individual complies with a prescribed regimen which relieves pain, discomfort and improves the general health status.

#### 4.3.2 The Theory of Self-care Deficit

According to George (1990:93) the theory of self-care deficit is the core of Orem's General Theory of nursing because it delineates when nursing is needed. Nursing is needed when an individual's self-care abilities are less than those necessary for meeting a self-care demand.

The individual may need help from others who have more knowledge and skills to improve the health status so as to cope with the effects of the disease or injury. Orem identified five methods of helping individuals.

- ▶ Acting for or doing for another.
- ▶ Guiding another.
- ▶ Supporting another (physically and psychologically).
- ▶ Providing an environment that promotes personal development in relation to becoming able to meet present or future demands for action.
- ▶ Teaching another person.

Orem further identified five areas of activity for nursing practice. These are:

- ▶ Entering into and maintaining nurse-patient relationships with individuals, families or groups until patients can be discharged from nursing.
- ▶ Determining how patients can be helped through nursing.
- ▶ Responding to patients' requests, desires, and needs for nurse contacts and assistance.
- ▶ Prescribing, providing and regulating direct help to patients and their significant others in the form of nursing.
- ▶ Coordinating and integrating nursing with the patients' daily living, other health care needed or received and social and educational services needed or received. Orem's Theory of Self-Care Deficit, is applicable in home-based care where sick individuals are assisted by family members, neighbours and care-givers whenever there is a self-care deficit.

### 4.3.3 The Theory of Nursing Systems

Orem, in Marriner-Tomey (1989:123), explained that nursing systems are formed when nurses use their abilities to prescribe, design and provide nursing for legitimate patients (as individuals or groups), by performing discrete actions and systems of action. These actions or systems regulate the value of or the exercise of individuals' capabilities to engage in self-care to meet the self-care requisites of the individual therapeutically.

The design and elements of the nursing system define the following:

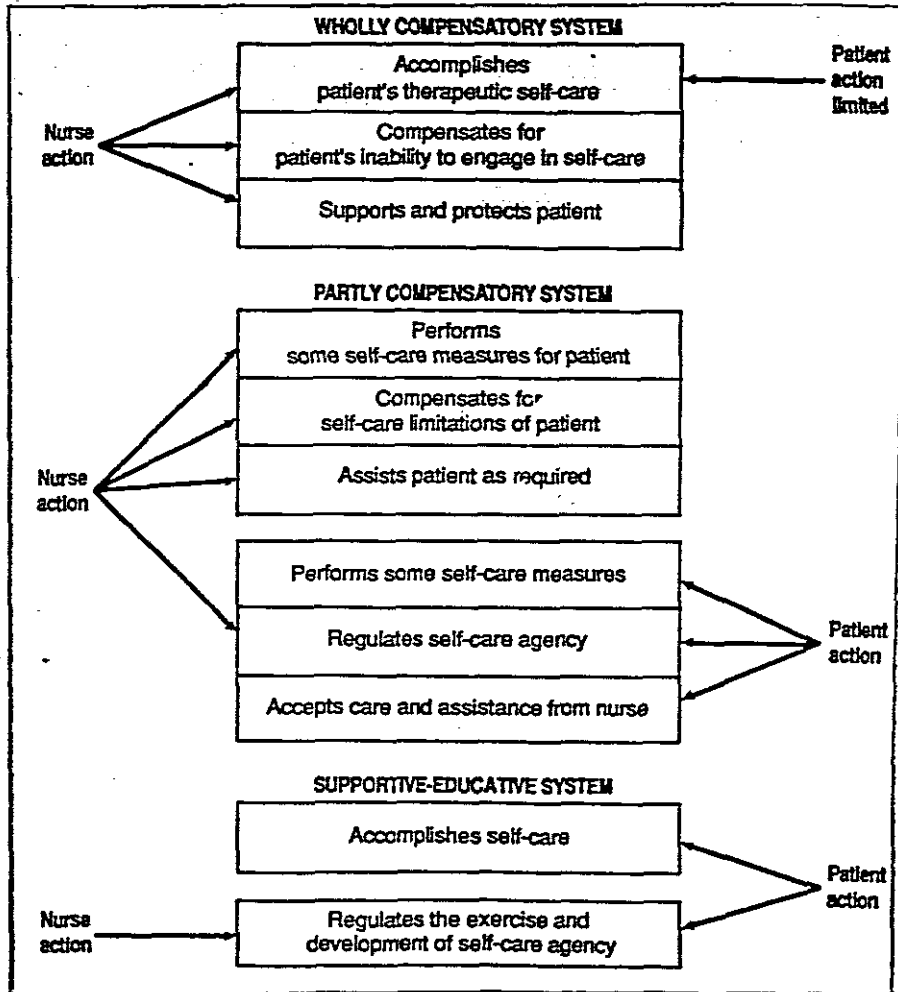
- The scope of nursing responsibility in the health care situations.
- The general and specific roles of nurses and patients.
- The reasons for nurses' relationships with patients.
- The kinds of actions in regulating patients' self-care agency and meeting their therapeutic self-care demand.

#### Figure 4.2 Diagrammatic Presentation of Orem's Theory of Nursing Systems

There are three types of nursing systems identified by Orem, namely:

- The wholly compensatory nursing system
- The partly compensatory system
- The supportive-educative system care demand

Figure 4.2 Diagrammatic Presentation of Orem's Theory of Nursing Systems



Source: (George, 1990:96)

The three nursing systems depicted in figure 4.2 are described by Orem as follows:

#### 4.3.3.1 The wholly compensatory systems

- ▶ In this nursing system, patients are completely dependent on nurses' actions for the maintenance of all activities of daily living, for example assistance with breathing through administration of oxygen, feeding and even changing

- ▶ The nurse's action is to compensate for the patients' inability to engage in any form of deliberate action, and to ensure that the patient is supported and well protected from harm.

#### 4.3.3.2 Partly compensatory system

- ▶ Both the nurse and the patient perform care measures or other actions involving manipulative tasks, or ambulation.
- ▶ The nurse helps and guides the patient wherever necessary and the patient accepts care and assistance from the nurse and a strong bond of nurse-patient relationship is established.

#### 4.3.3.3 Supportive-educative system

The supportive-educative systems are used in situations where the patient is able to perform or can and should learn to perform required measures of therapeutic self-care but cannot do so without assistance. The nurse's role and that of home-based care-giver is to promote the patient as a self-care agent.

### **4.4 ADAM'S CONCEPTUAL MODEL FOR NURSING**

Adam, cited in Marriner-Tomey (1994:494-5), in her conceptual model for nursing stressed the importance of three complements which constitute the nursing practice namely:

- The client
- The nurse (with her conceptual model as a base for the nursing process)
- The relationship between the nurse and the client

Adam considered the establishment of a helping relationship between clients and nurses as very important in nursing. This is possible where there is a climate of empathy, warmth, mutual respect, caring and acceptance which determines the effectiveness of nursing. The nurse is expected to enter into this relationship with a sound philosophy of nursing, guided by her experience, intuition and creativity.

The nurse and clients (sick or well), including their families, using a systematic process, seek ways of solving problems and involve other members of the interdisciplinary health team. The shared functions of the interdisciplinary health team are viewed by Adam as representing a schematic flower with each petal representing a distinct health discipline, for example nursing, physiotherapy, medicine, dietician and others. The centre of the flower indicates shared functions although each discipline makes a unique contribution to the promotion and preservation of health.

The interdisciplinary health team provides a linking mechanism through an effective, coordinated effort with the client and the family members. Clients are helped to find the best solutions to their problems from appropriate sources, at the best price, at the right time and on a continuous basis for the required period of time.

According to Marriner-Tomey (1994:497) Adam had expanded on Virginia Henderson's concepts within the structure of the conceptual model. The client is viewed as a whole-being made up of fourteen (14) fundamental needs namely:

- Breathing normally, moving and maintaining desirable positions.
- Selecting suitable clothing to dress and undress.

- Maintaining body temperature within normal limits by adjusting clothing and modifying the environment.
- Keeping the body clean and well-groomed.
- Having adequate rest and sleep.
- Eliminating body waste.
- Communicating well with others, expressing emotions, needs, fear or opinions.
- Avoiding dangers in the environment.
- Worshipping according to one's faith.
- Learn, discover, or satisfy the curiosity that leads to normal development and health, and use of available health services.
- Working in such a way that there is a sense of accomplishment.

The role of the nurse, according to Adam, is a complimentary-supplementary one. The focus of attention of the nurse's action is the client's deficit which may be lack of knowledge, will or strength. The desired outcome of nursing actions would be that of increased independence in meeting the fourteen basic needs or, in some cases, dying peacefully.

The researcher has included these fourteen basic universal concepts for the benefit of home care-givers whose continuous evaluation of their clients' needs at home will be based on their maintenance throughout the lifespan of the sick individual living with AIDS. Adam's conceptual model for Nursing is applicable in home-

based care for the sick individuals with AIDS-related illnesses. The sick individuals are assisted with those activities of daily living which an individual cannot perform on his/her own.

#### **4.5 APPLICATION OF THE ALBRECHT NURSING MODEL FOR HOME HEALTH CARE, OREM'S GENERAL THEORY OF NURSING AND ADAM'S CONCEPTUAL MODEL FOR NURSING IN HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS**

As indicated in the preceding paragraphs, the researcher is of the opinion that the three nursing care models, that is Albrecht's Nursing Model for Home Health care, Orem's General Theory of Nursing and Adam's Conceptual Model for Nursing are complimentary and applicable to the provision of home-based care for people with AIDS.

These authors view nursing as giving direct assistance to a person, sick or well, as required because of a person's specific inabilities in self-care, resulting from a situation of personal health. A well person is guided in health promotion and prevention of disease so as to maintain the healthy state.

Self-care is a learned behaviour, which is an essential part of human functioning and development. The active participation of the client, the family and the community in health related matters is emphasised by these authors, rather than seeing people being passive recipients of care given by health-care providers.

A person living with AIDS may be admitted to hospital for treatment of acute infection and discharged home, where self-care becomes a reality. Some patients may be incapable of providing self-care and be dependent on family members as care-givers, others may be capable of their own care, requiring only advice and teaching from trained care-givers or nurses.

A common variable of these models is the use of the nursing process approach in identifying the clients' needs and problems. Joint planning and implementation of an agreed-upon plan of action to solve the existing problems is done by the client, the nurse and the family. Emphasis is also on the coordination of care where there is involvement of the interdisciplinary health team to ensure that comprehensive care is provided.

A person living with HIV/AIDS infection needs an ongoing assessment of his or her needs and problems, to cope with the chronicity of the disease as well as the sudden onset of opportunistic infections which need more effective self-help care abilities.

Orem, Albrecht and Adam, all agree on providing an environment conducive to recovery for clients. The social setting the client has come from, and the will he has to return to it, has an effect on the individual's health and has to be monitored. Albrecht stresses an environment that considers the individual's demography, like age; for example, an elderly person may have difficulty in understanding and following all self-care responsibilities posed by a chronic disease such as cancer or AIDS. Sometimes, economic variables like unemployment affect the quality of care provided. Poverty affects many people who live in poor housing conditions, lack a safe, pure water supply, as in rural areas, and lack money to afford healthier food and in medications (Stanhope & Lancaster, 1992:757-8).

Orem, in George (1990:97-9), describes human beings as people who are able to reflect upon themselves and their environment. Various factors may influence the role behaviours of individuals, for example culture, environment, age, sex, health setting and finances. In home-based care, all these factors affect the individuals' health and provision of care. In the context of this study, a person living with AIDS suffers most because of the stigma associated with the disease as well as struggling to survive with scarce resources.

Adam, in Marriner-Tomey (1994:495) considers the environment already described in this chapter, with a climate of warmth, empathy, mutual respect, caring and acceptance by others. A person living with AIDS needs acceptance and love. A sense of belonging to a loving and supportive family or peer group and friends, tends to boost the individual's self-esteem, the will to live longer and accomplish all that is desired.

These authors share the idea of modifying adverse behaviours through health education and guidance. The health care-providers have a social mission of contributing to the public's improved health, by working towards greater client independence and satisfaction with care provided at home, with constant reviewing of beliefs and values of the public being served. Personalised attention to the individual's health status, social support and ongoing counselling is accomplished through home-based care.

The sick individual may be hospitalised for induction therapy for an acute opportunistic infection. Once stabilised he/she may be sent home for continuity of care. AIDS has no cure. So far, HIV/AIDS infection remains a downhill continuum with multiple complications and eventual death. A strong support system is necessary to alleviate feelings of helplessness.

## 5 CONCLUSION

The researcher has been inspired by the interrelatedness of the components of Albrecht's, Orem's and Adam's models, which emphasise the self-care responsibilities of individuals, who can achieve higher levels of health status when equipped with knowledge and skills in promotive, preventive, curative and rehabilitative health-care measures. These authors, in their complementary models view a client as a complex individual in need of holistic care which can be provided in a team approach. This approach is important in home-based care,

especially for people living with AIDS who present with numerous health problems as the individual develops full-blown AIDS, described in chapter two of this study.

## **CHAPTER 5**

### **RESEARCH METHODS**

#### **5.1 INTRODUCTION**

This chapter deals with the description of methods and procedures used in this study. It describes the research design, population, sample and sampling methods used as well as the instrument used to collect data.

#### **5.2 RESEARCH DESIGN**

A descriptive survey was undertaken. According to Polit and Hungler (1993:142) the main purpose of the descriptive study is to observe, describe, and explore aspects of a situation as it normally occurs. Polit and Hungler (1993:435) maintain that a descriptive study does not focus on relationships among variables, but is useful when investigating an emerging phenomenon. It provides an accurate portrayal of the characteristics of individuals, situations, or groups and the frequency with which certain phenomena occurs. The descriptive study helps to form a sound foundation for future research. In the context of this study on provision of home-based care for people living with AIDS, the variables of interest include knowledge, attitudes, opinions, experiences, needs and facts on sustaining continuity of appropriate care.

#### **5.3 AREA OF STUDY**

The study was undertaken at Umlazi and its informal settlements. Umlazi is an historically Black residential area, about 24 kilometres from the city of Durban. A detailed description of the area will be given in this section in order to depict the context within which the home-based care under study is rendered.

### **5.3.1 Size and population of Umlazi**

Umlazi is a township which is 24 kilometres south of Durban. It is reported to be the largest township in KwaZulu-Natal province, and the second largest township in South Africa, after Soweto. It occupies an area of between 4 500 to 4 800 hectares. The large number of informal settlements within and around Umlazi, aggravate the growth in population which was estimated to be 500 000 in 1995. This number has increased dramatically to approximately more than a million (1 000 000) at present (year 2000). The occupancy in informal areas ranges between 8-15 per informal dwelling unit, some of which are only two-roomed buildings. The increasing population in Umlazi has led to overcrowding, unemployment, increase in infectious diseases, including HIV/AIDS, Tuberculosis and various social problems. The Map of Durban Metro area reflecting the situation of Umlazi is on page 291 of this document.

### **5.3.2 The informal settlements**

During the 1960s and 1970s, there were only two informal settlements, namely Malukazi in the South and Mgaga in the West. Presently there are many more informal settlements scattered all over Umlazi for example Uganda, Bara-Bara, Chimora, Zamani and others. People living in Umlazi are mostly Blacks. There are more males than females, probably because of migrant labourers working in the Metro and Industrial areas within and outside Umlazi or in and around the city of Durban. This factor has implications for the rapid spread of HIV/AIDS due to multiple partner relationships encouraged by the disruption in family lives. Family life becomes disrupted when the husband leaves home and stays at a men's hostel where visits by family members are limited.

Some of the informal settlements have been improved to on-site plots with toilets and clean water supply. The owners of the plots may develop the plots at their

own pace. In some areas, subsidised two-roomed houses have been built. Central taps have been installed for approximately 30-40 informal houses. (Urban Strategy Statistics, 1996:16)

### 5.3.3 Type of formal housing

The houses that were constructed when Umlazi was first developed into a township, were four-roomed houses for low income families. Occupants of these houses paid rent. These houses were later bought by the occupants who improved them significantly and obtained title deeds. Later, private companies like Stokes and Stokes and other companies constructed houses for upper income families in some of the twenty-eight sections of Umlazi, for example in AA-section, BB-section, Z, W, Y, N and S-sections. (Townsend, 1991:34-5)

### 5.3.4 Infrastructure

#### 5.3.4.1 Water Supply, Transport and Electricity

Residents are provided with a good supply of water and electricity. The Water supply is provided by Durban Metro. There is good sanitation. Roads have been improved and in some areas improvements are still in progress. Transport facilities are good. Transport consists chiefly of buses, taxis, trains and private cars. Residents of Umlazi can reach community health services with ease, provided they can afford the transport costs. Moreover, most of these are within walking distance, approximately five kilometres away from their houses which is in line with the principles of Primary Health Care.

#### 5.3.4.2 Police stations and Administrative Offices

There are two police stations, one at V-section and the other at BB-section. These police stations are complemented by satellite police stations at U, W and J-

sections. In spite of this, the crime rate (including rape), remains high. There is one administrative complex area called "Emaweleni" situated in W-section. There is a magisterial court in V-section.

5.3.4.3 Social Institutions - Educational

Umlazi has about 109 schools under the management of Umlazi North and Umlazi South Districts. The number of schools is as follows:

Pre-Primary schools	07
Lower Primary Schools	31
Higher Primary Schools	26
Combined Higher Primary schools	09
High schools	29
Special schools	04
Technical College	01
Technikon	01
University	01
<b>TOTAL =</b>	<b>109</b>

(Tshabalala, 1998:41)

The above facilities are shared by the community members of Umlazi and also accommodate candidates outside Umlazi. According to the number of educational institutions reflected in section 5.3.4.3, there is good accessibility to education. It may be the quality of the education offered there which accounts for large numbers of school children going out of Umlazi to seek better education. It is important to know the availability of these institutions since some school children may have HIV/AIDS and their nearness to home will facilitate their learning.

There are special schools, which include:

- ▶ one for the mentally handicapped people at Q-section called (Entuthukweni)
- ▶ the school for the Deaf and Dumb at V-section
- ▶ the school for the physically handicapped the Mason Lincoln, previously known as Malandeni
- ▶ the school for the Blind at Nduduzweni at V-section.

There is one place of safety at V-section for a variety of children with histories of family abuse, abandonment for orphans and others. These institutions have been developed for the protection and welfare of the disabled and disadvantaged children, which is in line with the Child Care Act of 1983 in South Africa.

#### 5.3.4.4 Business and Recreational Facilities

There are supermarkets and medical centres in some sections of Umlazi. There are a few recreational facilities like soccer stadiums, tennis courts and taverns. Street vendors are found near and around busy areas like shopping centres, taxi ranks, railway stations, bus-stops, local schools, clinics and administrative offices. The telecommunication system is good.

#### 5.3.5 Health services

The available health services are as follows:

- ▶ A District hospital with seven satellite clinics. These clinics provide health care services for eight hours a day to the community.
- ▶ There is a good referral system during working hours. Working hours extend from 07:00-16:00 or 18:00 in some clinics. After hours the sick individuals hire private transport to the district hospital.

- ▶ Ambulances are unable to enter into some sections of Umlazi, especially in the evenings and during the night because of the high rate of car hijackings.
- ▶ Within the district hospital there are various clinics which include the following:
  - The Pulmonary Tuberculosis follow-up clinic which also controls the Directly Observed Treatment (DOT) in Umlazi and its informal settlements.
  - The Crisis Centre clinic for assault, rape and violence-related injured clients.
  - The AIDS clinic for referred clients requiring pre and post AIDS counselling and testing, and other clinics.
- ▶ Private practitioners and dentists are found in most sections of Umlazi.
- ▶ Street vendors sell herbal medicines next to major facilities like supermarket complexes, taxi-ranks and magisterial buildings.

#### 5.3.6 The AIDS Clinic

This is one of the clinics functioning within the district hospital's premises. It deals with individuals referred by doctors from the outpatients departments and the hospital wards, the surrounding clinics and hospitals for pre- and post-test counselling for HIV infection.

#### 5.3.6.1 Types of clients seen

- ▶ Referred clients as mentioned in the previous paragraph.
- ▶ Clients who voluntarily come for HIV testing for personal reasons.
- ▶ Clients who want to confirm previous HIV-positive results from tests done at other institutions.

#### 5.3.7 Staffing of the AIDS clinic

There are five staff members at the AIDS clinic namely:

- ▶ A professional nurse-in-charge of the AIDS clinic and coordinator of community outreach programmes working jointly with community facilitators and home care-givers.
- ▶ Another professional nurse who leads the AIDS counselling team.
- ▶ One enrolled nurse with additional qualifications in reflexology and aromatherapy who helps in pain relief by massaging with scented oils, and who recommends the use of natural therapy like a diet of leafy vegetables and fruits to clients.
- ▶ Two auxiliary nurses who are also AIDS counsellors.
- ▶ One general assistant responsible for environmental hygiene.
- ▶ One social worker and a medical practitioner from within the hospital, work together with the AIDS clinic staff forming a team. The AIDS team

aims at providing the best health care for people living with AIDS through home-based care, within existing resource constraints.

## **5.4 ETHICAL CONSIDERATIONS**

### **5.4.1 Permission to conduct the study**

This was obtained from the Hospital's Medical Superintendent and Deputy Director of Nursing in order to have access to the AIDS clinic. Key figures were also consulted, that is the Mayor of the South Central Area and councillors for permission to visit the areas utilised for data collection.

### **5.4.2 Anonymity and Confidentiality**

It was emphasised that participants should not indicate their names anywhere in the questionnaires. In this way, there would be no way of linking their responses to them. Participants were assured of their anonymity and of confidentiality.

### **5.4.3 Informed Consent**

Informed consent was obtained from participants after the explanation of the purpose of the study. They were informed of their freedom of choice to participate or decline involvement in the study. The study was conducted only with those who voluntarily agreed to participate. Polit and Hungler (1993:438) describe informed consent as an ethical principle that requires researchers to obtain the voluntary participation of participants, after informing them of the possible risks and benefits of the study.

## **5.5 POPULATION**

According to Brink (1996:32), a population is the entire group of persons or objects that is of interest to the researcher, and meets the criteria the researcher is interested in studying. In the context of this study, this includes all people living with AIDS at the AIDS clinic and at their homes. Home-based care-givers, social workers and traditional healers were included in the target population because of their roles which are complimentary in the provision of holistic care to people living with AIDS.

## **5.6 SAMPLE AND SAMPLING METHOD**

The purposive sampling method was used, complemented with snowball sampling to facilitate identification of suitable participants for the study. According to Brink (1996:141) purposive the sampling method is based on the judgement of the researcher regarding participants or objects that are typical of the topic being studied. In snowball sampling every participant in the sample is asked to identify other potential individuals that meet the selection criteria.

### **5.6.1 Sample of People Living with AIDS (PWAS)**

The size of the sample was thirty participants. They were selected mainly from the AIDS clinic records. The criteria for inclusion was:

- Confirmed to be HIV-positive or AIDS
- Has had pre- and post-HIV test counselling
- Has been seen by AIDS counsellors thrice or more
- Has been seen by a social worker for AIDS-related problems
- Not terminally ill
- Voluntarily agreed to participate in the research study.

The researcher, assisted by and working closely with members from the Aids Information Training Centre, social workers and key figures of the community, identified people living with AIDS. One person living with AIDS for more than ten years, has been very helpful to pinpoint others in various sections of Umlazi, thereby facilitating the snowball sampling. This was complemented by the list from the AIDS clinic of hospital 'Y' of people with chronic diseases, including AIDS, being nursed at home by care-givers. Other participants included in the study were family members, other care-givers and social workers.

#### **5.6.2 Sample of care-givers**

This sample included family members, trained care-givers or community health workers, who provide home-based care to clients with different chronic illnesses, including AIDS, in various sections of Umlazi and its informal settlements. The researcher was referred to these participants by a member of the National Association of People Living with AIDS (NAPWA), and AIDS clinic staff. The sample size was twenty-two participants who all voluntarily agreed to participate in the study.

#### **5.6.3 Sample of Social Workers**

The sample consisted of ten participants. This sample included social workers who deal with social problems of people living with AIDS, referred to them by the clinic nurses, doctors and AIDS clinic staff.

#### **5.6.4 Sample of Traditional Healers**

At the AIDS clinic some clients reported being treated by traditional healers for their illnesses. The traditional healers were invited to attend a meeting with AIDS counsellors and clinic staff. At this meeting, the ten traditional healers were given

the questionnaires to fill in during tea break. Questionnaires were written in English and Zulu to accommodate those who could not read and write English.

## **5.7 THE RESEARCH INSTRUMENT**

Questionnaires were used for data collection. Brink (1996:153-4) describes the questionnaire as a self-report instrument, where the respondent writes his or her answers in response to printed questions on a document. It is the most common research instrument. Respondents perceive a great deal of anonymity and are likely to provide honest answers.

The researcher used questionnaires for data collection in this study to ensure complete anonymity of respondents who would be answering questions at their own pace, having enough time to express their feelings more frankly and honestly.

Questionnaires are regarded as cheap when distributed to groups of people to fill in quickly and to be collected at the same time. The researcher made use of scheduled meetings of the four different categories of respondents to distribute questionnaires, which were collected on the same day where possible or on the next scheduled meeting. Data was collected from People Living with AIDS, caregivers, including family members, social workers and traditional healers.

### **5.7.1 Designing the questionnaire**

A short letter was included at the beginning of the questionnaire to give a brief explanation of the research and its purpose. Directions for completion of the questionnaire were given. Anonymity and confidentiality were assured.

Sets of questionnaires were formulated for the following groups of respondents:

- People living with AIDS
- Care-givers who were voluntary health care-workers or family members
- Social workers
- Traditional healers.

The rationale for the separation of questionnaires was the varying degrees of impact of AIDS on individuals, family or care-givers and the other categories included in the study as already mentioned. It was also based on the consideration of the varying degrees of responsibility for making home-based care comprehensive enough to provide effective care for the sick individuals with AIDS.

#### 5.7.1.1 Types of questions

Formulation of questions was guided by the objectives of the study, observations, informal discussions and available literature on HIV/AIDS infection and home-based care. Open-ended and closed-ended questions were used. The former type of questions enabled more in-depth probing into information obtained through closed-ended questionnaires.

#### 5.7.1.2 Questionnaire for care-givers

This section was divided into eleven (11) sections as follows:

##### Section 1 - Personal particulars

This section highlighted the age group of carers, their educational level and relationship with the sick individuals.

Section 2 - Basic preparation

The Basic Nursing preparation of care-givers is highlighted as an important factor towards the provision of high quality home-based care. Counselling skills and other qualifications relevant to nursing are part of this section.

Section 3 - Experience of care-givers in the care of people living with AIDS

The inclusion of this section was based on the degree of experience that care-givers should have to meet the needs of people living with AIDS.

Section 4 - The Support System

The main aim of this section was to identify the availability of care services and a support system for care-givers who may be family members or community health workers.

Section 5 - Knowledge of HIV/AIDS

This section focused on the knowledge care-givers had of HIV/AIDS infection and measures to prevent its spread, which is important when nursing AIDS clients.

Section 6 - Factors influencing provision of care

The inclusion of this section was to identify factors which might have a positive or negative influence on the decision to provide care for people living with AIDS.

Section 7 - Assessment of clients' needs

This section dealt with assessment of clients' needs. Sick individuals sometimes may not voice their needs due to severe illness. Care-givers being close to those

clients might be able to note cues that indicate a need for partial or complete assistance and be of help.

#### Section 8 - Availability of Local Community Services

This section focused on the availability of 24-hour community services, which are necessary for consultation and intervention at any hour of the day when severe opportunistic infections occur.

#### Section 9 - Coping with stress

This section dealt with stressful situations and coping mechanisms.

#### Section 10 - Benefits of home-based care for the individual with HIV/AIDS

Focus in this section is on assessing the benefits of home-based care for people living with AIDS as perceived by the care-givers.

#### Section 11 - Problems experienced in home-based care

This section focused on problems experienced by care-givers in home-based care which could adversely affect the nursing care provided to sick individuals.

#### 5.7.1.3 Questionnaire for People Living with AIDS

This section was divided into seven (7) sections as follows:

##### Section 1 - Personal particulars

This section highlighted the age group of people living with AIDS, their marital status, the number of children for - those with children - and their educational level.

Section 2 - Reaction to HIV/AIDS diagnosis

This section focused on reactions of individuals to the HIV/AIDS diagnosis as well as that of family members, employers and co-workers.

Section 3 - Knowledge on HIV/AIDS

Knowledge of HIV/AIDS infection and preventive measures are highlighted in this section.

Section 4 - Pain assessment and pain control

This section focused on pain assessment. The type or severity of pain experienced by individuals indicated by using the colour-coded rules provided. Measures used to control pain at home were also investigated.

Section 5 - Medication and other treatment

This section dealt with the type of medication and treatment used to deal with symptoms of the disease.

Section 6 - Care and Support

This section focused on the type of care and support available for people living with AIDS in the home-based care.

Section 7 - Counselling Sessions

Ongoing counselling sessions are an important aspect and help the clients to overcome problems as they arise. This section focused on the availability of counselling services and how these services are evaluated by clients.

#### 5.7.1.4 Questionnaire for Social Workers

This section was divided into three sections.

##### Section 1

This section dealt with the problems of AIDS clients and strategies to solve problems as they arise.

##### Section 2

This section highlighted problems encountered with relatives of sick individuals and the type of clients referred to specialists for further management of their conditions.

##### Section 3 - Referral System

This section highlighted the type of referral system available to clients who needed to be referred to specialists or social groups for further management of physical and psycho-social problems.

#### 5.7.1.5 Questionnaire for Traditional Healers

This section was divided into three sections as follows:

Section 1 - Personal particulars and educational level of traditional healers was highlighted.

Section 2 - Experience in traditional healing practice and the traditional healers' belief in combining Western medicine with traditional medicine were highlighted.

### Section 3 - Knowledge of HIV/AIDS

This section focused on traditional healers' knowledge of HIV/AIDS. This is significant because traditional healing involves skin cutting, using razor blades and acupuncture. It is evident that traditional healers need to know the precautionary measures to prevent cross-infection when performing these procedures on their clients.

#### **5.8 VALIDITY OF THE INSTRUMENT**

Polit and Hungler (1991:657) and Dane (1990:257) describe validity as the degree to which an instrument measures what it is intended to measure. In the context of this study, the instrument was intended to investigate the comprehensiveness of Home-based Care for People Living with AIDS. The instrument was tested for face and content validity. The researcher and a research expert looked at the various sections of the instrument. It appeared to be a relevant, comprehensive and good instrument. Two experienced researchers evaluated the content validity of the instrument and approved of it being appropriate to gather the required information for the study. This was further confirmed through pre-testing the instrument.

#### **5.9 PRE-TESTING THE INSTRUMENTS**

The instrument for people living with AIDS was pre-tested on five participants referred to the AIDS clinic who were not included in the main study. The purpose was to identify unclear questions, correct, re-word or exclude very sensitive or unnecessary questions.

The instrument for care-givers was pre-tested on five participants of home care-givers (*Onompilo*). Interpretation of the instrument into Zulu was necessary to accommodate those who could not read English well. This was done.

The instrument for social workers was pre-tested on two participants who recommended reduction of the number of open-ended questions. The test was modified to accommodate their comments, whilst maintaining its validity.

The instrument for traditional healers was prepared in English and Zulu. No pre-testing was done because of the small sample size required for data collection for the study.

#### **5.10 DISTRIBUTION OF THE QUESTIONNAIRES**

The questionnaires were handed directly to the selected respondents by the researcher. Direct distribution is preferred where feasible. It ensures a high return rate and enables the researcher to meet the deadlines (Polit & Hungler, 1991:292). Where they could be completed on the same day a high return rate was realised. Other respondents who could not attend to questionnaires immediately, were given time to complete them at their convenience. With follow-up, the return rate of these questionnaires was also good.

#### **5.11 CONCLUSION**

This chapter dealt with details of the research methods. Questionnaires were used for data collection and they contained open-ended and closed-ended questions. Data is analyzed and interpreted in the next chapter.

## **CHAPTER 6**

### **DATA ANALYSIS, PRESENTATION, INTERPRETATION AND DISCUSSION OF FINDINGS**

#### **6.1 INTRODUCTION**

This chapter presents an analysis of data, interpretation of data and discussion of findings of analyzed data from people living with AIDS who participated in this study. Analyzed data from home-based care-givers, social workers and traditional healers is presented in chapter seven.

Data is presented in the form of tables and graphs. Responses to open-ended questions are summarised and categorised into appropriate classifications through the process of content analysis (Polit & Hungler, 1991:513).

#### **6.2 SECTION 1: PERSONAL PARTICULARS**

This section presents the biographical data of participants in order to provide accurate, detailed information of participants in this study.

Key: N stands for total number of participants.

n = stands for portion of the sample that is relevant to the particular variable.

##### Item 1: Gender

This item was included to determine the gender distribution of the participants in this study who were identified as people with AIDS.

Table 6.1

Gender	Frequency	Percentage
Male	07	23
Female	23	77
TOTAL	30	100%

According to table 6.1, the majority 77% (23) participants were females. Males were 23% (7) of the total sample. These findings support the general view, which is further confirmed by Smith (1999:8), that females are the most affected with HIV/AIDS.

Item 2: Ages of participants in years

Table 6.2: Age distribution N=30

Age group in years	Frequency	Percentage
11-15	02	07
16-20	02	7
21-25	06	20
26-30	11	36
31-35	05	17
36-40	02	07
41-45	01	03
46-50	0	0
51-55	0	0
56-60	01	03
61-65	0	0
Above 65	0	0
TOTAL	30	100%

According to table 6.2, the majority of participants 36% (11) were in the 26-30 age group, followed by 20% (6) in the 21-25 age group and 17% (5) in the 31-35 age group. Fewer participants 7% (2) were in the 11-15 age group, the 16-20 group and the 36-40 age group respectively, except for 3% (1) participant in the 56-60 age group. Furthermore, in the 46-55 and 61-65 age group, and above 65 years.

The fact that the majority of people living with AIDS 73% (22) are young adults of child-bearing age who are also the most productive group, ranging between 21-35 years of age, is proved in table 6.2. In a survey reported by Smith (1999:8), it was found that HIV-positive teenage females have a prevalence of 43%.

The researcher is of the opinion that the single HIV-positive participant of the 56-60 age group in table 6.2, who was also a female, contracted HIV infection through the caring role. This reflects on the fact that the non-revealing of HIV-positive status jeopardises care-givers' health, in their caring roles in home-based care.

Item 3: Marital status

Table 6.3      Marital status of participants N = 30

Marital status	Frequency	Percentage
Single	29	97
Married	01	03
Other	0	10%
TOTAL	30	100%

Table 6.3 reflects that the majority of participants, 97% (29), were single and that only 3% (1) of the age group 41-45 years, was married. Findings in Table 6.3 are

supported by Munodawafa, Gwede, Mabuyira (1995:8) who indicate the heterosexual mode of HIV infection transmission in Zimbabwe to be very high amongst young sexually-active adults between the ages of 20-39 years. The incidence was noted to be especially high amongst females, possibly due to a high rate of promiscuity or the high risk of having multiple sexual partners. Unmarried young females, living under very low socio-economic conditions, are pressurised by the need to satisfy their immediate needs like food, shelter and clothing, and ignore preventive measures when they became commercial sex workers for rich adult men.

Item 4: Number of children

This item was included to identify the number of children whose parents could die as a result of AIDS and be left as AIDS orphans.

Table 6.4      Participants with children    N=30

<b>Participants with children</b>	<b>F</b>	<b>%</b>
Participants with children	12	40
Participants with no children	18	60

Figure 6.4 reflects that 40% (12) participants had children and 60% (18) had no children. This finding is in line with the literature review in chapter three of this study, where Alexander *et al.* (1994:908-910) argue that people with AIDS have the right to decide not to have children for fear of the danger of vertical transmission from sero-positive mothers. At the same time this is contrary to the fact that the highest incidence, 73% (22) of the participants, were in the child-bearing age group as reflected in table 6.3.

**Table 6.5**      **Number of children per participant with children n-12**

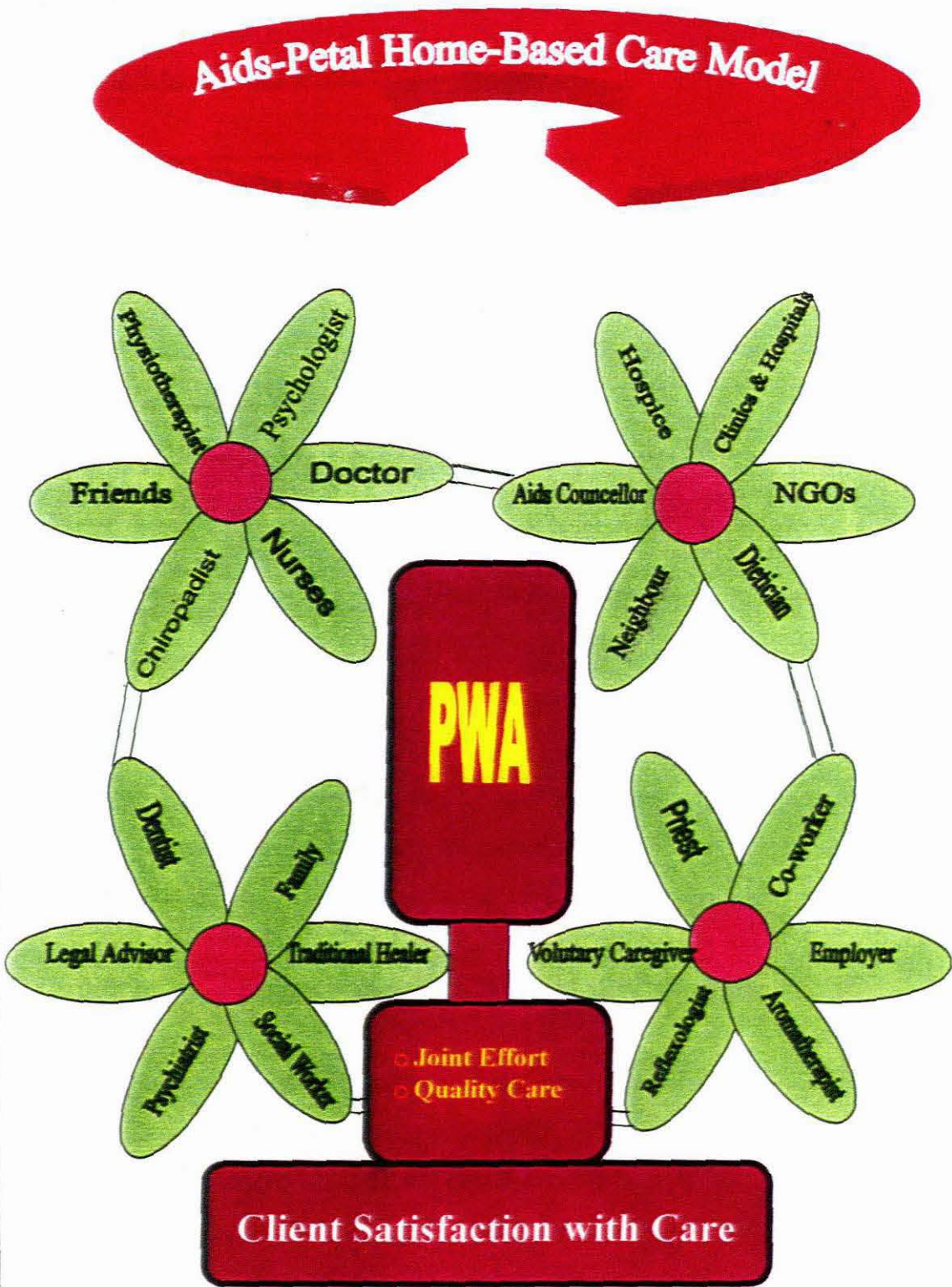
<b>No. of parents</b>	<b>%</b>	<b>No. of children per participant</b>	<b>Total No. for every 3 participants</b>
3	25	1	3
3	25	2	6
3	25	3	9
3	25	4	12
12	100%	-	30

Table 6.5 shows that the number of children per parent ranged between one (1) and four (4). The researcher further looked into the age groups of the twelve (12) participants (parents) with children and the following pattern emerged:

- ▶ 1 child each = 2 parents in the 16-20 age group and 1 parent in the 21-25 age group.
- ▶ 2 children each = 3 parents in the 21-25 age group.
- ▶ 3 children each = 1 parent in the 26-30 age group and 2 parents in the 31-35 age group.
- ▶ 4 children each = 1 parent in the 26-30 age group = 2 parents in the 36-40 age group

It is evident that some participants are very young mothers of school-going age. This is a challenge to the community with regard to reviewing the cultural values in regard to sex education and sexual behaviours.

Figure 8.1 The Aids – Petal Home-Based Care Model



Item 5: Age range of childrenTable 6.6: Age range of children in years

Age in years	Frequency	Percentage
1-5	13	43,4
6-10	07	23,3
11-15	09	30,0
16-20	1	3,3
TOTAL	30	100%

According to Table 6.6, the majority, 43,4% (13), of children ranged between 1-5. This was the youngest group, followed by 30% (9) of the 11-15 age group who were young teenagers, and 23% (7) of the 6-10 age group, who were young children. Only 3% (1) of the 16-20 age group was identified. No children were above 20 years. In view of the high death rates amongst people living with AIDS, it raises concern that the majority of children in the 1-5 age group, who are still very dependent on parents, are left as AIDS orphans and may be suffering from paediatric AIDS.

Item 6: Parents with sick children due to AIDS-related illnesses

This item was included because of the trend of ill-health of children born of parents with HIV/AIDS. All participants 100% (30) indicated that they had not noticed any serious illnesses which cause concern.

Item 7: Educational Level

N = 30

Table 6.7 Educational level of participants

<b>Educational Level</b>	<b>Frequency</b>	<b>Percentage</b>
Never been to school	02	07
Grade 1-3	0	0
Grade 4-6	12	40
Grade 7-9	07	23
Grade 10-12	09	30
<b>TOTAL</b>	<b>30</b>	<b>100%</b>

According to table 6.7 the majority of participants, 40% (12), had grade 4-6 level of education, followed by 30% (9) with grade 10-12 and 23% (7) with grade 7-9. A few participants 7% (2) had never been to school. No participants were reported in grade 1-3. These responses demonstrate that there are some people in Black communities with no education or who are semi-literate. This problem is being addressed by the South African Government through formal Adult Education Programmes.

The researcher had to translate the questionnaires into Zulu for those who could not read English and assist two participants in completing of questionnaires, since they could not read or write. This is a challenge for extensive educational programmes in all languages on AIDS Awareness through radio and pamphlets, written in Zulu, as well as pictures and educational short stories in television programmes.

Item 8: Post-standard 10 certificate/diploma or degreeTable 6.8 Participants with post-standard 10 Certificate/Diploma/Degree n=9

<b>Post Std 10 Certificate/ Diploma or Degree</b>	<b>F</b>	<b>%</b>
Police Certificate	01	11,1
No post-std 10 Certificate/ Diploma/Degree	08	88,9
<b>TOTAL</b>	<b>09</b>	<b>100%</b>

Table 6.8 reflects that out of 30% (9) participants in table 6.7 with grade 12 (matric), only 11.1% (1) had furthered his studies and obtained a police certificate. This may be due to lack of financial resources and facilities to pursue further studies.

### **6.3 SECTION 2: PARTICIPANTS' KNOWLEDGE ON HIV/AIDS**

#### Item 9 - Reaction to HIV/AIDS diagnosis

This item was included to establish how respondents reacted when they first discovered their HIV-positive status. Literature confirms that some people living with AIDS live in denial for a long period with continuing dangerous sexual behaviours, while others become depressed and isolated as they accept to living with the condition. They are challenged by stressful situations of stigmatisation and victimisation by society as described by Alexander *et al.* (1994:908-910) cited in chapter two of this report. According to Kunene (2000:8), inadequate knowledge and stigmatisation of the disease leads to social isolation, both in the home and in the community. Some AIDS clients are ostracised by their own

families who are overly concerned about their own protection, not knowing that AIDS is not a contagious disease.

**Table 6.9**      Reactions to HIV-positive status

N=30

<b>Reactional behaviours</b>	<b>Frequency</b>	<b>Percentage</b>
Denial	19	63,3
Anger	19	63,3
Disbelief	16	53,3
Loneliness	5	17,0
Depression	5	17,0
Embarrassment	3	10,0
Hope	3	10,0
Acceptance	3	10,0
Other Reactions	0	0

(Participants could give more than one response)

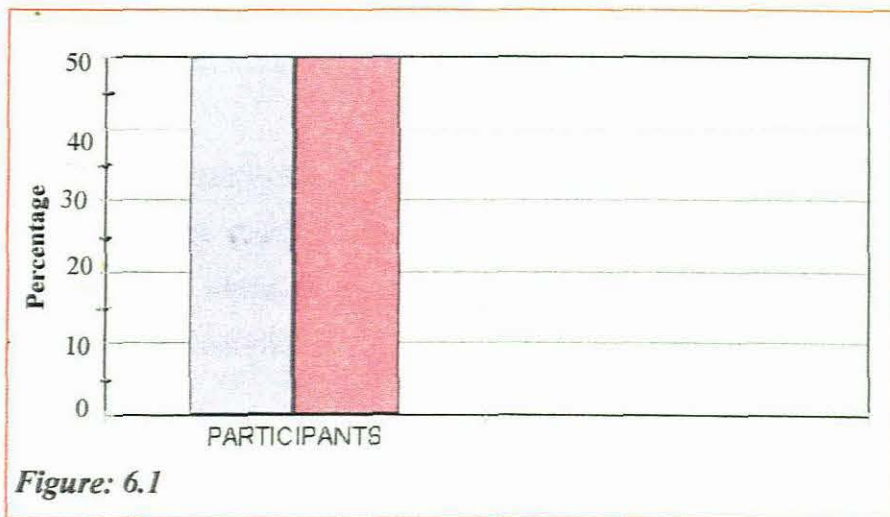
Table 6.9 reflects the participants' reactions to their HIV-positive status. Participants were permitted to indicate all applicable reactions to them from a table of reactions provided in the questionnaire. It is evident that the most common reactions were denial, anger with self and others, as well as not believing that they were really HIV-positive, as indicated by 63,3% (19), 63,3% (19) and 53% (16) of the participants respectively. 17% (5) and 17% (5) of participants respectively became depressed and lonely as they tried to come to terms with the diagnosis. Few participants, 10% (3) felt embarrassment, 10% (3) accepted their condition and 10% (3) hoped for a miraculous cure of the disease. It is obvious that a person with an HIV-positive status needs a good physical, social and emotional support system which could facilitate acceptance of the condition and develop hope

to live a normal life. This is possible by observing the principles of maintaining good health and prevention of spread of infection to others, as indicated in the Policy Document on HIV/AIDS: Clinical Care Guidelines for Adults (1998:159-165).

Item 10: Family’s knowledge on individual’s HIV-positive status

This item was included to establish whether the individual’s family knew about the HIV-positive status of the participant or not. This knowledge or lack of it has implications for the safety and protection of the family from infection. Findings on this aspect are depicted in figure 6.1.

Figure 6.1: Family’s knowledge of individual’s HIV-positive status



Key:  Yes  No

According to figure 6.1, 50% (15) participants informed their family members while the other 50% (15) did not inform their families. It is possible that the 50% (15) participants who did not inform their families feared adverse family reactions which include rejection, discrimination or total abandonment at the time when their support is needed most. Those who indicated that they informed their families of

their HIV-positive status were asked to indicate their family's reactions to their HIV-positive status. Responses are presented in table 6.10.

**Table 6.10** Family's reaction to Individuals' HIV-positive status n=15

<b>Family's Reactions</b>	<b>Frequency</b>	<b>Percentage</b>
Shock	9	60,0
Acceptance	7	46,6
Fear of Stigma	5	33,3
Denial	2	13,3
Rejection	2	13,3
Anger	2	13,3
Supportive	2	13,3

(Participants could give more than one response)

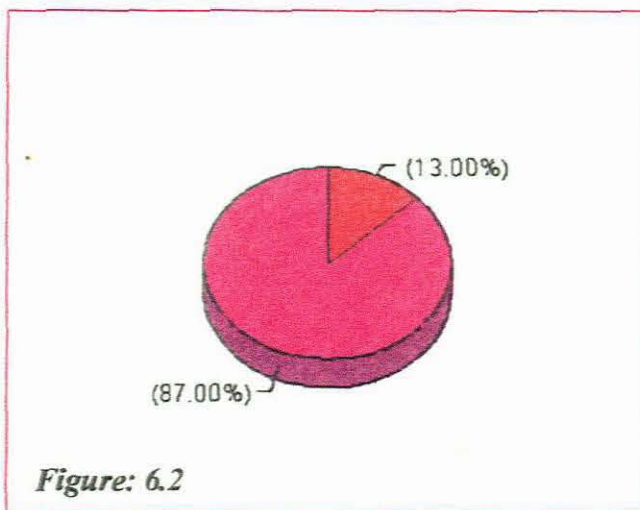
Table 6.10 reflects that the majority of the participants, 60% (9), indicated that family members were shocked when informed of one of their family members' HIV-positive status, whilst 46,6% (7) perceived that they accepted the condition as they would any other disease.

33% (5) noted that their family members lived in fear of social stigma, whilst 13,3% (2) were of the opinion that they reacted with denial, anger or rejection of the sick individual. It is pleasing to note that only 13,3% (2) which is a lesser percentage of participants, perceived rejection by family members. However, it is painful to find that though acceptance levels are perceived to be high, 46,6% (7), there is still a perception of very little family support because only 13,3% (2) participants indicated it. This confirmed the report by Kunene (2000) in Item 9 of this chapter on some AIDS clients who live in isolation, ostracised by their own families.

Item 11: Informing children of the HIV-positive status of their parents

This item was included to detect whether or not parents informed their children of their HIV-positive status. Van Loon (2000:154) referred to in chapter two of this study, mentions that sometimes children are thrust into the caring role of their sick parents. Participants' responses on informing of parents' children is reflected in figure 6.2.

Figure 6.2: Informing children of parents' HIV-positive status n=15



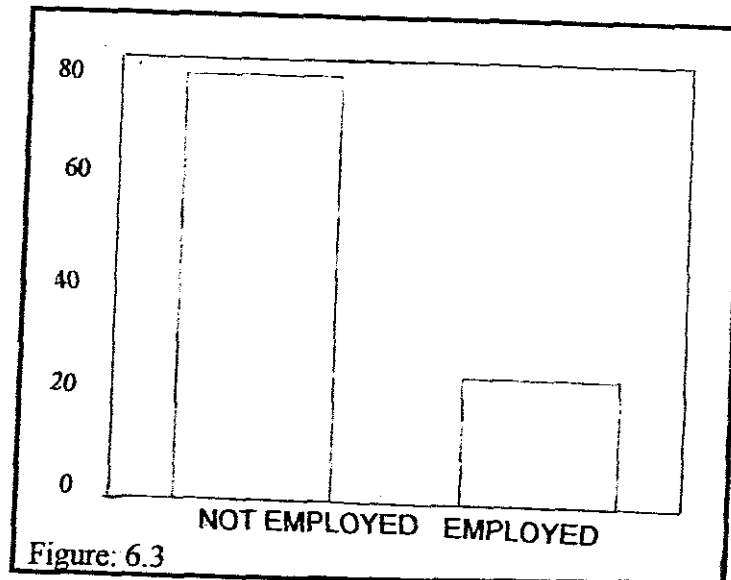
Key: ■ Informed their Children  
■ Did not informed their Children

Figure 6.2 indicates that, out of the 15 participants who informed their families, the majority of them, 87% (13), did not inform their children. They indicated that they feared exposing their children to embarrassment, stress and stigmatisation. Some felt that their children were too young to understand the details surrounding HIV/AIDS infection. Very few participants 13% (2), informed their children who, according to them, appeared to be mature enough to understand about the disease.

Item 12: Participants' employment status

This item was included to establish if participants were employed or not, and to ascertain their relationships with employers and colleagues with regard to their HIV-positive status. The findings regarding this information are depicted in figure 6.3.

Figure 6.3: Employment Status of Participants N=30



Key:  Employed  
 Not Employed

According to figure 6.3 it is clear that the majority of participants, 77% (23), were not employed. This supports the information from Love Life (2000:9-11) quoted in chapter two of this study, that many people living with AIDS are unemployed and poor. This causes inaccessibility of AIDS treatment which is costly and can be managed only by those covered by Medical Aid Schemes.

Figure 6.4: Informing Employer and colleagues on HIV-positive status of the individual n=7

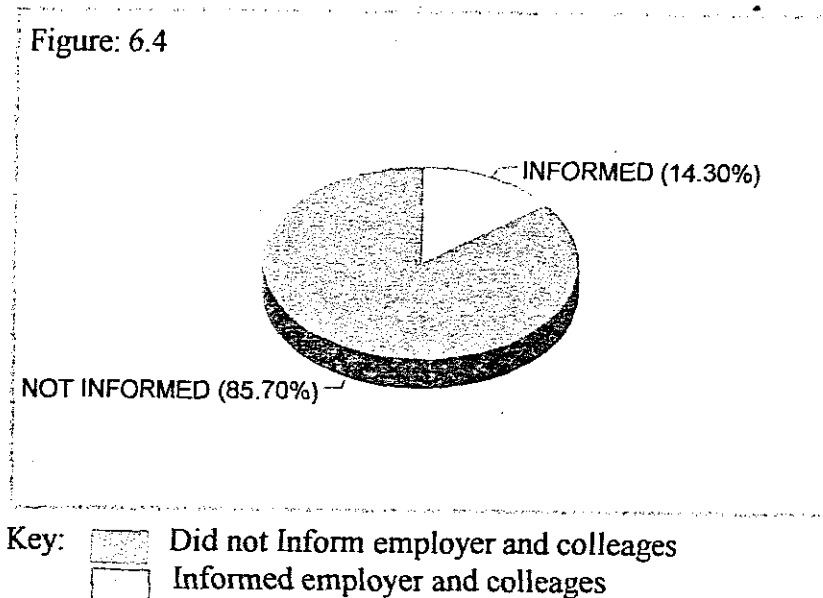


Figure 6.4 reflects that 85,7% (6) participants who were employed, did not inform their employers and colleagues of their HIV-positive status for fear of discrimination. Only 14.3% (1) participant informed his employer and colleagues as stated in figure 6.3. He stated that he gained full support of the employer and colleagues.

### **SECTION 3: PARTICIPANTS' KNOWLEDGE OF HIV/AIDS**

This section deals with the participants' knowledge on HIV/AIDS infection, particularly to establish if they can prevent spread of infection to others and recognise AIDS-related illnesses. In line with Orem's self-care theory, it was deemed important to investigate the participants' level of knowledge since adequate knowledge facilitates self-care, particularly in the supportive-educative mode.

Item 13: Transmission of HIV/AIDS infection to others

It is important to maintain high standards of infection control when dealing with clients with HIV/AIDS in a home setting. Participants were to indicate which activities could facilitate transmission of infection to others from the list of activities provided in table 6.11 N=30

Table 6.11 Transmission of Infection

<b>Transmission of Infection</b>	<b>Frequency</b>	<b>Percentage</b>
Sneezing and coughing	0	0
Sharing eating utensils	0	0
Cleaning vomitus	0	0
Sharing toilet seats	0	0
Used needle pricks	30	100%
Unprotected sexual intercourse	30	100%
Mosquito bite	0	0
Skin cuts or breaks	25	83%
Kissing	05	17
Tears	01	03%
Blood transfusion	28	93%
Handling loose stools without protection	30	100%

(Participants could give more than one answer)

Findings in table 6.11 reflect that all participants, 100% (30), knew that HIV infection could be transmitted through sharing of needles, sustaining a prick from a used syringe and needle, engaging in unprotected sex and handling of loose stools without wearing gloves.

A greater majority, 93% (28), indicated that one could be infected through blood transfusion. Skin cuts or cracks were identified by 83% (25). On the whole, the findings from this item revealed good, factual knowledge, which indicates reasonable effectiveness of health education programmes. It is only a minority who indicated inaccurate knowledge, for example 17% (5) who stated that kissing is one of the transmission methods and 7% (2) who did not include blood transfusion as one of the methods.

Item 14: Methods of preventing HIV/AIDS infection

This item was included to establish whether participants knew of methods of preventing HIV/AIDS infection to ensure that care-givers and other people are protected from infection. Findings are shown in table 6.12.

Table 6.12 Methods of preventing HIV/AIDS infection as indicated by participants N=30

Methods of Prevention	Frequency	Percentage
Use of condom	28	93,4%
Having one sexual partner	28	93,4%
Using gloves when handling secretions and blood	28	93,4%
Avoiding needle pricks	28	93,4%
Avoiding promiscuous behaviour	28	93,4%
No knowledge of preventive measures	2	6,6%

(Participants could indicate more than one preventive measure)

Table 6.12 reflects that the majority of participants, 93,4% (28), knew about the methods of preventing the spread of HIV infection, whilst the minority, 6,6% (2),

did not know. This is a challenge to provide extensive educational programmes to the community because of the risks of HIV/AIDS infection to those who do not know. Orem, in George (1990:96), emphasises the importance of the supportive-educative system, where a person who can perform or learn the required measures of therapeutic self-care should be taught promotive and preventive measures in order to become a self-care agent. This is important in the prevention or spreading of HIV/AIDS infection.

Item 15: AIDS-related illnesses that may affect individuals

Home-based care-givers for people living with HIV/AIDS are faced with many challenges in their caring roles. They may have to take care of clients with more than one condition from the list in Table 6.13. Participants were to indicate if they had suffered from any serious illnesses. They could indicate more than one illness. Their responses are shown in Table 6.13.

Table 6.13 Illnesses that affect individuals N=30

Illnesses	Frequency	Percentage
Pneumonia	10	33,3%
Tuberculosis	10	33,3%
Diarrhoea	10	33,3%
Oral Thrush	18	60,0%
Severe headaches	10	33,3%
Persistent fever	10	33,3%
Anorexia	10	33,3%
Fatigue	20	66,6%
Oral sores	19	63,3%
Weight loss	19	63,3%
Skin rashes	19	63,3%
Blindness	0	0
No infection	01	31,3%

(Participants could give more than one response)

Table 6.13 reflects the participants' responses to illnesses they had experienced. The majority of participants, 66,6% (20), had severe fatigue, 66,3% (19) had oral sores, 66,3% (19) had weight loss, 63,3% (19) had skin rashes, and 60% (18) reported severe oral thrush. The table indicates that 33,3% (10) participants suffered from each of the following illness; that is, Pneumonia, Tuberculosis, Diarrhoea, severe headaches, persistent fever, anorexia. Only 3.3% (1) participant reported to have never suffered from any illness. None reported blindness. These findings confirm the common problems of people living with AIDS as described by Alexander *et al.* (1994:908) and Van Dyk (1992:9-11) in chapter two. Adam's model (chapter four of this report) stresses the need for coordinated effort of the health care providers and family members, in helping the sick individuals experiencing different clinical manifestations of the disease, whether at home or in hospital, to find the best solutions to their problems timeously and continuously. Through home-based care, sick individuals are assisted by family members, community care-givers and nurses to cope with the effects of the disease.

Item 16: Occurrence of illness in regard to time and space

Inclusion of this item was to establish if respondents' illnesses were occurring for the first time, second time, third time or repeatedly on and off. According to Mzobe (2000:13) HIV/AIDS has two phases called the HIV/AIDS cycle (chapter two of this report). In the first phase the individual is asymptomatic, and in the second phase the individual presents with clinical manifestations indicated in table 6.13 of this chapter. These occur on and off until death takes place.

It has been observed that clients with HIV/AIDS, once opportunistic infections occur, tend to be sickly every now and then and are encouraged to take care of minor ailments at home. Findings on this aspect are shown in table 6.14.

**Table 6.14** Frequency of occurrence of illness in individuals N=30

	<b>Time and Duration</b>	<b>Frequency</b>	<b>Percentage</b>
Illnesses occurring for:	First time	12	40,0
	Second time	01	3,0
	Third time	0	0
	Repeatedly on and off	16	54,0
	Never been affected	01	3,0
<b>TOTAL</b>	-	30	100%

Table 6.14 reflects that 54% (16) participants have been repeatedly ill on and off. This indicates the lowered resistance to infection with gradual decline of health status which will finally terminate in death of affected individuals. 40% (12) participants have been sick for the first time, 3% (1) participant has been sick for the second time. 3% (1) participant has not been affected by a serious illness.

#### **6.4 SECTION 3: PAIN, type of pain and pain control**

The inclusion of this item was to establish if illnesses experienced by participants were accompanied by pain, severity of pain and which parts of the body were chiefly affected.

##### Item 17: Assessing presence of pain experienced by individuals

Participants were requested to indicate if they experienced pain with their illness. Participants' responses are shown in a pie diagram in figure 6.5.

Figure 6.5: Pain experienced with illness N=30

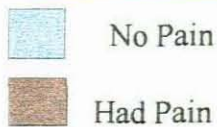
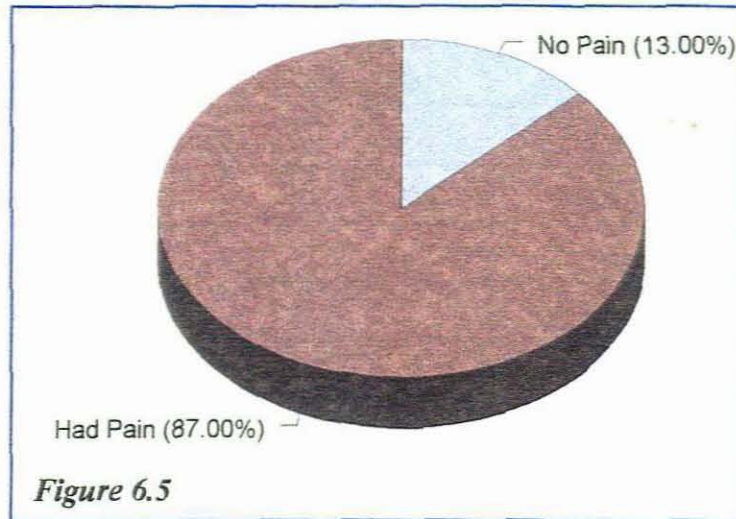


Figure 6.5 reflected that 87% (26) of participants experienced pain with their illnesses and only 13% (4) of participants indicated no pain experienced. It is clear that most opportunistic infections are accompanied by pain. Pain control is an important aspect when nursing terminally ill patients at home, as described in chapter three of this study.

Item 18: Description of pain with regard to part of the body affected

Participants were requested to indicate the part of the body affected by pain during illness episodes. Responses were as shown in Table 6.15.

Table 6.15 Individual's part of the body affected by pain N=30

Chest pains	10	33,4%
Whole body pains	8	27,0%
Headaches	4	13,3%
Stomach ache	3	10,0%
Stomatitis	1	3,0%
No pain experienced	4	13,3%
TOTAL	30	100%

Table 6.15 reflects that 33,4% (10) participants had chest pains, and 27% (8) indicated that they had whole body pains. Those with headaches were 13,3% (4) and 13,3% (4) reported no pains associated with their illness. Only 3% (1) reported stomatitis. These findings and those in table 6.13 are in line with Van Dyk (1992:9-11) who describes similar clinical manifestations to be commonly occurring in the acute HIV/AIDS stage.

Item 19: Assessment of severity of pain using the pain assessment ruler

Since pain is subjective, a colour-coded ruler produced by Roxane Laboratory adapted from Swanson and Nies (1995:805), was used to indicate severity of pain by participants. The severity of pain was noted in words which interpreted each colour coding. Participants' responses to severity of pain were addressed according to the colour-coded ruler as shown in table 6.16.

**Table 6.16** Pain assessment according to colour-coded rules N=30

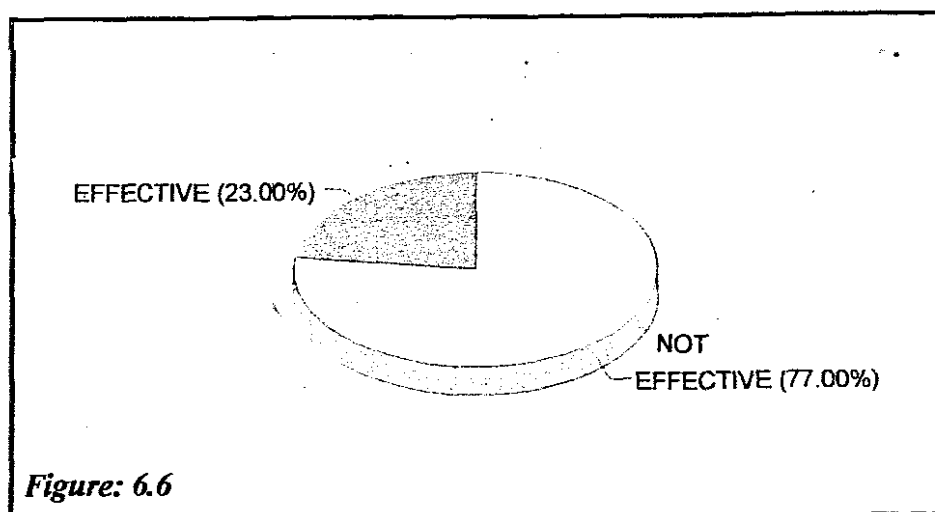
Colour Code	Description of severity of pain in words	Frequency	%
White	No Pain	4	13%
Light Grey	Mild Pain	02	07%
Dark Grey	Discomforting Pain	12	40%
Light Blue	Distressing Pain	08	27%
Blue	Intense Pain	01	03%
Deep Blue	Excruciating Pain	03	10%
<b>TOTAL</b>		<b>30</b>	<b>100%</b>

Table 6.16 reflects that the majority of participants 40% (12) had discomforting pain, whilst 27% (8) had distressing pain, 03% (1) had intense pain, 10% (03) had excruciating pain, 7% (2) had mild pain and 13% (4) had no pain. It is clear that HIV/AIDS disease is associated with different degrees of pain as the disease progresses.

**Item 20:** Pain control in the home environment

Pain control in the home environment was assessed to ascertain if home-based care is ideal for nursing the terminally ill clients with severe pains and complications. Pain controlling measures were established. Participants' responses with regard to the effectiveness of pain controlling measures at home are reflected in figure 6.6.

Figure 6.6: Effectiveness of pain control at home N=30





Key:  Effective pain control  
 Pain control not effective at home

Figure 6.6 reflects that 77% (23) of participants view home care to have less pain control measures. Pain controlling measures at home improve when there is a support system available for the terminally ill person, for example the assistance from the Highway Hospice already discussed in chapter three. Pain control described to be effective by 23% (7) of the participants is stated to be due to use of the following measures:

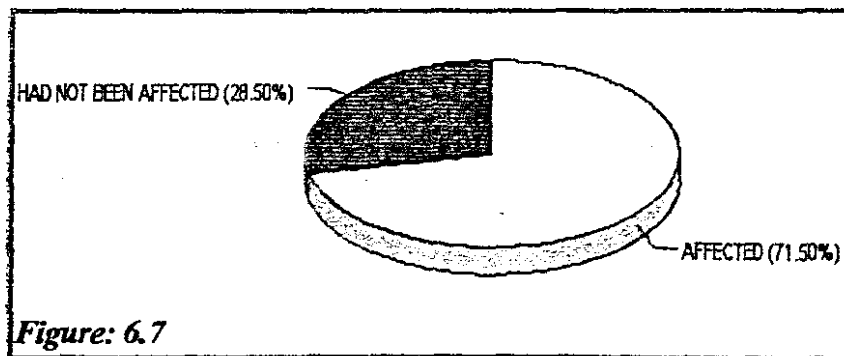
- ▶ Diversional therapy like listening to music.
  
- ▶ Adequate rest, application of heat to certain areas of the body e.g. hot water bottle.
  
- ▶ Massaging with herbal medicines.

- ▶ Reassuring and comforting the sick individual and never leaving him/her alone.
- ▶ Taking of prescribed pain-relieving medicine like Panado tablets whenever necessary.

Item 21: Effects of pain on people living with AIDS who are employees

Inclusion of this item was aimed at identifying if illness and severe pain had affected the individual's productivity at work. Responses from participants are reflected in Figure 6.7.

Figure 6.7: Effect of pain on affected individuals n=7



Key:  Had been affected by pain  
 Had not been affected by pain

Figure 6.7 shows that the majority of participants, 71,5% (5), who were employed were affected by illnesses and pain which interfered with employment. They had long records of absenteeism due to ill health, with weakness and fatigue with

painful hands and feet being outstanding problems. This may account for the high rate of unemployment amongst the people living with AIDS. Unemployment is a contributory factor to many problems which affect people living with AIDS, for example lack of money to buy nutritious meals and purchasing of medicines needed to boost the immune system. This has adverse effects on the health status and thus impacts negatively on home-based care. Uncontrolled pain causing insomnia, depression and anxiety, according to Nzimakwe (1997), may be minimised through massaging of painful limbs with scented oils or herbal medicines by traditional healers, as discussed in chapter three of this study. 28,5% (2) had not been affected by pain.

#### 6.5 SECTION 4: MEDICATION AND OTHER TREATMENT

This section deals with medication and other treatments used by people living with AIDS to cope with the symptoms of AIDS aimed at improving their health status and improving pain-relieving measures in a home setting.

##### Item 22: Establishing if participants were on long-term medication

Participants were asked if they were on long-term medication or not. They had to list the type of medications they used. The issue of medications for people living with AIDS is a very thorny one as discussed at length in chapter two. Participants' responses are reflected in table 6.17.

Table 6.17 Participants on long-term medication N=30

	Frequency	Percent
Participants on long-term medication	16	53
Participants not on long-term medication	14	47
TOTAL	30	100%

The above table reflects the number of participants on long-term therapy which is 53% (16) and those not on long-term therapy 47% (14). It is evident that the incidence of participants not on long-term therapy for their sicknesses is high. This is in line with findings that 77% (23) of the participants were unemployed and could not afford purchasing some of the long-term therapy recommended to improve and maintain their health status.

Item 23      Type of medications currently taken by participants

Inclusion of this item was to identify the type of medications used by participants so as to identify if they had access to expensive medications like anti-retroviral therapy. This has implications for home-based care-givers who must continue to administer or supervise the taking of medications at home as prescribed. Medications used are shown in table 6.18.

Table 6.18      Type of medications used by participants n=16

Long-term medications used	Frequency	Percent
Herbal medicines	16	100
Anti-Tuberculosis Drugs	11	69
Moducare	06	38
Long-term antibiotics	01	6

(Participants could give more than one response)

According to table 6.18 all 100% (16) participants on long-term medication were on herbal medicine. This supports literature cited in chapter two of this study which reflects that many clients choose herbal medicine because of their belief in traditional healing which is an African heritage. Anti-tuberculosis treatment was

used by 69% (11) participants. This proves that tuberculosis is becoming a major opportunistic infection associated with AIDS. Moducare is a popular nutrition supplement and immune system booster, used by 38% (6) of the participants. Only 6% (1) participant was on long-term antibiotic therapy for chronic chest infections. This latter finding was contrary to the researcher's observation that many patients with AIDS are kept on long-term Cometraxozole (Bactrim).

Item 24: Source of medication

This item was included to establish where participants obtain their supplies of medications. Responses of participants are reflected in table 6.19.

Table 6.19 Sources of medications for participants n=16

Source of medication	Frequency	Percent
Traditional healers/ <i>Inyangas</i>	16	100
Clinics	10	62,5
Hospital	8	50,0
Private Doctor	02	12,5
Chemist	02	12,5

(Participants could give more than one response)

According to table 6.19 all, 100% (16) participants on long-term medication obtained herbal treatment from traditional healers/*Inyangas*. According to Nzimakwe (1995:22), traditional medicine is always available and very convenient to get, since traditional healers are members of the community, sharing the same culture with the client and within walking distance. Helpless clients are often kept at the traditional healer's home for close monitoring of clinical manifestations and effects of the herbal medication. This is good for people living with AIDS who

need the psycho-social element of traditional healing which involves use of good communication methods, reassurance, sympathy and empathy. 62,5% (10) participants obtained their medication from the clinics. This is in line with the Primary Health Care approach of utilization of clinics as first points of contact with clients and as follow-up system. 50% (8) of these participants obtained their supply from the hospital. These may be clients on anti-tuberculosis treatment who needed repeated investigations and medical check-up. Only 12,5% (2) of participants consulted private doctors, and 12,5% (2) purchased the medication from the chemist. This is to be expected in view of the high unemployment rates or being in jobs which do not provide them with medical aid as already discussed in chapter two.

Some participants indicated their belief in using both Western medicine and traditional medicine simultaneously. Nzimakwe (1995:22) states that the rising incidence of diseases of unknown aetiology, and incurable diseases, like AIDS and some cancers, has increased the combining of Western methods of healing with traditional indigenous healing methods.

Item 25      Use of other forms of healing

This item was included to identify the perceived value of other forms of healing like acupuncture, prayers and use of Holy Waters for therapeutic purposes. In the home environment the client is free to use the form of treatment of his/her choice, the care-givers supervise the taking of this treatment. Responses to item 25 are reflected in table 6.20.

**Table 6.20** Use of other forms of healing N=30

Form of healing	Frequency	Percent
Prayers	30	100
Holy water	20	67
Acupuncture	12	40

(Participants could give more than one response)

The findings in table 6.20 indicate that 100% (30) participants use prayers as a form of healing. This finding supports the general belief that prayers are the best medicine as they involve the laying on of hands, facilitating close contact with the sick individual. It is pleasing to note that all participants 100% (30) believe in God's Healing Powers through prayer. Some participants, 67% (20), used Holy Water which is believed to be medicinal. The remaining 40% (12) respondents indicated use of Acupuncture for pain relief which is both a Western and a traditional way of treating pain.

## 6.6 SECTION 5: CARE AND SUPPORT SYSTEM

People living with AIDS need good care when sick and nursed at home and an ongoing support system to cope with stresses associated with AIDS. The family is a good support system when well motivated and equipped with knowledge and skills on how to take care of a sick individual as described in chapter three of this study. Chapter two reports on the support of the youth and initiatives by non-Governmental organizations to support projects that are implemented by the community to prevent further spread of HIV infection and nursing care of sick individuals at home. Findings on this aspect are reflected in table 6.21.

**Item 26**      **Perceptions on how the participants were cared for at home**

Participants were asked to explain their perceptions of how they were cared for at home. Their responses are shown in table 6.21.

**Table 6.21**      **Perceptions on how the participants were cared for at home** N=30

<b>Type of care</b>	<b>Frequency</b>	<b>Percent</b>
Assisted with activities of daily living	30	100
Reassured continuously	30	100
Always showered with love	30	100
Problems relating to illness are shared	15	50
Confidentiality is maintained	30	100

(Participants could indicate any perception)

As illustrated in table 6.21, all participants 100% (30) stated that they were assisted with activities of daily living when not well. Their needs and problems were assessed by family members and care-givers on a daily basis and whenever there was a need. Love, confidentiality and reassurance proved to be the key aspect in home-based care as expressed by the participants. Only 50% (15) of participants could freely share their illness related problems with family members. This may be associated with their non-revealing of their HIV-positive status to family members as already stated in section two of this chapter.

**Item 27**      **Rating of care received at home**

Home-based care is the continuity of hospital care following discharge of a patient as already stated in chapter three. The inclusion of this item was aimed at identifying the comprehensiveness of home-based care, in order to holistically meet

the needs of a person with chronic illness being nursed at home. Criteria used to rate care provided is reflected in table 6.22.

**Table 6.22** Rating of care received at home N=30

<b>Rating of care provided</b>	<b>Frequency</b>	<b>Percent</b>
Excellent	4	13
Very good	4	13
Good	22	74
Poor	0	0
Very poor	0	0
<b>TOTAL</b>	<b>30</b>	<b>100%</b>

Table 6.22 indicates that 74% (22) participants rated home-based care as good. This is encouraging, as it shows the dedication of care-givers including family members in their caring roles in spite of limited resources. 13% (4) participants rated home-based care as excellent, and 13% (4) participants rated home-based care as very good. This is possible if there is ownership of home-based care projects by the community with a good referral and support system as discussed in chapter three of this study.

**Item 28: Ways of improving home-based care**

This item was included to gain input from clients themselves on how best to improve the existing quality of care provided in a home setting. Responses were many and varied, and included the following:

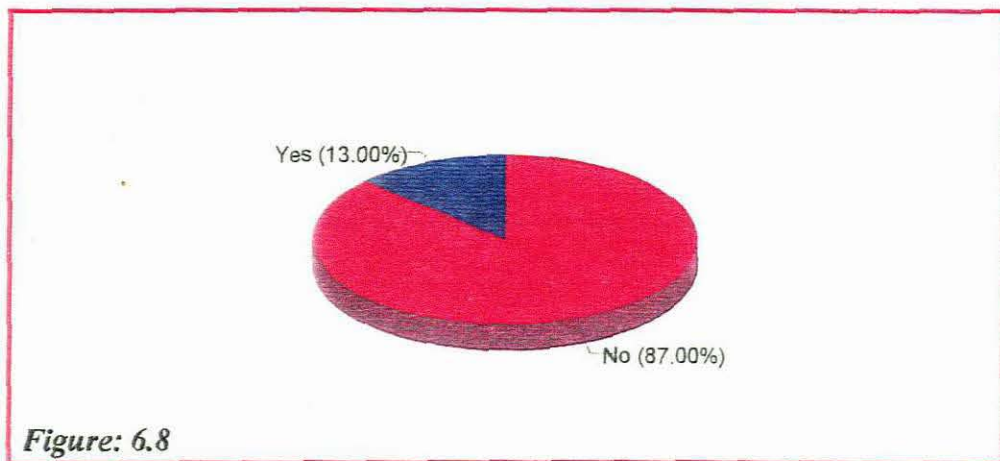
- ▶ Improvement of transport facilities.
- ▶ Improvement of the communication system, with client knowing where, how and when to contact a health service during emergencies.

- ▶ Inclusion of tablets for pain in the care-givers' kit bags to supply clients found to be in pain but without means of buying their own supply. However, it is important to ensure that the home care-givers are educated adequately on the use of analgesics.
- ▶ Adequate utilization of church members as a support system with known members who possess empathy, sympathy, perseverance and a friendly attitude. The changing beliefs in the church are a positive step whereby church leaders encourage their followers to openly speak about HIV/AIDS within their communities, and raise funds for those put into hardship and destitution due to HIV/AIDS.
- ▶ Training and providing of more community care-givers to help family members in their caring roles.
- ▶ Family teaching, to equip the family with strategies of preventing the infection from spreading, for example practising safe sex by using condoms and mutual faithfulness of patients.
- ▶ Improvement of community resources, e.g. AIDS counselling centres, youth centres, rehabilitation centres and other.
- ▶ Inclusion of disposable napkins in the kits of care-givers to provide for sick individuals with severe diarrhoea in acute stages of illness.
- ▶ No mention, however, was made on providing means of obtaining food supplements for the unemployed, and recreational facilities which could provide for release of stress and improve on sharing and socialising with others.

Item 29      Availability of pension or disability grant for people living with AIDS

In this item participants were to indicate whether or not they received disability grant or pension to provide for their basic needs. This is very important in view of the high rate of unemployment and the increasing costs of managing a person with AIDS during episodes of illness. Figure 6.8 reflects participants' responses.

Figure 6.8: Availability of pension or disability grant N=30



Key:  Yes  
 No

Figure 6.8 reflects that the majority of participants, 87% (26), were not receiving pension or grant. They were provided by family members with basic needs e.g. food, clothing and payment of medical bills. It had been identified in section two of this chapter that 77% (23) of participants were not employed. This is evidence of the adverse economic impact of HIV/AIDS infection on individuals and their families. The remaining 13% (4) participants were receiving pension.

Item 30      Providers of support to clients

This item was included because of the importance of a joint approach to provision of holistic support to AIDS clients. It was meant for participants to indicate those who supported them in times of illness and on a continuous basis. Participants' responses are shown in table 6.23.

Table 6.23      Providers of support to clients N=30

Responses	Frequency	Percent
Family	30	100
Health care workers	30	100
Neighbours	30	100
Employers	07	23
Colleagues	20	67
Any other (NGOs)	15	50

(Participants could give more than one response)

Table 6.23 reflects that family members, health care workers and neighbours were a good support system to sick individuals as indicated by 100% (30) participants. 67% (20) of participants reported that their colleagues provided support whenever needed. 50% (15) indicated that Non-Governmental Organizations like the AIDS Information Training Centre provided support and guidance to sick individuals. 23% (7) stated that employees provided support to sick individuals. Only 23% (7) stated that employers provided support to sick employees. This finding could be influenced by the fact that 77% (23) were unemployed as indicated in section two of this chapter. In addition, the majority, 86% (6), of the seven (7) participants who were employed, were reluctant to inform their employers of the HIV-positive status for fear of discrimination by employers, co-workers or dismissal from work.

It is evident that the majority of employees lack knowledge of their statutory rights specified in the Labour Relations Act No. 66 of 1995 (LRA) and other workplace legislation which protects workers against unfair discrimination and dismissals (AIDS Workplace Policy, November, 2000:7).

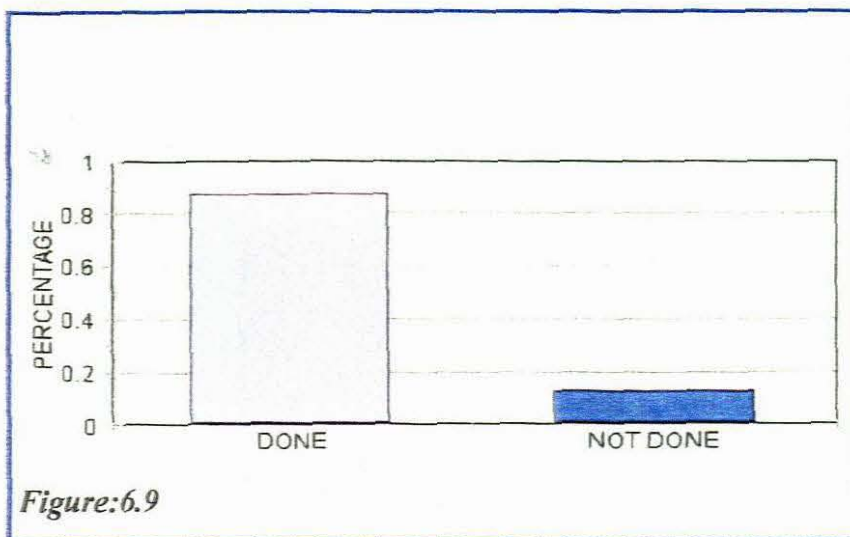
## 6.7 SECTION 6: COUNSELLING SERVICES

### Item 31: Counselling sessions

Inclusion of this item was to identify if clients' rights were observed or not. Participants were to indicate whether or not counselling was done after the HIV-positive status was diagnosed. Pre- and post-HIV test counselling is a requirement according to policy on HIV-testing (AIDS Workplace Policy, November 2000). The success of home-based care is influenced by positive attitudes which may be enhanced through counselling.

Participants' responses are reflected in Figure 6.9.

Figure 6.9: Pre- and post-HIV test counselling N=30



Key: HIV Pre and Post test counselling done.  
 HIV Pre and Post test counselling not done.

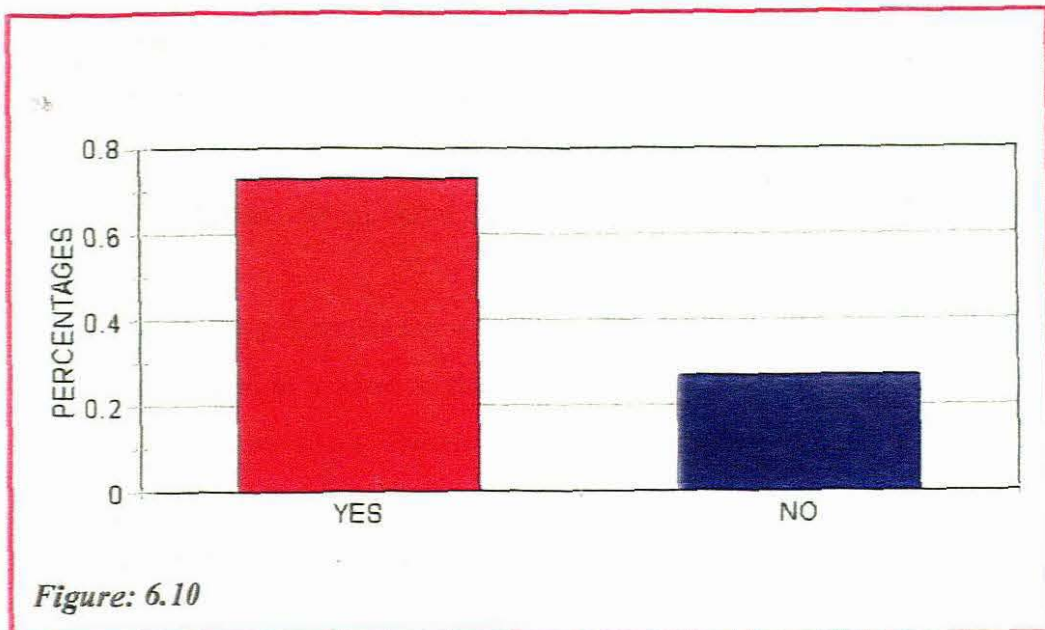
Figure 6.9 shows that the majority of respondents, 87% (26), had been counselled post-HIV/AIDS testing. This is the normal procedure that shows adherence to policy.

On the other hand 13% (4) participants did not undergo post-HIV/AIDS test counselling. They stated that they feared confirmation of the previous HIV/AIDS test results done elsewhere which tested positive, where they had denied that the results were accurate. Repeated illnesses due to AIDS-related diseases had made them to accept their condition. This poses a challenge of making counselling services available to all clients pre- and post-HIV testing, to facilitate acceptance of the condition and make plans to assist them to have healthy productive lives, and observing precautionary measures of preventing transmission of infection to others.

Item 32: Availability of AIDS counsellors

Inclusion of this item was to allow participants to indicate whether or not AIDS counsellors were available to them. Analysis of this information is reflected in figure 6.10.

Figure 6.10: Availability of AIDS counsellors N=30



*Figure: 6.10*

Key: ■ Yes Aids Counsellors available  
■ No Aids Counsellors not available

Figure 6.10 reflects that the majority, 73% (22), of participants indicated that the counsellors were always available. 27% (8) participants indicated that they had no access to AIDS counsellors. This poses a challenge of making AIDS counsellors available to all HIV-positive people in order to provide ongoing counselling sessions and help them cope with psycho-social problems associated with this disease.

Item 33      HIV/AIDS counselling helped individuals with HIV/AIDS infection

In this item participants were requested to indicate how AIDS counselling sessions helped them. Responses were as follows:

- ▶ Counselling sessions helped them in relieving stress by facilitating airing of feelings and emotions.
- ▶ Facilitated acceptance of the HIV-positive status with willingness to continue living as normally as possible.
- ▶ More knowledge was gained on promotive and preventive health, as well as curative and rehabilitative aspects of the disease.
- ▶ Access to new or latest information including medical advances is always available.
- ▶ Psychological, social and spiritual needs of the individual are addressed.
- ▶ Counselling assists the individual to deal with issues of sexuality, damaged relationships as a result of the HIV-positive status and coping with clinical manifestations of the disease and reactions to drug therapy.
- ▶ Counselling assists the individual to cope with impending death.

Item 34: Counselling officers / members

This item was considered important to determine if counselling was provided by people who are qualified and could be trusted to possess the necessary skills and competencies. Participants were asked to indicate people responsible for conducting AIDS counselling sessions as shown in table 6.24.

Table 6.24 Counselling Officers / Members N=30

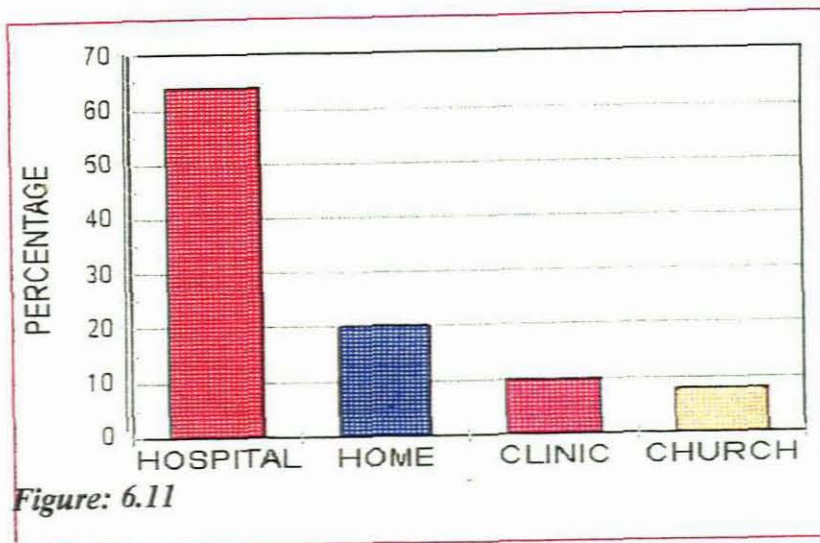
People conducting counselling	Frequency	Percent
AIDS Counsellors	22	75
Nurses	4	13
Priest	1	03
Community Health Workers	1	03
Friends	1	03
Other family members	1	03
TOTAL	30	10%

Table 6.24 illustrates that the majority of participants 75% (22) obtained counselling from trained AIDS counsellors. The formal training that AIDS counsellors undergo empowers them with the required counselling skills to conduct counselling sessions professionally. 13% (4) of the participants indicated that nurses conduct counselling sessions. The researcher having undergone formal training in AIDS counselling, believes that it is important to equip all nurses with professional counselling skills. The community health workers, priests, friends and other family members were each identified by 3% (1) participant only. It is clear that there should be more people trained in counselling skills including family members, friends and community members. They will be of help to counsel all those with problems in order to cope with stressful situations associated with HIV/AIDS and related illnesses.

Item 35: Place for conducting counselling sessions





This item was included for respondents to identify the place where counselling sessions could be held. This would facilitate proper placement of counselling services in the near future, to ensure that these services can be effectively utilized by the community members. Figure 6.11 shows the respondents' responses.

Figure 6.11: Place for conducting counselling sessions N=30



*Figure: 6.11*

Key: Place conducting counselling:-

-  = Hospital
-  = Home
-  = Clinic
-  = Church

According to figure 6.11 the majority of participants, 63% (19), stated that counselling sessions were done in hospital. This may be ideal for easy referral to

other members of the interdisciplinary team when a need arises. Those who referred to a home setting comprised 20% (6) of the sample. Only 10% (3) were of the opinion that clinics were to be used for counselling sessions and 7% identified churches. This poses a challenge for the church to be more involved, since it is an important social institution which should give spiritual care and counselling to AIDS clients, lest they feel rejected by their own churches.

## **6.8 CONCLUSION**

In this chapter data collected from people living with AIDS infection was analyzed. It highlighted their adverse reactions to HIV/AIDS diagnosis, the management of opportunistic infections, pain controlling measures in hospital and in the home setting, counselling services, support systems and continuous assessment of clients' needs. Data collected from those participating in care, that is home care-givers including family members, social workers and traditional healers will be analyzed in the seventh chapter.

## **CHAPTER 7**

### **DATA ANALYSIS AND INTERPRETATION OF FINDINGS FOR CARE-GIVERS, SOCIAL WORKERS AND TRADITIONAL HEALERS**

#### **7.1 INTRODUCTION**

Analysis of data obtained from questionnaires completed by home care-givers, social workers and traditional healers is presented in this chapter. Findings will confirm the need for a holistic approach and joint effort or partnership in the care of people living with AIDS. Data will be presented in the form of tables and graphs.

#### **7.2 HOME CARE-GIVERS**

Home care-givers were either family members or community volunteers who dedicated themselves to the nursing care of sick individuals with AIDS-related illnesses and other chronic diseases.

##### **SECTION 1: PERSONAL PARTICULARS**

This section deals with personal particulars of care-givers in order to obtain a clear profile of them as valuable care-providers in a home setting.

###### **Item 1: Gender of participants**

Inclusion of this item was to verify if care-providers were males or females. Findings are shown in table 7.1

Table 7.1     Gender of participants   n=22

Gender	Frequency	Percentage
Male	0	0
Female	22	100
Total	22	100%

Table 7.1 reflects that 100% (22) of the participants were females. This finding supports the general view that nursing is a female-dominated profession. Women have always been associated with caring and nurturing, according to the genesis of nursing in primitive societies as documented by Dolan, Fitzpatrick and Herrmann (1985:1). The New Testament (Romans, 16:2) cited in Spradley and Allender (1996:70) refers to a woman as a person with noble character, who opens her arms to the poor, extends her hands to the needy, and a helper of many. It is not surprising to find that women even today are noted home care-givers to sick individuals.

Item 2: Age group in years

This item was included in order to identify the ages of care-givers. Caring for people with AIDS-related illnesses particularly in their terminal stages of illness is very demanding and stressful. It therefore becomes difficult for the young (teenagers) and elderly to cope with caring roles. Findings of age group classification are shown in table 7.2

Table 7.2     Age distribution of care-givers n=22

Age group in years	Frequency	Percentage
11-20	0	0
21-30	05	22,8
31-40	09	40,9
41-50	07	31,8
51-60	01	4,5
61 and above	0	0
Total	22	100%

According to table 7.2 the majority of participants, 40,9% (9), were in the 31-40 age group. This is the most productive group which, due to unemployment rates, is readily available for home-based care, followed by 31,8% (7) in the 41-50 age group, 22,8% (5) in the 21-30 age group and 4,5% (1) of 51-60 age group. There were no participants of the age groups 11-20 years and above 60 years respectively. It is evident that care-givers are mainly young adults and middle-aged people. They provide community services by caring for people with chronic illnesses like hypertension, tuberculosis and AIDS. Some receive small incentives of R300 as travelling allowances, as cited by Qulo in chapter three of this study.

### Item 3: Relationship with client/s

This item was included to identify if the care-giver was a family member or a member of the community. Van Dyk (1992:9-11), in chapter two of this study, reports his observation of family members of a person diagnosed as HIV-positive. He states that family boundaries become more rigid and strict confidentiality concerning the disease is contained amongst family members out of fear of

stigmatization. The participants therefore may not wish to expose a relationship with an HIV-positive person. Findings on this aspect are shown in figure 7.1

Figure 7.1 Participants' relationship with clients - N=22

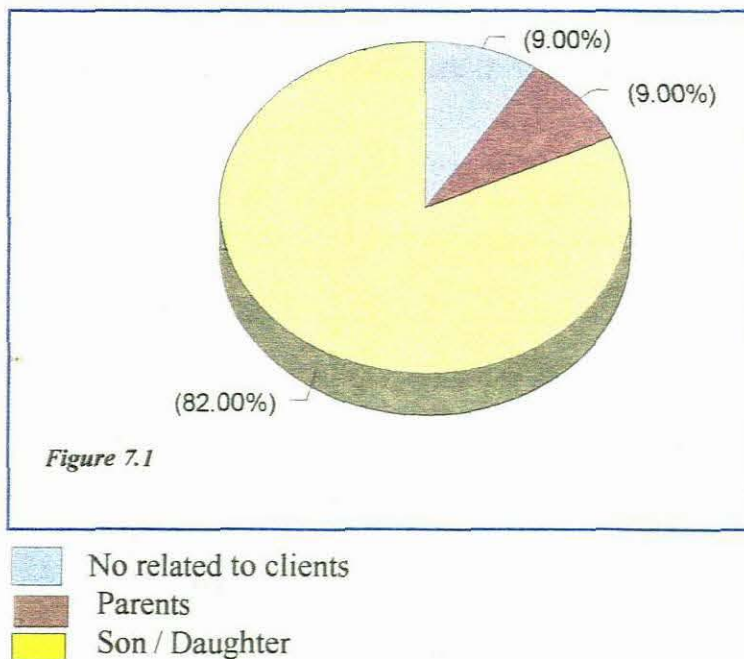


Figure 7.1 shows that the majority of participants, 82% (18), had no relationships with the sick individuals, while the minority of participants, 9% (2), were parents of the sick individuals and family members respectively. The majority of people with an HIV-positive status do not inform their families, fearing their adverse reactions like rejection or total abandonment, as cited by Lambert and Lambert (1987) in Alexander *et al.* (1994:910).

Item 4: Educational level

This item was included to identify the educational levels of participants, so as to establish if they had enough information that permits people to take steps towards self-protection as emphasised through educational programmes. They are able to properly monitor their clients' compliance with drug therapy prescribed for their clients. Findings of this aspect are shown in table 7.3.

Table 7.3      Educational level of participants    n=22

Level grade	Frequency	Percentage
1-3	0	0
4-6	0	0
7-9	4	18
10-12	16	73
Above Grade 12	2	9
Total	22	100%

Table 7.3 reflects that the majority of participants, 73% (16), had a standard 10 certificate or grade 10-12, the remaining 18% (4) had grade 7-9, there were none in grade 1-3 and 4-6 respectively, 9% (2) had above grade 12. Participants in grade 7-9, fit well into all home-based care programmes. Participants in grades 10-12 probably account for the high turnover in home-based care since they are qualifying to enter higher education or the job market and usually take part in home-based care temporarily.

Item 5: Post-standard 10 certificate/diploma or degreeTable 7.4 Participants with post-standard 10 certificate/diploma or degree

	Frequency	Percentage
Professional nurse with basic degree	01	05
Professional nurse with Diploma	01	05
No post standard 10 qualification	20	90
Total	22	100%

According to table 7.4 the majority of participants, 90% (20) had no further education past matric. The remaining 10% (2) participants were professional nurses. It is pleasing to note that amongst home-based care-givers, there are professional nurses who could be utilised in the supervising of care provided by other care-givers thereby giving them moral support in their house-to-house visiting roles.

**SECTION 2: BASIC NURSING PREPARATION FOR HOME-BASED CARE**

Basic nursing preparation for home-based care has been described by Nzimakwe (1997:23) cited in chapter three, of this study, as an important tool that equips care-givers with relevant knowledge and skills in basic nursing care, as well as the counselling and communication skills necessary when nursing clients with chronic illnesses like AIDS in a home setting.

Item 6: Basic nursing preparation of participants

Inclusion of this item was to ascertain whether participants had basic nursing skills or not. This would help in proper planning of their educational programmes based on their nursing background. Participants' responses are shown in figure 7.2

Figure 7.2 Basic nursing preparation of participants n=22

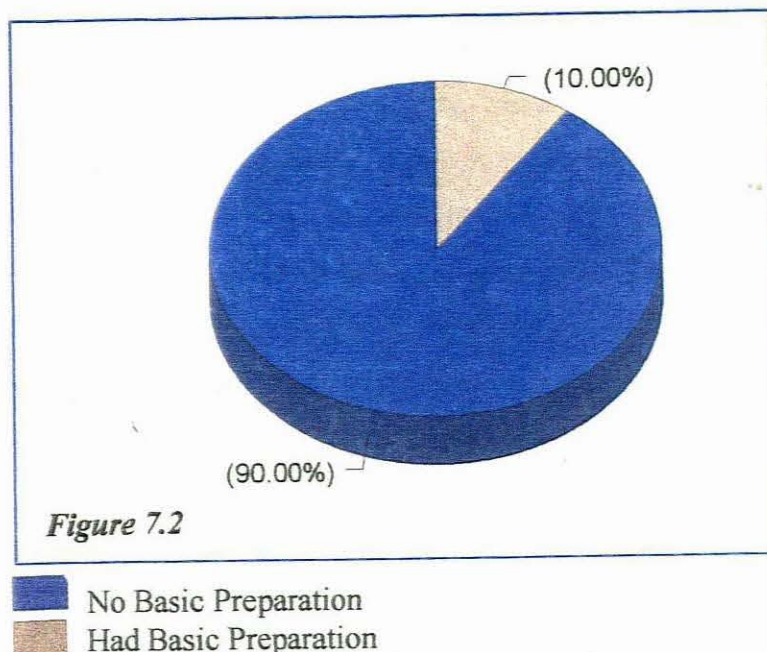


Figure 7.2 reflects that 90% (20) of participants had no basic nursing preparation, while 10% (2) of participants were trained professional nurses. Findings show the need of ongoing educational programmes for care-givers to help them cope with the challenges of HIV/AIDS diseased clients nursed at home.

Item 7: Other qualifications/certificates relevant to nursing

It was deemed necessary to find out if participants had any other qualifications relevant to nursing. This would facilitate a plan of action in the drawing up of educational programmes for care-givers. Participants' responses are shown in table 7.5.

Table 7.5 Qualifications certificates relevant to nursing n=22

Certificates/qualifications	Frequency	Percentage
Home-based care	20	90%
First Aid nursing	4	18%
Geriatric nursing	2	9%

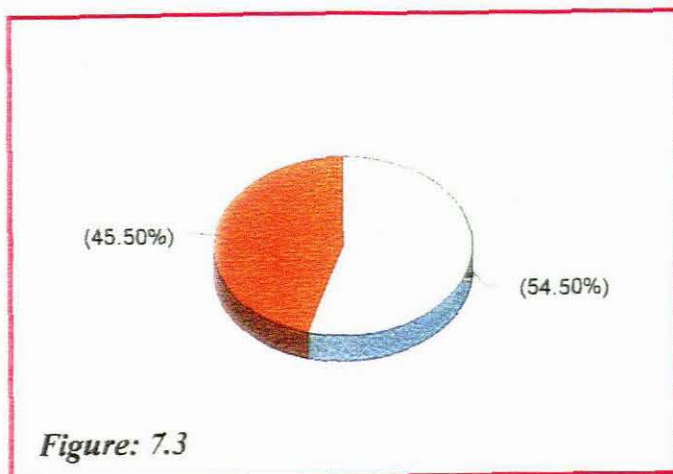
(Respondents had more than one qualification or certificate)

Table 7.5 reflects that the majority, 90% (20) of participants had home-based care certificates. This course provides them with the necessary basic nursing skills. There were 18% (4) with First Aid nursing certificates and 9% (2) with Geriatric nursing certificates. These qualifications appear to have complemented the formal basic nursing education already described as important by Nzimakwe (1997), cited in chapter three of this study. The National Department of Health, in its concern for lack of coordination and consistency in home-based care training, has compiled a national training manual which is still being piloted and will serve as a foundation for all home-based care training programmes.

Item 8: Counselling skills

Counselling helps in relieving stress and improves coping mechanisms in affected individuals. It is important for AIDS counsellors to have counselling skills obtained through formal counselling training courses. Inclusion of this item was to identify if participants had counselling skills or not, for future proper planning of counselling training courses by programme planners for home care-givers. Findings are shown in figure 7.3.

Figure 7.3 Participants attendance at a counselling course n=22





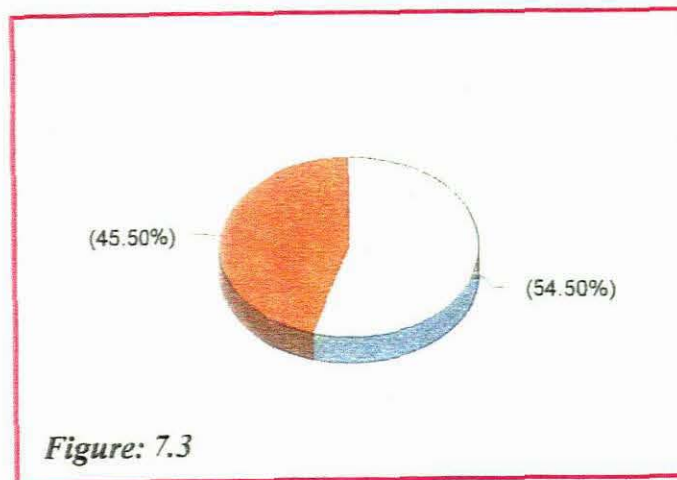
Key:  Had no Counselling Training  
 Had Counselling Training

Table 7.5 reflects that the majority, 90% (20) of participants had home-based care certificates. This course provides them with the necessary basic nursing skills. There were 18% (4) with First Aid nursing certificates and 9% (2) with Geriatric nursing certificates. These qualifications appear to have complemented the formal basic nursing education already described as important by Nzimakwe (1997), cited in chapter three of this study. The National Department of Health, in its concern for lack of coordination and consistency in home-based care training, has compiled a national training manual which is still being piloted and will serve as a foundation for all home-based care training programmes.

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Figure 7.3    Participants attendance at a counselling course    n=22



**Figure: 7.3**

Key:  Had no Counselling Training  
 Had Counselling Training

According to figure 7.3, 54,4% (12) participants had attended counselling courses, 45,5% (10) participants indicated that they had not undergone any training and use their long experience in the nursing of sick individuals at home.

It is important that all care-givers should have formal training in counselling of clients, in order to have the necessary skills when dealing with very sensitive issues like HIV/AIDS infection, death and care of orphaned children as a result of AIDS.

Item 9: Place where counselling courses were obtained by care-givers

Inclusion of this item was to establish if participants had undergone training courses which produce proof of training (certificates) at the end of training, at valid training centres. This acts as proof of having adequate counselling skills needed in home-based care as stated in page 174 of this report. Findings are reflected in table 7.6.

Table 7.6 Place where counselling courses were attended n=12

Place of training	Year	Duration of course	Frequency	Percentage
United States of America	1993	3 months	01	8,5
Durban City Health	1998	2 weeks	06	50
Durban City Health	1999	2 weeks	05	41,5
Total	-	-	12	100%

Table 7.6 reflects that 50% (6) participants trained for two weeks in Durban's City Health Department in 1998, while 41,5% (5) trained in the Source Centre in 1999, 8,5% (1) participant obtained her counselling certificate in 1993 from the United States of America, duration of the course was three months.

### SECTION 3: EXPERIENCE IN THE CARE OF PEOPLE LIVING WITH HIV/AIDS INFECTION

The sensitive and chronic nature of HIV/AIDS infection and serious opportunistic infections require an experienced person capable of providing physical, spiritual and psycho-social support and care to sick individuals during acute stages of illness. An experienced care-giver is believed to show sympathy, empathy and understanding of varying degrees of symptoms produced by illnesses associated with AIDS, as already described by Van Dyk (1992) in chapter two of this study.

#### Item 10: Previous experience in care of AIDS clients

Participants were asked to indicate the number of people living with AIDS they have nursed to assess their experience in taking care of these clients. Responses are shown in figure 7.4.

Figure 7.4 Participants' experiences according to number of clients nursed  
n=22

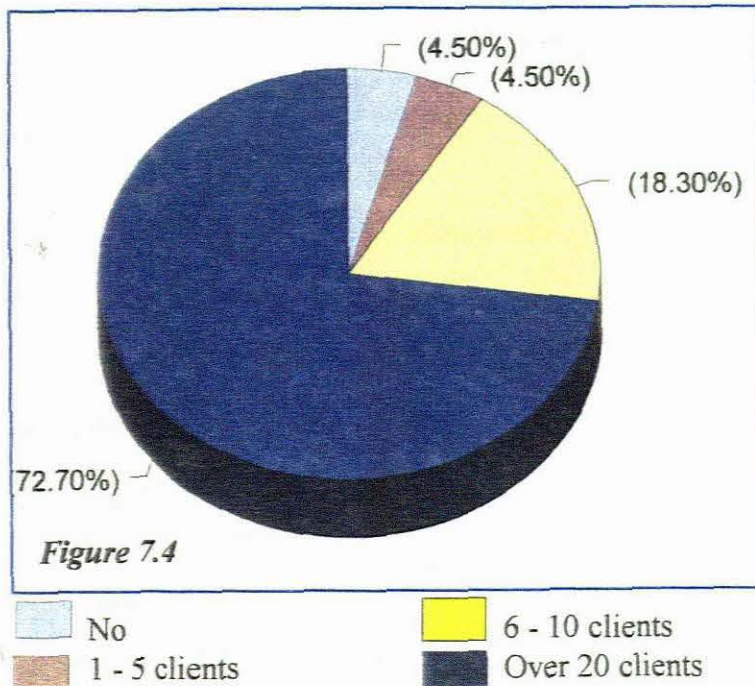


Figure 7.4 reflects that 72,7% (16) participants had each nursed 1-5 clients, 18,3% (4) participants had nursed over twenty (20) clients, and 4,5% (1) participant had nursed 6-10 clients. The remaining 4,5% (1) participant had never nursed a client with HIV/AIDS. It is clear that the majority of the participants have reasonable experience of nursing clients with chronic illnesses, particularly AIDS-related illnesses.

**Item 11: Participants opinion of their clients' rating of home-based care**

Inclusion of this item was to assess the participants' views on how their clients rate the quality of care provided through home-based care. This acts as an evaluation tool to assess the quality of care provided and maintain high standards of care as well as improve what is regarded as good to excellent care at home. Findings are shown in table 7.

**Table 7.7 Participants' opinions of their clients rating of home-based care**

Rating scale	Frequency	Percentage
Excellent	18	81,8
Good	4	18,2
Average	0	0
Poor	0	0
Total	22	100%

According to table 7.7, the majority of participants, 81,8% (18), believe that many people living with AIDS regard home-based care as excellent, and 18,2% (4) of the participants were of the opinion that home-based care was rated as good by their clients. There were none of the opinion that home-based care was average or poor. It is pleasing to note that home-based care is regarded as excellent by

clients themselves, and see it as poor in spite of scarce resources. The researcher strongly believes that this high rating is in line with advantages of home-based care for people living with AIDS as cited in chapter three of this study.

Item 12: The likelihood of being infected when nursing a person with HIV/AIDS

Inclusion of this item was to assess the participants' possibilities of contracting HIV infection through their caring roles. The findings are shown in table 7.8.

Table 7.8 Participants' likelihood of being infected with HIV infection during caring roles n=22

Rating scale	Frequency	Percentage
Will never be infected	18	81,8
Likely to be infected	4	18,2
Total	22	100%

According to table 7.8, 81,8% (18) participants indicated that they could not be infected since they observed the precautionary measures of prevention against HIV/AIDS infection. The remaining 18,2% (4) felt that there was the likelihood of contracting HIV infection when nursing AIDS clients without using protective materials, for example gloves, which are not always available.

#### **SECTION 4: SUPPORT SYSTEM FOR HOME CARE-GIVERS**

A good support system which may be colleagues, health care personnel, non-Governmental Organizations' members, family members or any significant group/s, is vital to help care-givers solve and overcome problems associated with

their caring roles for people living with AIDS. Participants' views with regard to working with others and the support system available to them is assessed in this section.

Item 13: Preferences on working alone or with others in the caring roles

This item was included to establish whether participants preferred working alone or with others when providing home care. Participants' responses are shown in table 7.9.

Table 7.9 Preference on working alone or with others n-22

	Frequency	Percentage
Working with others	20	91,0
Working alone	01	9,0
Total	22	100%

According to table 7.9, the majority of participants preferred working with others. The reasons given for their choice were as follows:

- ▶ As a group they share experiences and workload.
- ▶ They jointly solve problems related to their caring roles.
- ▶ They feel more secure as they visit clients in their homes.

The remaining 9% (2) participants preferred working alone. They reasoned that being alone facilitates good bonding between the care-giver and the sick individual. This also ensures that confidentiality is maintained.

Item 14: Groups that provide good support to care-givers

In view of the stresses associated with care of clients with AIDS-related illnesses at home, a holistic approach to support for the care-givers needs priority attention. Inclusion of this item was to ascertain the groups which provide this support as shown in table 7.10.

Table 7.10 Groups that provide support to care-givers

Groups	Frequency	Percentage
Social workers	10	45
Non-Governmental Organizations	05	23
AIDS counsellors	04	18
Nurses	02	09
Doctors	01	05
Total	22	100%

According to table 7.10, 45% (10) participants indicated that social workers provided good support to them in their caring roles. The support of non-Governmental Organizations was noted by 23% (5) participants. As an example the AIDS Foundation helped with funding of home-based care projects as discussed in chapter three of this study. 18% (4) of the participants highlighted that they got support from AIDS counsellors. Few participants, 9% (2), indicated nurses' support and only 5% (1) mentioned doctors' support. The researcher is of the opinion that the limited nurses' support to care-givers is due to the fact that nurses are also on duty in hospitals or clinics and cannot provide expected support to care-givers in their caring roles. This is a challenge for effective implementation of District Health Nursing and home visiting by nurses, and a good security system. There is no support indicated by care-givers who were volunteers from family members, unlike people living with AIDS who got full support from their families throughout their illnesses, as stated in chapter 6 of this study.

## SECTION 5: KNOWLEDGE ON HIV/AIDS

Care-givers are expected to be knowledgeable on aspects of mode of transmission of HIV/AIDS infection and preventive measures, so as to prevent auto-infection and transmission of infection to others. This knowledge is also important to prevent unfounded fears perpetuated by the myths about the transmission of HIV infection.

### Item 15: Knowledge on transmission of HIV/AIDS infection

Participants' knowledge on how HIV infection is transmitted from one person to another was assessed according to table 7.11.

Table 7.11 Transmission of HIV infection from one person to another

Mode of infection	Frequency	Percentage
Unprotected sex	22	100
Skin cuts or breaks	22	100
Blood transfusion	18	81,8
Used needle prick	18	81,8
Handling loose stools without protection	12	54,5
Cleaning vomitus without protection	6	27,2
Kissing	1	4,5
Sharing toilets	0	0
Mosquito bites	0	0
Tears	0	0
Sharing of eating utensils	0	0

(Participants could give more than one response)

Table 7.11 reflects that the majority of respondents, 100% (22), were aware that HIV infection is transmitted from one person to another through unprotected sexual relations and through skin cuts. 81,8% (18) of participants indicated that blood transfusion and used needle pricks are also transmission agents. 54% (12) participants indicated that handling loose stools without wearing gloves, and 27,2% (6) that cleaning vomitus, may lead to infection of care-givers. Only 4,5% (1) participant indicated that HIV infection is transmitted through kissing. These findings reflect good factual knowledge by participants of the mode of transmission. It is pleasing to note that care-givers' knowledge on transmission of infection from one person to another is better than that of people living with AIDS and could therefore confidently give health education to them.

Item 16: Practices necessary for preventing transmission of HIV infection when nursing clients

This item was included to ensure that participants involved in home-based care were clear about the methods of preventing HIV infection. Findings are presented in table 7.12.

Table 7.12 Practices for preventing transmission of HIV infection n=22

Practices	Very necessary		Necessary		Not necessary		
	Frequency	%	Frequency	%	Frequency	%	Total %
Hand washing after contact with the clients	6	27%	16	73%	0	0	100%
Wearing gloves when handling body fluids	22	100%	0	0	0	0	100%
Avoiding recapping injection needles after use	22	100%	0	0	0	0	100%
Covering abrasions/cuts with waterproof covering	21	95%	1	5%	0	0	100%
Use of condoms during sexual intercourse	22	100	0	0	0	0	100

(Respondents could give more than one answer)

Table 7.12 reflects that all participants, 100% (22), indicated that it was very necessary to wear gloves when handling body fluids, to avoid recapping of injection needles after use and use of condoms during sexual intercourse. 95% (21) of participants indicated the importance of covering abrasions or cuts with waterproof covering when attending to AIDS clients. Only 27% (6) indicated that it is very necessary to wash hands after contact with a client with AIDS. 73% (16) stated hand washing as necessary in-between handling of clients, and 5% (1) participant indicated that covering abrasions and cuts with waterproof covering was necessary. Findings reflect that participants know about preventive measures against infection by the HIV virus. There were no other preventive measures mentioned by participants.

#### **SECTION 6: FACTORS THAT INFLUENCE PROVISION OF CARE**

Health care provision may be affected by many factors which may have a positive or negative influence on the individuals' health status. AIDS is noted for being a chronic disease without a cure. It is a killer disease when precautionary measures are not observed i.e. using a condom during sexual intercourse.

Item 17:      Extent to which the following factors negatively influence provision of home-based care for people living with AIDS

Participants were questioned on the extent to which factors listed on the questionnaire negatively influence the provision of care for people living with AIDS, using a provided rating scale. Findings are shown in table 7.13.

**Table 7.13** Extent to which the following factors negatively influence provision of care n=22

Factors	Strongly agree		Agree		No influence		
	Frequency	%	Frequency	%	Frequency	%	Total %
Fear of contracting AIDS	2	9,1	10	45,5	10	45,5	100
Age of care-giver	3	13,7	6	27,3	13	59,1	100
Age of the client	7	31,8	11	50,0	4	18,2	100
Lack of resources	9	40,9	9	40,9	4	18,2	100
Social stigma	9	40,9	8	36,4	5	22,7	100
Level of education	5	22,7	11	50,0	6	27,3	100
Lack of counselling skills	7	31,8	12	54,5	3	13,7	100
Concern about personal safety	7	31,8	13	59,1	2	9,1	100
Stressful situations	5	22,7	13	59,1	4	18,2	100

(Participants could give more than one response)

Table 7.13 reflects the participants' views of different factors which adversely influence the provision of care as follows:

- ▶ The majority of participants, 81,8% (18), agreed on the negative influence of the clients' age on care provision, while 18,2% (4) participants indicated that this had no influence. 81,8% (4) noticed no influence of this factor, while stressful situations were mentioned by 81,48% (18) participants.
- ▶ 77,3% (17) participants agreed on social stigma as a negative factor while 22,7% (5) did not agree.
- ▶ 72,7% (16) participants agreed that care-givers' level of education, if low, has a negative influence on the provision of care while 27,3% (6) had not noted the difference.

- ▶ 54,5% (12) participants agreed that fear of contracting AIDS negatively influences the provision of care while 45,5% (10) indicated that this had no influence if preventive measures are observed.
- ▶ 41% (9) participants agreed that the age of the care-giver had an influence on the care provided while 59% (13) participants indicated that age had no influence. The researcher disagrees with the 59% (13) participants whose views are that age had no influence on the care provided for people living with AIDS since it has been mentioned in item two of this chapter that care-givers are mainly young adults and middle-aged people.
- ▶ 13,7% (3) participants indicated that lack of counselling skills had no influence on the provision of care, which contradicts what has been discussed in chapter six in that counselling skills are a priority requisite for all care-givers. According to the findings in this table participants appear to have different views on factors that negatively affect the care given to people living with AIDS and being nursed at home.

## **SECTION 7: ASSESSMENT OF CLIENTS**

The ongoing assessment of clients' needs and identification of problems is a priority when nursing clients with chronic illnesses like AIDS. Clients who are critically ill and dependent on care-givers for the maintenance of daily activities receive wholly compensatory nursing care as described by Orem (1990) cited in chapter four of this study.

### Item 18:      Assessment of clients' needs

This item was included to ascertain if clients' needs were assessed regularly in order to identify their problems and needs, so that active steps could be taken to

address those problems promptly and prevent complications. Robert and Rakel (1990) cited in chapter three of this study provide an assessment for chronic illnesses of clients nursed in a home setting. All the participants, 100% (22), indicated that their clients were assessed to solve their problems.

Item 19: Frequency in assessing clients' needs

Participants were asked to indicate how often their clients' needs were assessed, whether on daily, weekly, monthly or three-monthly intervals. This is important in order to ensure that the care-giver intervenes only where there is a self-care deficit, as supported by Orem's self-care theory. Findings are shown in table 7.14.

Table 7.14 Frequency in assessing clients' needs n=22

Duration	Frequency	Percentage
Daily	14	63,6
Weekly	8	36,4
Monthly	0	0
Every three months	0	0
Total	22	100%

Table 7.14 shows that 63,6% (14) participants indicated that clients were assessed daily to identify their problems and needs. 36,4% (8) participants assessed their clients on a weekly basis. It is pleasing to note that the majority of participants had time to visit their clients frequently. This is proof of their dedication to their caring roles, and is in line with Robert and Rakel's patient needs assessment tool described in chapter three.

Item 20: People who assessed clients regularly

Inclusion of this item was to establish people who assessed clients on a daily and weekly basis as indicated in table 7.15.

Table 7.15 People who assessed clients regularly; n=22

	Frequency	Percentage
Care-giver herself	22	100
Community health workers	11	50
Nurses	5	22,7
Other (Traditional Healers)	5	22,7
Doctors	4	18,1

(Participants could give more than one response)

As illustrated in table 7.15, 100% (22) participants indicated that they were assessed regularly by care-givers themselves, 50% (11) mentioned community health workers' involvement, and 22,7% (5) and 22,5% (5) of participants respectively indicated nurses' and traditional healers' involvement in the assessment of clients. The minimal number indicating nurses' involvement is possibly due to ineffective district nursing and home visiting, which is not a common practice. Clients were also assessed by traditional healers as indicated per consultation. Few participants, 18,1% (4), indicated doctors' involvement in assessing of clients who consult them during acute episodes of illnesses or for check-ups.

## SECTION 8: AVAILABILITY OF LOCAL COMMUNITY HEALTH SERVICES

According to chapter five of this study, there is one district hospital with eight satellite clinics serving the Umlazi population of approximately one million. The increasing population, accompanied by a high rate of people with acute illnesses as a result of AIDS, demand improved health services. Findings on this aspect are described in item 21.

Item 21: Period of hours with regard to availability of local community health services and referral system between hospital and hospice care

Inclusion of this item was to identify whether health services in the community areas of Umlazi were available for 24 hours or not, as this would provide support for the home-based care-givers e.g. for urgent referral and/or consultation. Findings on this aspect are shown in table 7.16.

Table 7.16 Period of hours with regard to availability of local community health services

Hours of work	Duration	Frequency	Percentage
8 hours	07:00-16:00	22	100
10 hours	07:00-18:00	0	0
24 hours	07:00-07:00 (next day)	0	0
Total	-	22	10%

According to table 7.16, 100% (22) participants indicated that services were available at local clinics free of charge, from 07:00 to 16:00 daily until Friday.

The services were not available from 16:00 until the next day and over the weekends. The referral system between home and hospital, hospital and hospice, also between home and hospice, is depicted in table 7.17.

Table 7.17 Referral system between home, hospital and hospice care N=22

	Good		Inadequate		Total
	Frequency	%	Frequency	%	Percentage
Home and hospital	21	95,4	1	4,5	100
Hospital and hospice	18	81,8	4	18,2	100
Home and hospice	1	4,5	21	95,4	100

According to table 7.17, 95,4% (21) participants indicated that there was a good referral system between home-based care and the hospital, and 4,5% (1) participant indicated that he had a problem with transport, especially in the evenings. 81,8% (18) participants indicated that the hospital to hospice care referral system was good, although 18,2% (4) participants viewed it as inadequate. Only 4,5% (1) participant viewed the referral system between home-based care and hospice care as good while the majority 95,4% (21) participants indicated that it was inadequate.

The researcher believes that the majority of participants had observed what is actually happening in their communities. Sick individuals are referred to hospital from home for management of acute illnesses. Some sick individuals with AIDS are nursed at home, and visited by hospice care members as discussed in chapter three of this study. According to the Highway Hospice Association brochure, hospice care is provided both at home and in In-care Units throughout the terminal stages of the sick individual. This helps in the relief of pressure on relatives or care-givers for brief periods. Findings on the referral system between home-based

care, hospital and hospice care to ensure continuity of care, indicate that it is satisfactory. However, there are still many issues that need to be addressed to ensure comprehensiveness of care across a continuum (World Health Organization Fact Sheets on HIV/AIDS, 2000:3.1).

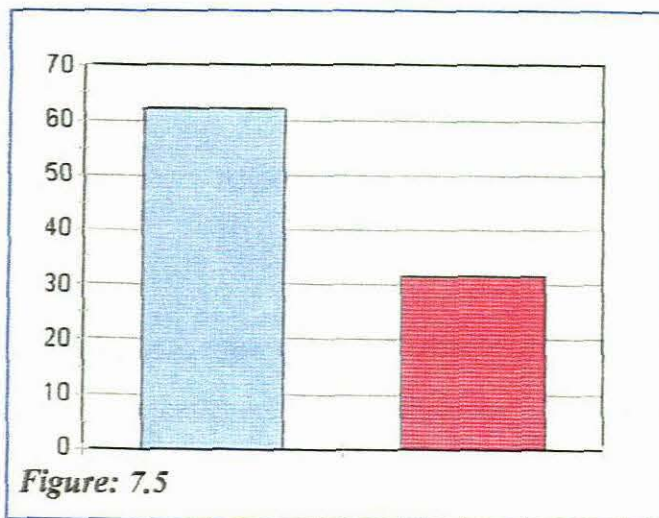
## SECTION 9: COPING WITH STRESS

According to Alexander *et al.* (1994) cited in chapter two AIDS is described as a chronic disease associated with many stressful situations. The coping strategies with chronic illnesses are also described by Miller (1983) cited in chapter two. The participants' experiences of stressful situations are assessed in item 22.

### Item 22: Experience of stressful situations

Participants were asked if they had experienced any stressful situations in their caring roles. Findings are shown in figure 7.5.

Figure 7.5 Participants experience of stressful situations n=22



KEY:  
- Yes  
- No

According to figure 7.5, 68,2% (15) of the participants had experienced stressful situations, and 31,8% (7) participants had not experienced stressful situations. The stressful situations described by participants were listed as follows:

- ▶ Non-family care-givers indicated that some family members of the sick individual expected them to do everything including bathing and feeding the sick individual. This negates the principle of self-care as described by Orem in George (1990:94) cited in chapter three of this study.
- ▶ Lack of emergency transport facilities for referral to hospital when the sick individual is critically ill.
- ▶ Death of more than one member in a family resulting in family members left without enough funds to meet financial expenses.
- ▶ The non-revealing of the HIV-positive status of the sick individual to family members, when the sick individual feared that family members might ostracise him/her.

Participants reported that peer group support, support by social workers and non-governmental organizations with ongoing counselling sessions helped them to cope with very stressful situations.

#### **SECTION 10: BENEFITS OF HOME-BASED CARE FOR THE HIV/AIDS INDIVIDUAL**

Home-based care is regarded to be beneficial to people living with AIDS. Sick individuals enjoy being nursed in their own homes amongst family members where their cultural values are observed at all times. The participants' perceptions on the benefits of home-based care are shown in item 23.

**Item 23: Participants' perceptions on benefits of home-based care**

Participants' perceptions on benefits of home-based care are shown in table 7.18.

**Table 7.18 Participants' perceptions on benefits of home-based care n=22**

Perceptions on benefits of home-based care	Strongly agree		Agree		Disagree		Total %
Periods of isolation are never experienced by the client	10	45,5	11	50	1	4,5	100
The needs of the client are assessed continuously	8	36,4	14	63,6	-	-	100
Strict routine with regard to medication times are observed	8	36,4	2	9,1	12	54,5	100
The client is forced to sleep at specific times of the day	6	27,2	8	36,4	8	36,4	100
Familiar surroundings prevent fear	14	63,6	8	36,4	-	-	100
Boredom of bed-rest is uncommon	9	40,9	9	40,9	4	18	100
The individual's dignity and privacy is maintained	12	54,5	8	36,4	2	9,1	100
Complementary treatment, i.e. acupuncture, massaging are accessible and available on demand	7	31,8	7	31,8	8	36,4	100
Clients' satisfaction with care is low compared to hospital care	1	4,5	3	13,6	18	81,9	100
The individuals and the family share moments of happiness, pain and loss	18	81,9	3	13,6	1	4,5	100

Table 7.18 reflects the following findings: All participants, 100% (22) agreed that home-based care provided familiar surroundings to the sick individual, thereby preventing fear. The same number, 100% (22), agreed that the needs of clients were assessed continuously. 95% (21) participants indicated that periods of isolation were never experienced by clients in home-based care, and the same number of participants 95% (21) indicated that the individual and the family shared moments of happiness, pain and loss. This finding demonstrates that participants perceive the home environment as a shelter where sick individuals can rest assured

that they are loved and accepted, and can enjoy the remaining days of life with their families.

81,9% (18) participants indicated that boredom of bed-rest when confined to bed was uncommon. This is possible since the sick individual is always with family members and friends who do not have to observe visiting times as in hospitals. 18,2% (4) participants perceived boredom as common in home-based care. The same number 81,9% (18) of participants did not agree that home-based care provided low client satisfaction while 18,2% (4), being in the minority, indicated that home-based care was rated low compared to hospital care.

63,6% (14) participants indicated that complementary treatment like acupuncture and massaging were provided on demand by hospice care staff members when requested and also by traditional healers. The same number of participants 63,6% (14) indicated that strict routine to medication times was observed more easily compared to the hospital where many patients have to be cared for. Those taking Western medicines which were complimented with herbal medicines were sixteen (16) out of thirty (30), and those who were on anti-tuberculosis medications as noted in item 23 of this chapter, get individual attention and assistance with regard to taking medication.

The researcher believes that although home-based care was rated by 81,9% (18) participants as good for people living with AIDS, it may be of a low standard as compared to hospital care. In hospital there is a multi-disciplinary team approach in dealing with chest problems, with different pain control methods and use of technological appliances for treatments and diagnostic procedures.

**SECTION 11: PROBLEMS EXPERIENCED BY CARE-GIVERS IN HOME-BASED CARE**

Problems experienced by care-givers in home-based care has been described in chapter two of this study. A list of problems has been provided for participants to indicate the type of problems experienced in home-based care.

Item 24: Problems experienced by care-givers in home-based care

Inclusion of this item was to ascertain the type of problems experienced by care-givers in their caring roles on home-based care. Findings are shown in table 7.19.

Table 7.19 Problems experienced by care-givers in home-based care n=22

Problems experienced in home-based care	True		False		Total %
	F	%	F	%	
Lack of counselling skills	16	73	6	27	100
Lack of basic nursing skills	10	45,5	12	54,5	100
Lack of resources, i.e. gloves, etc	12	54,5	10	45,5	100
Uncooperative clients	16	73	6	27	100
Lack of transport, especially at night	19	86,4	3	13,6	100
Family members may have to stop working and take care of the sick individual	13	59,1	9	40,9	100
Fear of contracting the disease	11	50	11	50	100
Access to the sick may be difficult	12	54,5	10	45,5	100
Travelling long distances to see the sick people	8	36,4	14	63,6	100
Clients die in unsatisfactory living conditions due to poverty	9	40,9	13	59,1	100
Families become needy and dependent on outside help i.e. other family members or friends	18	81,8	4	18,2	100
Death of breadwinner leaving the family destitute	20	90,9	2	9,1	100

(Participants could indicate more than one aspect)

Table 7.19 reflects that the majority of participants, 90,9% (20) indicated the perceived hardships of the poor grieving family members following death of the breadwinner, followed by 86,4% (19) who indicated a lack of transport to transport sick individuals to hospital after 16:00 when the clinics have closed. 81,8% (18) participants noted that some families were very needy and dependent on outside help e.g. provision of food by other families, friends or care-givers. This is in line with the previous findings in this chapter that 77% (23) of people living with AIDS were unemployed and dependent on family members for maintenance of their basic needs. 73% (16) participants indicated that lack of counselling skills and dealing with uncooperative patients presented problems in their caring roles.

59,1% (13) participants indicated that family members had to stop working to take care of the sick family members, and 54,5% (12) reported lack of resources e.g. gloves being their major problem. 50% (11) participants feared contracting the disease due to lack of protective material, and 45,5% (10) participants lacked basic nursing skills and were dependent on care-givers to do everything for the client, even social aspects e.g. collecting of pensions. 40,9% (9) indicated their experiences when nursing those who died in unsatisfactory conditions e.g. living alone, as problematic.

### **7.3 ANALYSIS OF DATA FROM SOCIAL WORKERS**

Social workers are professionals usually called medical social workers who perform social work. They work with people who are physically ill or disabled. They help clients and their families make psychological and social adjustments to the illness and obtain the needed community services including income maintenance. Ten social workers were included in this study.

**SECTION 1: DEALING WITH CLIENTS WITH AIDS-RELATED PROBLEMS**

AIDS is a chronic disease associated with many stressful situations which may cause psycho-social problems to those affected by the disease and their families e.g. the problem of discrimination and stigmatization by the community, neighbours, friends or co-workers. It is important to identify if people living with AIDS are receiving help from social workers in order to cope with their problems.

Item 1:        Attending to clients with AIDS-related problems

Inclusive of this item was to identify whether the participants attended to clients with AIDS-related illnesses or not. All the participants 100% (10) indicated that they had attended to clients with AIDS-related problems. It is pleasing to note that in spite of the non-revealing of HIV-positive status by sick individuals, they do consult specialists for help.

Item 2:        The Psycho-social problems dealt with by the social workers

Inclusion of this item was to establish the type of psycho-social problems of the clients attended to by the social workers. Findings are shown in table 7.20.

**Table 7.20** The Psycho-social problems of People Living with AIDS that the social workers dealt with n=10

Problems	Frequency	%	No of responses	%	Total %
Depression	10	100	0	0	100
Worry about welfare of children after death of parent	10	100	0	0	100
Hopelessness	10	100	0	0	100
Disclosing HIV-positive status to family, spouse or lover	7	70	3	30	100
Not done post-AIDS test counselling	1	10	9	90	100

(Participants could give more than one response)

According to table 7.20 all 100% (10) participants indicated that the problems they encountered among their clients are depression, worry about the welfare of children. Their worry highlighted about children's welfare is in line with the high death rate of AIDS parents which results in high numbers of orphans. 70% (7) participants had attended to clients with problems of revealing their HIV-positive status to their families, spouses or lovers. 30% (3) participants indicated that they had not yet counselled a client with HIV-positive status disclosing. Only 10% (1) participant indicated attending to a client who had not undergone a post-AIDS test counselling session.

These findings emphasise the need for counselling and social welfare intervention particularly about available community resources for example care of orphans. This would reduce the levels of depression, worry and hopelessness due to uncertainty.

**Item 3: Intervention strategies applied to People Living with AIDS by the social workers**

Inclusion of this item was to identify the intervention strategies applied by participants in their problem-solving processes. All 100% (10) participants were unanimous in indicating their intervention as including the following:

- ▶ Counselling the individual
- ▶ Counselling clients as couples
- ▶ Advising the clients on preventing the spreading of infection to others
- ▶ Advising them on coping strategies for the disease.

These intervention strategies are appropriate for the psychological problems identified in table 7.20. They are in line with Orem's supportive-educative nursing system, which emphasises client education to perform the required measures of therapeutic self-care; for example knowing and applying the precautionary measures against spread of infection to others, cited in chapter four of this study.

According to Sarafino (1994:23), social workers may arrange for the needed nursing care at home after a client leaves the hospital. They may refer clients for vocational counselling and occupational therapy if illness or disability requires a career change. This is a common practice in regard to sick individuals who are employed.

**Item 4: Clients compliance with advice given by the social workers**

This item was included to verify if participants' clients were complying with given advice or not. In this aspect, the clients' autonomy was observed. This refers to their freedom of choice to make self-directed choices. The social workers should promote the individuals' or groups' rights to involvement in decision-making and

give full information on the consequences of non-compliance with treatment (Spradley & Allender, 1996:181).

All, 100% (10) participants indicated that clients were complying with given advice, and working well with them towards resolution of existing problems. This is in line with Albrecht's Nursing Model for Home Health care which emphasises client and family involvement in the caring roles, explaining the importance of involving other members of the health team in the caring roles and observing the legal and ethical constraints, as cited in chapter four of this study.

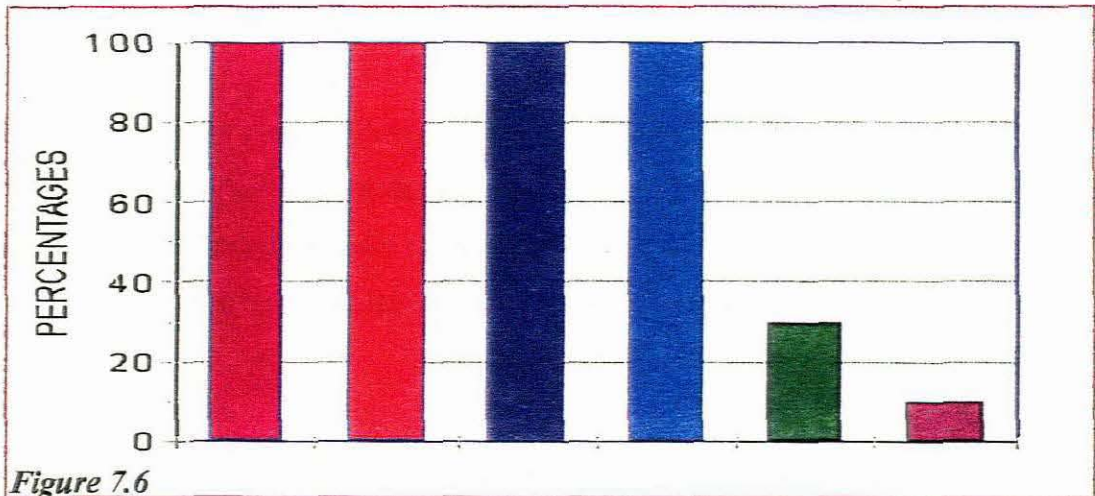
## **SECTION 2: PROBLEMS RELATED TO RELATIVES OF THE SICK INDIVIDUAL**

It has been stated in item 26, chapter six of this study, that there were people with AIDS who had problems with their families when they revealed their HIV-positive status. Inclusion of this aspect was deemed important in order to establish the types of problems experienced.

Item 5: Problems experienced by the social workers in relation to relatives of their clients

Inclusion of this item was to identify the type of problems experienced by social workers from relatives of their clients. Findings are shown in figure 7.6.

**Figure 7.6:** Problems experienced by social workers in respect of relatives of their clients



**Figure 7.6**

- Key:
- Unwilling to take care of the sick individual
  - None permitted to talk openly about the disease
  - Fear of contracting the disease
  - Denial of the disease existence
  - Total rejection by the family
  - No visitors allowed for the sick individual

According to figure 7.6, all, 100% (10) participants indicated that they had attended to problems of relatives of their sick individuals. These problems were relatives' unwillingness to take care of the sick individual, fear of contracting the disease, denial of the existence of the disease and preventing other family members to talk about the disease openly to others in fear of stigmatization. 30% (3) participants indicated that their clients were rejected by family members whilst 70% (7) did not respond to this item. Only 10% (1) indicated that no visitors were allowed to visit the sick individual at home, whilst 90% (9) did not respond

to this item. The researcher believes that with ongoing counselling of family members, acceptance of an infected individual is possible, with the family forming a stronger support system throughout the lifespan of the sick individual.

### **SECTION 3: REFERRAL SYSTEM FOR PEOPLE LIVING WITH AIDS**

Referral system for People Living with AIDS has problems due to the issue of not revealing the HIV-positive status by individuals. Even those who know of the individuals' HIV-positive status cannot easily refer the sick person without his/her consent. This is in line with the rights of an AIDS client discussed in chapter two of this study.

#### **Item 6: Assessing the perceptions of participants on the referral system**

Inclusion of this item was to assess whether the referral system for people living with aids was perceived as good or not. The issue of early discharge from hospital makes it imperative to have a good referral system to ensure continuity of care at home and in the community.

All the participants, 100% (10) in this study indicated that the referral system is good. This is in line with the provision of health care in South Africa using the Primary Health Care approach which emphasises good and proper referral system of clients with serious problems to appropriate specialists or services to prevent complications.

#### **Item 7: Type of clients referred to other professionals for further management**

This item was included to identify the type of clients referred to other professionals or specialists by the participants. All the participants 100% (10)

gave the same response to this item by indicating that the type of clients they referred to other professionals or specialists included the following:

- ▶ Clients in need of disability grants.
- ▶ In need of medical attention.
- ▶ Requiring legal advice.
- ▶ Terminally ill without the next-of-kin or friends to help.
- ▶ Abandonment by family members.
- ▶ Family discord e.g. desertion or divorce.
- ▶ Orphaned children in need of protection.

According to Albrecht's Nursing Model in Home Health, cited in Spradley and Allender (1996:499) the combination of this model's three elements, that is structure, process and outcome, ensures a good referral system, and a high clients' satisfaction with care as positive outcomes. In a home setting, the client and the family are structural elements, the sick individuals; seriousness of signs and symptoms of the disease lead to a modifying element known as client classification, where the client is referred to hospital or a specialist agreed upon, for better management and quick relief of acute symptoms.

The type of care given is the process element. The right combination of structure and process elements produce positive outcomes which are a speedy recovery, early discharge and clients' satisfaction with type of care provided. Only 10% (1) participant indicated to have referred clients with spiritual problems to their Ministers of Religion and support groups.

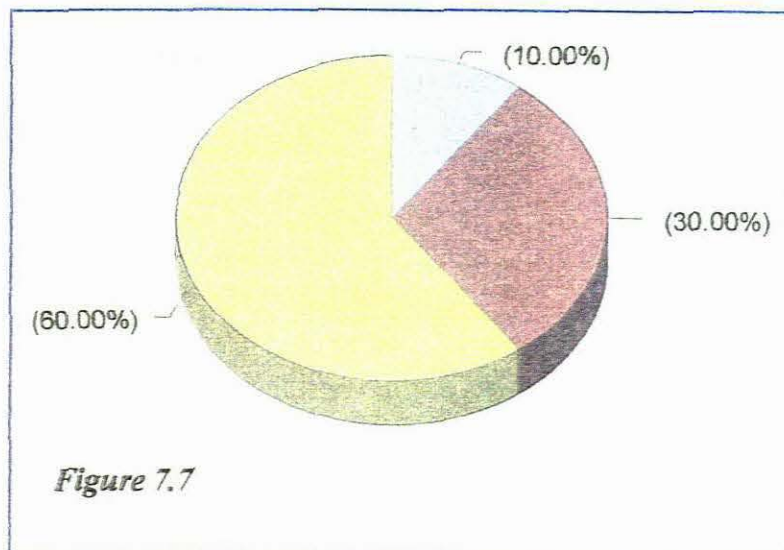
According to Sarafino (1994:103), social groups play a major role in relieving stress, since they provide comfort, caring and boosting of one's esteem with a feeling of membership in a group which has the same interests and social activities. This is in line with the Hospice Day Care Centres which provide such



facilities to people living with AIDS and other chronic illnesses already discussed in chapter three of this study. This is further supported by Adams' Theory of Nursing, which emphasises provision of an environment that depicts caring, love, comfort and sympathy, encouraging the sick individual to pursue healthy lifestyles as cited in chapter four of this study.

Item 8: Perceptions of the social workers on the possible ill-effects on non-referred clients to them

This item was included in order to ascertain the consequences of people living with AIDS not undergoing counselling by social workers with regard to AIDS-related problems. Findings are reflected in figure 7.7

Figure 7.7 Perceptions of social workers on possible ill-effects of failure to refer clients to them



Key:  Clients suffer in silence.  
 Present with severe depression.  
 Clients die sooner than expected.

According to figure 7.7, 60% (6) participants indicated that clients not referred to them present with severe depression. 30% (3) participants highlighted that clients die sooner than expected. Only 10% (1) participant indicated that clients referred to them suffer in silence. The researcher believes that the denial stage is prolonged in these clients.

#### SECTION 4: THE INTERVENTION IN REGARD TO AIDS ORPHANS

The escalating rate of AIDS is discussed in chapter two of this study. It is painful that young parents die and leave their young children with grandparents who are also sickly due to ageing. This has implications for home-based care.

##### Item 9: Participants' perceptions of the intervention in regard to the AIDS orphans

This item was included so as to assess the social workers' perceptions of the intervention in regard to AIDS orphans. Findings are reflected in table 7.21.

Table 7.21 Participants' perceptions of the intervention in regard to AIDS orphans n=10

Perceived Interventions	Participants' Responses		No response		Total
	Frequency	%	Frequency	%	%
Poster care	10	100	0	0	100
Placement in Institutions	8	80	2	20	100
Staying alone with the oldest sibling looking after the younger ones	4	40	6	60	100
Extended family care	0	0	0	0	0

(Participants could give more than one response)

According to table 7.21, all the participants indicated that orphans are best placed in foster care. 80% (8) indicated placement in institutions, whilst 20% (2) did not respond. Only 40% (4) indicated that orphans might be left in the care of an older child whilst 60% (6) did not respond. There were none who indicated extended family care. The researcher believes that it is not safe for children to stay alone nowadays because of the high rate of crime, and that extended family care is not available because many families are struggling to meet their own basic needs as nuclear families. This is due to poverty as a result of the high rate of unemployment and the breakdown in the African lifestyle of the extended family system.

Item 10: Common problems experienced by AIDS orphans

AIDS orphans experience many psycho-social problems, as cited by Stein (1998:40) already described in chapter three of this report. All 100% (10) of the participants indicated awareness of the following problems:

- ▶ Exposure to hard labour at a tender age, as they enter the job market to help with family finances.
- ▶ Exposure to sexual abuse, even becoming victims to some members of the family.
- ▶ Become school dropouts.
- ▶ Become street children as they run away from the oppression by relatives.
- ▶ Are sometimes rejected by peer group.
- ▶ Live in isolation as a result of the stigma associated with AIDS.

The researcher notes the similarities of responses to items in this section dealing with social workers' experiences and perceptions. This shows that the social workers experience the same problems when dealing with clients. This could be used to form stable and uniform policy guidelines for social workers dealing with people with AIDS.

#### **7.4 ANALYSIS OF DATA FROM TRADITIONAL HEALERS**

According to Ngidi (1999:19) traditional healing is a transformation from illness towards health. The healing process is through using indigenous medicines, rituals, counselling or psychotherapy. In the process of healing there is an element of hope, faith, trust, sharing and power. These promote healing to take place. The traditional healer is a therapist (*Inyanga*) who mainly treats diseases with herbs using extracts from plants e.g. roots, bark and leaves. At some stage animal products are used e.g. animal fat mixed with powder during skin sacrifices or tattooing as part of treatment of clients. The inclusion of traditional healer in this study is to identify their role in treating people with AIDS-related illnesses as well as the effectiveness or shortfalls in their traditional healing methods. They work closely with the family and home-based care-givers. The sample size for this category was ten (10).

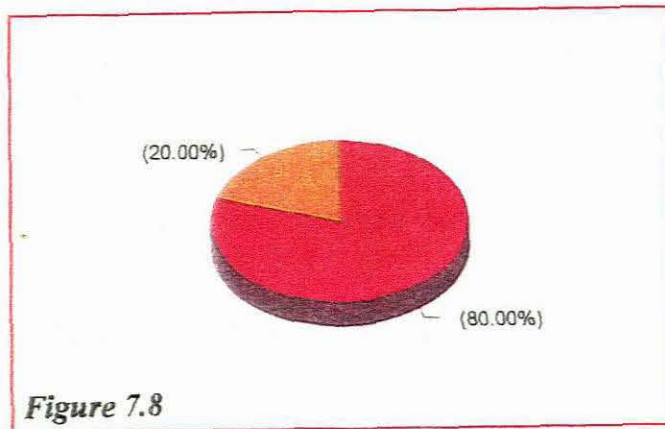
#### **SECTION 1:**

##### **7.4.1 Personal particulars**

Participants' personal particulars were obtained to have their profiles which were of use in this study. The researcher believes that the average traditional healer is of mature age, with a long experience of healing work. The particulars included were age, gender and educational levels.

Item 1: Gender of participants

Traditional healers are commonly men, but there are females who are also practising traditional healing. Inclusion of this item was to identify whether traditional healers consulted by clients with AIDS were males or females. Findings are reflected in figure 7.8.

Figure 7.8 Gender of participants

Key:  Male  
 Female

Figure 7.8 reflects that 80% (8) participants were males and 20% (2) were females. This confirms the general view that there are more males practising traditional healing than females. This is similar to Western medicine where males outnumber females in the medical profession.

Item 2: Age group in years

The age of the traditional healer is important in this study as it reflects his experience of healing work in his/her own neighbourhood. He/she should be of mature age e.g. above 21 years. Findings are reflected in table 7.22.

**Table 7.22** participants' age group in years

<b>Age group in years</b>	<b>Frequency</b>	<b>Percentage</b>
26-35	01	10
36-45	01	10
46-55	07	70
56-65	01	100%
<b>Total</b>	<b>10</b>	

According to table 7.22, the majority of participants 70% (7) were of age group 46-55 years, 10% (1) participant was identified from each of these age groups e.g. 26-35 years, 36-45 years and 56-65 years. It is evident that participants were mature adults who may have adequate experience in traditional healing.

#### **7.4.2 Educational level and registration as traditional healers**

Educational level of participants has been identified as an important aspect with regard to meeting the medical needs of clients by traditional healers. According to Nzimakwe (1995:24) she stated that at some stage, traditional healers refer clients to doctors or hospital for an opinion on an incurable disease, this referral may be in writing. They also have to undergo training in mixing and preparing of medicines in order to prevent overdosage and drug reactions to clients. This is possible when they have at least an average education of grade 7-9 and upwards.

#### **Item 3: Educational level of participants**

Educational level of participants is reflected according to grades in table 7.23.

**Table 7.23** Educational level of participants

<b>Educational level</b>	<b>Frequency</b>	<b>Percentage</b>
Grade 1-3	1	10
Grade 4-6	0	0
Grade 7-9	4	40
Grade 10-12	5	50
Post Standard 10 certificate	0	0
Diploma or Degree	0	0
<b>Total</b>	<b>10</b>	<b>100%</b>

According to table 7.23, the majority of participants 50% (5) had grade 10-12, followed by 40% (4) with grade 7-9 and 10% (1) with grade 1-3. There were none with grade 4-6. It is evident that participants had adequate education except for one who could not complete the questionnaire in English but could use the questionnaire written in Zulu with minimal assistance of the researcher.

**Item 4:** Registration with *Inyanga* or Traditional Healers Association

Participants were required to indicate if they had registered with the *Inyanga* or Traditional Healers Association or not since this requirement is in line with government policy (National Health Plan of South Africa, 1994:72) aimed at ensuring safe practices.

All 100% (10) Traditional healers in this study were registered practitioners of the *Inyanga* / Traditional Healers Association. This makes it possible to have the necessary control and monitoring which is in line with the medical profession where all doctors are registered with the South African Medical, Dental and Supplementary Health Service Profession Amendment Act 1 of 1998:3 (Juta's Statutes of South Africa Volume 5, 2000:3-138).

**SECTION 2:****7.4.3 Experience in traditional healing practice**

Traditional healing experience is important. If adequately experienced, traditional healers will know the importance of referring clients to doctors or clinics in good time, and why clients should be encouraged to continue with hospital treatment. They will understand and be educated on how and why medications should be kept free from contamination. They will be able to prevent cross-infection through inoculations or skin cuts by using contaminated razor blades for therapeutic reasons.

**Item 5: Length of period in traditional healing practice**

Inclusion of this item was to identify the number of years the participants had spent as traditional healers. Findings are shown in table 7.24.

**Table 7.24 Length of period in traditional healing practice**

<b>Length of period in years</b>	<b>Frequency</b>	<b>Percentage</b>
1-5	01	10
6-10	05	50
11-15	02	20
Over 15 years	02	20
<b>Total</b>	<b>10</b>	<b>100</b>

According to table 7.24 the majority of participants, 50% (5) had a practice experience of 6-10 years, followed by 20% (2) with 11-15 years experience, another 20% (2) with over 15 years experience. Only 10% (1) participant had an

experience of 1-5 years. These findings reflect that participants have adequate experience and could be used as valued assets in palliative care of people living with AIDS and in promotion of condom use by the community members.

Item 6:           Signs and symptoms that clients treated by traditional healers presented with

Traditional healers were requested to state the signs and symptoms of the disease from clients they had treated. All the participants 100% (10) stated that their clients presented with the following clinical manifestations:

- ▶ Diarrhoea and vomiting
- ▶ Oral thrush
- ▶ Sores covering the whole body and dark patches on the skin
- ▶ Herpes zoster (sores)
- ▶ Severe skin rashes
- ▶ Severe headaches and mental confusion

All these clinical manifestations are in line with those cited by Van Dyk (1992) in chapter two of this study. Clients with these clinical manifestations consult with traditional healers and home-based care-givers and family members supervise taking of these medicines.

Item 7:           How participants made the diagnosis of HIV/AIDS

The diagnosis of HIV-infection can only be confirmed through a positive test result. All 100% (10) participants stated that their clients confided in them that they had undergone the HIV test which proved positive.

Item 8: Participants' perceptions on the success of their treatment

Participants were asked for their opinion on the success or effectiveness of their treatment in treating clients with AIDS. Responses showed that all 100% (10) participants perceived their treatment as having been successful in relieving the symptoms of the disease and prolonging their lives. They also stated that their treatment was aimed at relieving symptoms and not curing the disease. It is a milestone that traditional healers no longer claim to have a 'cure' for AIDS. They can therefore correct those who still bring about false hopes to sick individuals of having a cure for AIDS. This contradicts the perceptions of traditional healers in an earlier study by Ngidi (1999:40) where the majority 90% (19) of traditional healers claimed that AIDS is a curable disease. This change in beliefs on AIDS curability is an indication that ongoing educational programmes for traditional healers are being made available and are having positive results.

Item 9: Beliefs of participants in combining Western medicine with traditional medicine

Inclusion of this item was to establish the participants' views if combining traditional medicine with Western medicine was good or bad, and whether these should be combined or not. It was found that all, 100% (10) participants believed in combining the two types of treatment. They reasoned that they do not have scientific methods of treating clients and therefore refer those with severe clinical manifestations to doctors for further management. This finding shows a departure from earlier practices where the traditional healers openly claimed that there were diseases which could be treated by traditional medicine only.

Item 10: Action on a non-response to treatment

Participants were to indicate what steps they took when a client failed to respond to the prescribed treatment. All, 100% (10) participants stated that they refer their clients to doctors early before they showed signs of complications to the disease.

### SECTION 3:

#### 7.4.4 Knowledge on HIV/AIDS infection

Participants knowledge on HIV/AIDS infection was assessed. Their thorough knowledge on this disease is vital so as to prevent its spread which may occur through use of unsafe therapeutic procedures like use of contaminated acupuncture needles and razor blades.

##### Item 11: Knowledge on AIDS as a curable disease or not

Inclusion of this item was to establish if participants believed that AIDS is a curable disease like other diseases or not. All, 100% (10) of participants indicated that AIDS is not a curable disease as indicated also in this item. It is pleasing to note that traditional healers are aware that AIDS has no cure, but whatever treatment is given is to treat the symptoms of the disease, reduce pain and boost the immune system.

##### Item 12: Transmission of infection from one person to another

Participants were to explain how the infection could be prevented from being transmitted from one person to another. The participants' responses were the following:

- ▶ Abstinence from sex by teenagers and young adults until they get married.
- ▶ Faithfulness to each other by married couples or lovers.
- ▶ Effective use of condoms during sexual activity.

- ▶ Proper socialization of young children and youths by parents on sex and sexuality, and this further emphasised in school programmes.
- ▶ Heavy penalties or fines for rapists of women and young children.

All the participants, 100% (10) believed that the above-mentioned practices could be the answer in preventing the spread of HIV/AIDS infection. These findings reflect the same knowledge base as indicated by people living with AIDS, in chapter 6 of this report.

Item 13:      Methods used for treating clients with AIDS

Participants were asked to indicate their methods of treatment from a provided list of healing methods. Responses are shown in table 7.2.5.

Table 7.25      Methods used for healing clients with AIDS N=10

Healing period	Frequency	Percentage
Use of herbs	10	100
Holy water	0	0
Animal product ie. skins or fat	0	0
Skin cut with razor blades	10	100%

(Participants could give more than one response)

According to table 7.25, all the participants, 100% (10) used herbs and skin cuts with razor blades whenever necessary on some clients, as their healing methods.

## **7.5 CONCLUSION**

In this chapter information on roles of home care-givers who are family or non-family members, social workers and traditional healers has been analyzed and interpreted. The analysis revealed that a team approach is vital in treating clients with AIDS with an ongoing health education and counselling of clients and care-givers. The next chapter will present the summary, conclusions, limitations and recommendations.

## **CHAPTER 8**

### **SUMMARY, LIMITATIONS, DISCUSSION OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS**

#### **8.1 INTRODUCTION**

This study investigated home-based care as a continuum of the comprehensive health care provision for the people living with AIDS in Umlazi Metro area of Health Region "F" or Ilembe Region of KwaZulu-Natal. Extensive literature search provided a broad theoretical base of national and international perspectives of HIV and AIDS. The provision of home-based care in a home setting for people living with AIDS has been highlighted which included its advantages and disadvantages.

Various categories, for example people living with AIDS, care-givers, social workers and traditional healers expressed their views on the provision of home-based care in Umlazi Metro area and its informal settlements. The strategies that deal with the impact of AIDS on individuals, families, orphans, communities, various institutions e.g. schools, hospitals and clinics have been highlighted. The theories selected as the framework for this study address the provision of nursing care to sick individuals. The researcher is of the opinion that the application of these three theorists' models e.g. Albrecht's Nursing Model for Home Health Care, Orem's General Theory of Nursing and Adams' Conceptual Model for Nursing would ensure provision of high quality nursing care to clients with AIDS in a home setting in a manner that facilitates self-care.

#### **8.2 SUMMARY**

A descriptive survey study was conducted in the Umlazi Metro area of Region "F" or Ilembe Region of KwaZulu-Natal. The participants comprised people living

with AIDS, care-givers (family and non-family members, social workers and traditional healers. It was considered important to include all these categories since their involvement in the provision of care to sick individuals in a home setting ensure good quality, comprehensive care for people living with AIDS. Through use of questionnaires, participants were able to express their views on provision of nursing and other forms of care to clients with AIDS in a home setting.

The analyzed data confirmed the assumption on which this study was based, namely: "HIV/AIDS infection is a chronic disease affecting all body systems."

Almost all sick individuals with AIDS need home-based care. Being nursed at home, HIV/AIDS clients enjoy the support, acceptance and love from family members. This facilitates their regaining of functional independence. Proper guidance to family members and other care-givers on preventive measures against spread of the infection from one person to another is important.

There were similarities in the perceptions on most of the aspects in relation to home-based care provision by the four categories who took part in this study. The perceived similarities were that home-based is the best place for people with chronic illnesses including AIDS. The familiar surroundings reduce fear, provide warmth and security. The sick individuals are able to complement western medicine with traditional medicine as they want. The family becomes the pillar of the support system to the sick individuals with AIDS, and a coordinated effort is ensured to overcome problems identified through continuous assessments as the disease progresses.

The three models of Albrecht, Orem and Adam as indicated in chapter four of this study are complementary, there is consensus (meaning agreement held by all people) in the provision of a conducive environment to recovery for clients,

assessment of problems and needs, involvement of family members and the multidisciplinary team in solving problems. The conclusions drawn from the findings relate to the assumption and the stated objectives. The objectives of the study were:

- ▶ To determine the type of nursing care provided for people living with AIDS at home.
- ▶ To elicit participants' views on the quality of care provided at home.
- ▶ To determine the type of support given to people living with AIDS, their families and the non-family care-givers.
- ▶ To determine strategies implemented to prevent the spread of HIV/AIDS infection.
- ▶ To develop a model that can be adopted in providing high quality care to people living with AIDS in a home setting.

### **8.3 LIMITATIONS OF THE STUDY**

- ▶ The study was done in Umlazi Metro area and its informal settlements. Umlazi is only a small portion of Region "F" or Ilembe Region of KwaZulu-Natal. There are many people with AIDS who are nursed at home in the whole province of KwaZulu-Natal. For this reason it is not possible to generalise the findings.
- ▶ The purposive sampling complemented with snowball sampling method was used since it was not easy to identify the individuals with AIDS and their families. The researcher experienced difficulties in getting the participants, and depended on the availability of the care-givers, thus data collection stretched longer than expected.

- ▶ Previous research on home-based care for people living with AIDS at provincial or national levels was not available and this presented problems as the researcher could not make meaningful comparisons with other findings.
  
- ▶ Ethical implications posed serious problems which delayed the commencement and completion of this study. These included the following:
  - The non-revealing status of HIV-positive status by those infected by the HIV-virus made it very difficult to reach them during data collection. Where records were available from the clinic to confirm this, it was still difficult to enter the home and be able to personally assess the conditions, resources and problems that might be encountered in providing Home-Based Care.
  
  - Permission granted by the hospital authority imposed the limitation that the researcher should only liaise with the AIDS Clinic staff and not with the hospitalised clients.
  
  - Some authorities in the community were reluctant to give permission, for example the municipal councillors; they indicated that they were not in a position to grant permission on a study on Clients with AIDS since this is a sensitive issue that involves confidentiality of one's HIV-positive status. They referred the researcher to social workers who were working hand-in-hand with the community health care-givers in various sections of Umlazi, including the informal settlements.
  
  - Some family members of people who were nursed at home for AIDS-related illnesses refused to participate. They expressed their fear of

victimization and did not believe that the sick individual had AIDS since she/he had not informed them of the HIV-positive status. The researcher's repeated assurances of confidentiality and anonymity were not accepted by them.

- ▶ In the social workers' category, there was a demand for the re-writing of the questionnaire, in a way that, according to them, would make it more user-friendly, by omitting the personal particulars portion and the open-ended questions. Omitting the personal particulars was a significant limitation because, in the researcher's opinion, it was important to determine if differences in age groups and the length of service of the social workers had any impact on the approaches and outlook towards sensitive issues like AIDS. The deletion of open-ended questions prevented in-depth insight into the social needs and problems that the social workers had to contend with in respect of HIV/AIDS. It was also not easy to reach this category, due to the type of work they perform and this limited the sample to ten participants.

## **8.4 DISCUSSION OF FINDINGS AND CONCLUSIONS**

The individual objectives are used as a foundation for discussion of findings in this section.

### **8.4.1 Objective One**

\*To determine the type of nursing care provided for people living with AIDS at home.

Several aspects were investigated to achieve this objective.

8.4.1.1 Reaction to HIV/AIDS diagnosis and its impact on care of the sick individual

The data analyzed from people living with AIDS revealed that when they first discovered that they were HIV-positive their reaction was that of disbelief, depression and fear of informing the family members. It is noted that though family members also reacted negatively when informed of the HIV-positive status of the sick individual, the sick person was accepted and provided with the needed nursing care. Very few sick individuals reported perceived rejection by family members. However the family support is perceived as inadequate by those who revealed their HIV-positive status. This supports Kunene's (2000:8) report that some clients with AIDS are ostracised by their own families who become overly concerned about their own protection, not knowing that AIDS is not a contagious disease. Therefore adverse reactions to the HIV/AIDS diagnosis by affected individuals or family leads to social isolation both in the home and in the community.

8.4.1.2 AIDS-related illnesses that affected individual's management of the disease

The sick individuals presented with a variety of signs and symptoms of HIV/AIDS infection. One or more systems of the body were affected and clients were treated symptomatically, assessed continuously on a daily basis to evaluate the effectiveness of care provided and the onset of new signs and symptoms that indicated progression of the disease. Specific management of acute conditions of diarrhoea and vomiting through intravenous infusion in hospital, and managing tuberculosis clients through use of the Directly Observed Treatment System, improved the health and the nutritional status of the clients. Adam's conceptual model for nursing encourages the helping relationship, to enhance coordinated effort of the individual, family members or non-family care-givers, and other

members of the multidisciplinary team to relieve signs and symptoms of the disease by finding solutions to problems timeously, for example provision of palliative care and hospice care to the terminally ill clients with AIDS.

#### 8.4.1.3 Perceptions on type of pain and pain controlling measures

Data collected from people living with AIDS revealed that the majority 87% (26) of those who participated in this study experienced severe body pains. The type of pain experienced was beyond the home remedies. There were shared perceptions between people with AIDS, care-givers and traditional healers that pain associated with AIDS-related illnesses is best controlled in hospital, where there is a variety of pain-killer medications, technology used by physiotherapists and reflexologists as well as psychologists through use of psychotherapy. It is therefore concluded that since clients prefer being nursed at home, the discharge plan for each individual client should accommodate pain control at home. In-Hospice care services have to be extended and facilitated to community hospice care facilities to improve the quality of care at home.

#### 8.4.1.4 Type of medication used by people living with AIDS

The investigation revealed that people with AIDS used both Western and herbal medicines. All the participants 100% (16) indicated that they used herbal medicines which they obtained from the traditional healers of their choice in the community. To address this aspect, the South African Government showed concern when it enforced legislation of traditional healing under the Traditional healers / *Inyangas*' Association to ensure safe practices. Many people had Tuberculosis, 69% (11) of the (16) participants. These clients were reported to be on the Directly Observed Treatment System for Tuberculosis with Anti-Tuberculosis medications which were monitored by the care-givers, family members or nurses at the nearest clinics to sick individuals. This is in line with

the new strategies employed by the Department of Health to overcome the spread of Tuberculosis and its resistance to drug therapy.

#### 8.4.1.5 Use of other forms of healing

The use of other forms of healing were evaluated for example use of Prayers as a form of healing, which involves laying of hands on the sick, individual/s with AIDS. 100% (30) of people living with AIDS expressed their belief in the healing powers of Prayers. 67% (20) indicated that they used Holy water as medicinal treatment while 40% (12) indicated that they still believe in the use of acupuncture for pain relief. In respect of what has been discussed the researcher concludes that there is no clearly defined type of care provided in a home setting for sick individuals with AIDs; however findings show that a holistic, client-centred and family-centred care which involves other members of the multidisciplinary team e.g. traditional healers and doctors, is used.

#### 8.4.2 Objective two

\*To elicit participants' views on the quality of care provided at home.

Participants were asked to explain their perceptions of how they were cared for at home. They all expressed great satisfaction with care provided and stated that they were assisted with Activities of Daily Living when unwell and showered with love and continuous reassurance. Confidentiality was also maintained. They shared their problems with family members and care-givers who assisted them with resolution of problems identified. The care received at home was rated as excellent by 13% (4) participants, very good by 13% (4) participants and good by 74% (22) participants. It is therefore clear that the quality of care provided at home is perceived as good, and in line with the continuous, comprehensive nursing care standards required in South Africa. The researcher concludes that, while the

clients express satisfaction and rate the care as good, the challenge to continuously upgrade the facilities and resources for home-based care still needs urgent consideration.

#### 8.4.3 Objective Three

\*To determine the type of support given to people living with AIDS, their families and non-family care-givers.

People living with AIDS stated that their family members, health care workers and neighbours were their main supporters throughout their illnesses. The few who revealed their HIV-positive status at work, were supported by colleagues and employers. Work place policies protect the rights of those workers living with HIV and AIDS (AIDS workplace policy, November 2000). However it was noted that 86% of the employees who were aware of their HIV-positive status did not inform their employers. The researcher therefore cannot draw the conclusion that support at the workplace is adequate. The conclusion drawn is that the need to educate HIV/AIDS clients remains an urgent priority.

#### 8.4.4 Objective four

\*To determine strategies implemented to prevent the spread of HIV/AIDS infection.

A diversity of ways to fight the spread of infections were highlighted as follows:

- ▶ The Department of Health provided the 2000-2005 Strategic Plan for HIV/AIDS/STD and Tuberculosis management. People living with AIDS, having pulmonary tuberculosis as an opportunistic infection are put on the Directly Observed Treatment of Anti-tuberculosis therapy. In home-based

care, family members or community health care workers supervise the taking of anti-Tuberculosis treatment and ensure effective coordination with clinic staff and chest clinics for assessment of the effectiveness of treatment and treating of new problems.

- ▶ The South African Government has approved the use of the anti-retroviral therapy - Nevirapine, to pregnant women so as to prevent vertical transmission from sero-positive mothers. This means that pregnant mothers' fear of transmitting HIV-infection to their unborn children will be reduced and they have to concentrate on improving their own health status and home environment.
- ▶ The adverse effects of AIDS on orphans has been highlighted. According to the Interim Policy Recommendations (November 1996) of the South African Ministry for Welfare, there are specific organizations like the Durban Children's Society which provide help for the orphaned children through linking with resources, for example the placement in institutions for orphaned children or for adoption. Clients who are sick in Umlazi area and have no next-of-kin are also linked with home-based care community health workers for assistance.
- ▶ There are ongoing health education programmes provided by the Government, Non-Governmental organizations e.g. the AIDS Training and Information Centre which aim at making the communities aware of AIDS and its physical and psycho-social impact on individuals, families, communities and the State. Health education sessions are provided by social workers, nurses and community health care workers through home-based care projects and use of media like radios and television and in hospitals and clinics.

- ▶ The Department of Health has provided a guide on syndromic management of sexually transmitted diseases. Through home-based care, clients with sexually transmitted diseases are also supervised by care-givers on compliance with treatment. Safe sex practices are encouraged so as to prevent the spread of infection to others.
- ▶ Counselling services have been provided where individuals, families or couples can have access to voluntary HIV-counselling and testing as well as counselling for any other problems.
- ▶ The National AIDS programme has been provided. It includes educating school children on life-skills and HIV/AIDS education programmes. This is of help, especially to those children who have tasks of taking care of sick parents with AIDS-related illnesses at home.
- ▶ The National Department of Health provides support to all the provinces with the supply of male condoms which are supplied free of charge in health facilities and in non-traditional outlets like truck stops and local shops. In home-based care, non-family home-based care-givers, traditional healers and AIDS counsellors facilitate use of condoms so as to prevent the spread of infection. This is in line with Albrecht's Nursing Model for Home Health Care which puts emphasis on the well coordinated **structural** elements, for example the clients, their families, other non-family care-givers, health care provider agency. The **process** elements, for example effective application of preventive measures against the spread of infection, ongoing health education and support. These lead to quality care referred to as the **outcome** elements by Albrecht.

The researcher concludes that there is a need for better coordination to ensure that all the initiatives listed here are complementary to one another so as to have a synergic effect in the fight against AIDS.

#### 8.4.5 Objective five

\*To develop a model that can be adopted in providing high quality care to people living with AIDS in a home setting.

The proposed model is presented in the next section which deals with recommendations.

### 8.5 RECOMMENDATIONS

In terms of findings and conclusions of this study the researcher makes the following recommendations:

- ▶ AIDS is an infectious, communicable disease which has no cure. According to Nzimande (1993:10) a communicable disease is defined according to the Health Act No. 63 of 1997 of the Republic of South Africa. "It is any disease which can be communicated directly or indirectly from one person or animal or through any agent to any person or from any person suffering therefrom or who is a carrier thereof to any other person".

The researcher recommends that AIDS be a notifiable disease. This will prevent the spread of the HIV-virus as in other communicable diseases. The legal aspects relating to communicable diseases will be observed like provision of adequate protective material, e.g. globes, use of condoms, identification of carriers and prevention of infection by them if placed under medical surveillance with strict restrictions of movement measures taken at inland borders, ports or airports to prevent introduction of further HIV-infection from the neighbouring countries.

- ▶ There should be fair and even distribution of resources which are scanty in peri-urban areas and rural areas, for example, hospice care and community-based hospice care services for the terminally ill people with AIDS who are nursed at home, for example enough supply of gloves, plastic aprons, food parcels for the needy families identified through community outreach programmes.
- ▶ There should be enough counselling services that are evenly distributed throughout the Region which will be accessible to people with AIDS who cannot travel long distances because of severe body pains and general body malaise. This would increase clients' and family support system.
- ▶ All South African citizens should come together and through coordinated effort, develop strategies that ensure positive sexual behaviours and change of lifestyle that prevents the spread of the infection from one person to another. Whilst information in this regard is widely disseminated, proper educational programmes should be intensified.
- ▶ There should be more job opportunities to improve the state of poverty faced by many families who have sick individuals with AIDS-related illnesses. The support for the income generating self-help projects should be intensified. This will be in line with Orem's Supportive-Educative system of encouraging people to help themselves through an ongoing learning process. Some families feel abandoned as they struggle to buy basic and highly nutritious foodstuffs for the sick individuals and their families. Whilst laws against discrimination of these people from employment exist, there should be more severe sanctions imposed on those who contravene these regulations for example terminating the worker's services because of an HIV-positive status while he/she has a right to continue working and get medical assistance, sick leave and compassionate leave where applicable (AIDS Workplace Policy, November 2000:20).

- ▶ Community health nursing must be strengthened to cater for home-based care projects. This would help families to learn to cope with problems of caring for chronic illnesses at home with scanty resources. More home-based care-givers should be trained as well as training of family members who form the main support system of a sick individual with AIDS-related illnesses.
  
- ▶ Security services should be provided for 24 hours a day to cater for the clinics which operate for 8 hours presently, because of lack of security services especially at night and over the weekends. This has an impact on home-based care provision when there is no transport at night when sudden opportunistic infections occur e.g. severe diarrhoea and vomiting.
  
- ▶ The researcher further recommends that community hospice care services should be extended to reach more areas of the Region and in all provinces as this will enrich the nursing care of a terminally ill client at home.
  
- ▶ Future research on this study is recommended to be done in other areas of this Region, in the whole of the KwaZulu-Natal province and in other provinces as well, in order to enable generalisation of findings. This is important to facilitate development of strategies to provide quality care to clients nursed at home and in the making of appropriate national, provincial and regional policies on home-based care as the continuum of the comprehensive health care service, especially for people living with AIDS who approve of home-based care environment as being suitable to their state of health.
  
- ▶ All health care stakeholders who are members of the multidisciplinary team, various sectors of the government should work collaboratively in the country's research projects on AIDS to facilitate progress in the development of a vaccine against AIDS or an AIDS cure.

- ▶ Youth centres should be created as means to curb the rapid spread of HIV/AIDS and sexually-transmitted diseases among youth. The researcher is of the opinion that all provinces should adopt the strategy of providing youth-friendly centres outlined in the strategic framework for the youth programme as described by Heunis *et al* (2000:58) in Chapter two of this study.

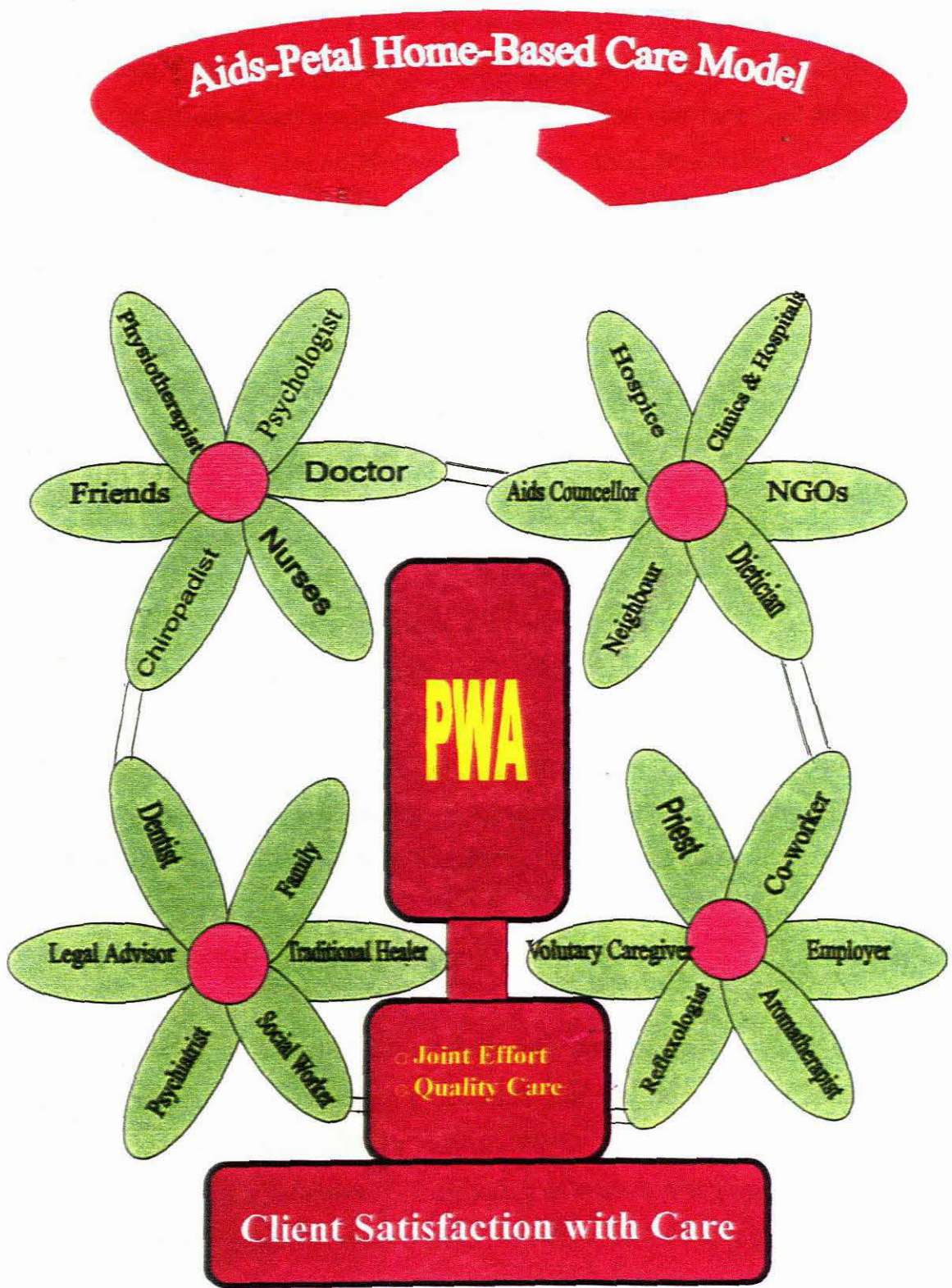
## **8.6 PRESENTATION OF THE PROPOSED AIDS PETAL HOME-BASED CARE MODEL**

It has been stated earlier, in undertaking this study, that the researcher intended developing a model that can be used as a guide in nursing sick individuals with AIDS in a home setting. In constructing this model, the researcher used the three models of the three theorists used in this study, namely Albrecht, Orem and Adam as the basis of a holistic care guide for all stakeholders in home-based care for people living with AIDS.

According to Adam (1991) cited in Marriner-Tomey (1994:496), a helping relationship and a systematic process are perceived as an integral component of the interdisciplinary health team, in which members of the team in various disciplines perform specific functions. These functions or roles, when well-coordinated, contribute to good health or improved health status of clients, geared towards independence. This helping relationship amongst members of the interdisciplinary team and clients is interpreted by Adam as a schematic flower with each petal representing a distinct health discipline e.g. nursing, nutrition or medicine. Orem (1990) also puts emphasis on the importance of the mastery of the general and specific roles of nurses and patients, described in chapter four of this study. According to Albrecht, health care providers should consider involving clients, families and other disciplines in the caring roles.

On the basis of findings of this research and recommendations made, a model entitled *AIDS Petal Home-Based Care Model* has been constructed. This model is presented in figure 8.1.

Figure 8.1 The Aids – Petal Home-Based Care Model



The figure presented in figure 8.1 depicts the need for all stakeholders to play their roles in the joint effort to overcome the spread of HIV-infection and provide care to sick individuals with AIDS nursed at home. The sick individuals, form the core of this model, since they are the directors of the type of care they need and expect in a home setting. The AIDS Petal Model for Home-Based Care is important since it has been highlighted that people living with AIDS suffer a diversity of physical illnesses, different degrees of pain on various parts of the body, as well as a multitude of psycho-social problems.

The various members of the multi-disciplinary team identified in this model include:

#### **8.6.1 The Client**

In the context of this study the client is a person living with AIDS and nursed at home for AIDS-related illnesses she/he is a key figure of this study who has to participate in all health-related matters with regard to health promotion, disease prevention or prevention of its spread, as well as rehabilitation to prevent complications. This is supported by Orem in her Theory of Nursing systems whereby the need for supportive education is emphasised to facilitate self-care.

#### **8.6.2 The Family**

The family is an important social group that provides good psycho-social and emotional support, socialization process and material resources for its members' growth and well-being. This includes people living with AIDS who need family support throughout their lives. Therefore it is evident why people with an HIV-positive status refrain from informing their families in fear of abandonment or rejection. The ongoing counselling of family members is highlighted to facilitate acceptance of the infected family members.

### 8.6.3 Other members of the multidisciplinary team

Other members of the multi-disciplinary team can be divided into three separate groups, described in Stanhope and Lancaster (1988:38) as follows:

#### - The Independent Practitioners

Independent practitioners include doctors, dentists, chiropodists, podiatrists and optometrists. These practitioners perform different roles which are important in the management of AIDS clients in a home setting for example, doctors diagnose and treat clients, dentists attend to client' oral health since mouth complications are common clients with AIDS. Chiropodists and podiatrists, both deal with the diagnosis and treatment of foot conditions since clients with AIDS always complain of painful feet with pains likened to pins and needles and callouses. Optometrists attend to eye problems since some clients with AIDS present with blurred vision or blindness as the complication of AIDS.

#### - The Dependent Practitioners

Dependent practitioners are allowed to perform a specific range of services that must be done under supervision and authorization of independent practitioners for example nurses, dental hygienists, social workers, psychologists, pharmacists, physiotherapists, occupational therapists and speech therapists. This group of practitioners perform the following basic functions which are in line with the literature described in chapter two of this study:

- \* History-taking and performing of physical examinations to define health and medical problems.

- \* Institute therapeutic regimens within established protocols and referring the client to other health care providers whenever there is a need.
  
- \* Providing counselling to individuals, families and groups as means of health promotion and maintenance.

- The Support staff

Support staff members carry out work tasks authorised or delegated by either dependent or independent practitioners. Members of this group include housekeepers, food processing workers, AIDS counsellors, legal advisors, reflexologists and aromatherapists who help clients in pain relief using special techniques and oils, non-family members, home care-givers, hospice staff, special groups or organizations, e.g. the AIDS Training Information Centre and others, church members who provide spiritual comfort and encouragement to infected and affected individuals or groups, the traditional healers who provide indigenous traditional healing to clients who were reported to prefer use of western and traditional healing methods for their illnesses.

In view of the findings in this study, the nurses support was noted as very limited. The researcher is of the opinion that nurses' involvement in home-based care should be encouraged through community outreach programmes, since nurses have to coordinate the various functions of the team members, to ensure effective patient care and continually evaluate efficiency of existing services e.g. counselling services or clinics services.

This model has close linkages with Ngidi's AIPAP Model (AIDS Partnership prevention Model, 1999:171) where the roles of the various sectors were

highlighted which include: Religion, Housing, Community, Traditional Healers, Health Sector, Educational Sector, Political Sector, Economy and Labour Unions, and Individuals and various support groups.

## **8.7 CONCLUSION**

The findings of this study have highlighted the provision of nursing care provided in a home setting for people living with AIDS. Their problems and those of family members or care-givers, as well as the intervention of social workers and traditional healers has been highlighted. Limitations to the study have been noted, recommendations which could provide innovative changes have been made. Home-based care is highlighted as good by people living with AIDS and care-givers though the researcher doubts its congruency on account of numerous problems noted in this study. Therefore further research studies are to be conducted as recommended, to establish its continuity as a comprehensive health care service. The AIDS Petal Model on Home-Based Care is provided to give direction for practice, education and research.

In this study, aspects on HIV/AIDS perspectives have been highlighted as well as how home-based care is provided in Umlazi Metro area of Region "F" with its informal settlements. AIDS has no cure, its chronic nature and the stigma associated with it continues to be a challenge to individuals, families and the community. This study has highlighted the problems experienced in nursing clients through home-based care and at the same time the benefits of home-based care have been identified as important aspects in the provision of a comprehensive service to people living with AIDS.

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UNAIDS Report on the global HIV/AIDS epidemic. June 2000. UNAIDS Publications.

**ANNEXURE 1**

**QUESTIONNAIRE ON HOME-BASED  
CARE FOR PEOPLE LIVING WITH AIDS**

Dear Participant

**REQUEST FOR COMPLETION OF A QUESTIONNAIRE FOR RESEARCH  
PURPOSES**

Kindly complete the attached questionnaire. The purpose of this questionnaire is to collect information on Home-Based Care provided to sick individuals. Strict confidentiality will be ensured. please do not write your name anywhere in this questionnaire.

Please answer all questions. There are no right or wrong answers. Your own views and opinions are important.

Please indicate your responses with a tick (✓) in appropriate spaces or give explanations where needed.

Thank you for participating in this study.

  
**L.N. NYEMBE**

**QUESTIONNAIRE FOR PEOPLE LIVING WITH AIDS**

---

**SECTION 1: PERSONAL PARTICULARS**

---

1. Gender

Male  Female

2. Age group in years

11-20   
21-30   
31-40   
41-50   
51-60   
61 and above

3. Marital Status

Married   
Single   
Divorced   
Widowed   
Separated   
Cohabitant

4. Number of Children

1  2  3  4  5   
6  7  8  9  10

5. Age ranges of children in months and years

- Under 1 year old
- 1 - 10 years
- 11 - 20 years
- 21 - 30 years

6. Educational level

- Never been to school
- Grade 1 - 3
- Grade 4 - 6
- Grade 7 - 9
- Grade 10 - 12

Post Standard 10 Certificate (Diploma(s), Degree(s) (please state)

---

---

**SECTION 2**

---

**REACTION TO HIV/AIDS DIAGNOSIS**

7. Kindly state your reaction when first informed about your HIV-positive status. (Tick (✓) any appropriate box.)

- |            |                          |               |                          |
|------------|--------------------------|---------------|--------------------------|
| Disbelief  | <input type="checkbox"/> | Embarrassment | <input type="checkbox"/> |
| Denial     | <input type="checkbox"/> | Loneliness    | <input type="checkbox"/> |
| Anger      | <input type="checkbox"/> | Hope          | <input type="checkbox"/> |
| Depression | <input type="checkbox"/> | Acceptance    | <input type="checkbox"/> |

Any other reaction? (please state) \_\_\_\_\_

---

8. Does your family know of your HIV-positive status?

Yes  No

If yes to No. 8 how were they informed? i.e. They were informed by:

Yourself  Doctor  Nurse

Other (please state) \_\_\_\_\_

If "yes" to No. 8, state how the family members reacted towards your HIV-positive status?

Shocked  Denial  Rejection  Anger

Fear of stigma  Acceptance

Other reaction (please state) \_\_\_\_\_

If "No" to No. 8, give reasons for choosing not to disclose your HIV/AIDS status

---

---

9. If you have children, have you informed them of your HIV-positive status?

Yes  No

If "yes", how did they react

Shocked  Denial  Rejection  Anger

Fear of stigma  Acceptance

Other reaction (please state) \_\_\_\_\_

If "No", to No. 9 give reasons for not informing them \_\_\_\_\_

---

---

10. Are you employed?

Yes  No

If "Yes" to No. 10, does your employer know about your HIV/AIDS Status?

Yes  No

If "Yes" to above, what was your employer's reaction to your HIV Status?  
(please state)

---

---

How did your co-workers react? (please state) \_\_\_\_\_

Who informed them? (State) \_\_\_\_\_

---

SECTION 3

---

**KNOWLEDGE ON HIV/AIDS**

11. Indicate how HIV/AIDS infection is transmitted from one person to another (Tick (✓) all appropriate spaces)

- Sneezing and coughing
- Sharing eating utensils
- Cleaning vomitus
- Sharing toilet seats
- Prick with used needle
- Unprotected sexual intercourse
- Mosquito bite
- Through skin cuts or breaks
- Through kissing
- Through tears
- Blood transfusion
- Handling loose stools without protection

12. Can HIV/AIDS infection be prevented from spreading?

Yes  No

If "Yes" to No. 12, list the methods or strategies of prevention that you know.

---

---

---

---

---

13. Do you feel you have enough knowledge to protect yourself from infections which cause illness?

Yes

No

14. Have you had any serious illness lately?

Yes

No

If "yes" to No.14, indicate if your illness was due to one or more of the following conditions:

- Pneumonia
- Tuberculosis
- Diarrhoea
- Oral Thrush
- Severe headaches
- Persistent fever
- Anorexia
- Severe Fatigue
- Oral sores
- Weight loss
- Skin rashes
- Blindness

Other (please state) \_\_\_\_\_  
\_\_\_\_\_

15. Indicate whether the illness(es) listed below was (were) occurring for the:

- First time
- Second time
- Third time
- Repeatedly, on and off

---

**SECTION 4**

---

**PAIN AND PAIN CONTROL**

16. Have you experienced pain with your illness?

Yes

No

If "yes" to No. 16, describe this pain with regard to part of body affected:

---

---

17. Severity of pain by choosing the correct colour in the provided colour-coded rules for pain assessment.

Key to colour coding as per pain assessment ruler. (Tick (✓) appropriate box.

0 =     1 =     2 =     3 =     4 =     5 =

Describe the measures used to control pain at home \_\_\_\_\_

---

18. In your opinion, is pain control adequate in a home environment?

Yes

No

If "No" to No. 18 state your ideas as to how best pain controlling measures may be applied.

---

---

19. Does illness and type of pain you have affect your employment?

Yes  No

If "Yes" to No.19, state how your employment has been affected by the illness?

---

---

---

**SECTION 5**

---

**MEDICATION AND OTHER TREATMENT**

20. Are you on any long-term medication?

Yes  No

If "Yes" to No.20, name the medication(s) you are currently taking.

---

---

21. State for how long you have been using the medication in:

Weeks   
Months   
Years

22. Indicate where medication obtained (Tick (✓) all appropriate spaces

- In hospital
- Chemist
- Private Doctor
- Traditional Healer

23. Have you had any problems with your prescribed medication?

- Yes  No

If "Yes" to above, describe the kind of problems you have had.

---

---

24. Indicate if you are using Western medicines, or Traditional medicine.

- Western medicine
- Traditional medicine
- Both Western and Traditional medicines

Give reasons for your choice of medication

---

---

25. Do you use other forms of healing like:

- Acupuncture
- Prayers
- Holy water

26. State which method(s) provide(s) best relief of symptoms.

---

---

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**SECTION 6**

---

**CARE AND SUPPORT**

27. In your own words, explain how sick individuals are cared for at home.

---

---

---

28. How would you rate the care that you get home?

- Excellent
- Very good
- Good
- Poor

29. Do you have any ideas on how to improve the present care provided?

Yes  No

If "Yes" to the above, briefly give your opinion so as to improve care provided.

---

---

30. Do you have any kind of psycho-social support?

Yes  No

If "Yes" to No. 30, state the kind of psycho-social support available to you.

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**ANNEXURE 2**

**QUESTIONNAIRE FOR HOME CARE-GIVERS**

Research topic *An investigation into home-based care as a continuum of the comprehensive health care provision for people living with AIDS in Umlazi area of Ilembe Region and its informal settlements*

Dear Colleague

**REQUEST FOR COMPLETION OF A QUESTIONNAIRE FOR RESEARCH PURPOSES**

Kindly complete the attached questionnaire. The information is required solely for the research purposes. Strict confidentiality will be ensured. Please do not write your name anywhere in this questionnaire.

Please answer all questions. There are no right or wrong answers. Your own views and opinions are important.

Please indicate your responses by placing a tick (✓) in the appropriate spaces or give explanations where needed.

Thank you for your cooperation.

  
**L.N. NYEMBE**

---

**SECTION 1: PERSONAL PARTICULARS**

---

1. Gender

Male       Female

2. Age group in years

11-20        
21-30        
31-40        
41-50        
51-60        
61 and above     

3. State your relationship with the client(s)

---

4. Educational level

Never been to school   
Grade 1-3   
Grade 4-6   
Grade 7-9   
Grade 10-12

Post Standard 10 Certificate / Diploma /Degree(s) (Please state)

---

---

**SECTION 2**

---

**5. BASIC NURSING PREPARATION**

- Registered Nurse
- Enrolled Nurse
- Auxiliary Nurse
- No Basic Nursing preparation

Other (please state) \_\_\_\_\_

**6. OTHER QUALIFICATIONS / CERTIFICATES RELEVANT TO NURSING**

- First Aid Nursing
- Geriatric Nursing
- Home-Based Care

Other (please state) \_\_\_\_\_

---

**7. COUNSELLING SKILLS**

Have you attended any counselling course?

Yes  No

If "Yes", state:

- Where?
- When?
- Duration?
- Name of Certificate (if any)

If "No", state how you obtained counselling skills.

---

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---

**SECTION 3**

---

**8. EXPERIENCE IN CARE OF PEOPLE WITH HIV/AIDS**

How many people with HIV/AIDS have you nursed before the present client(s)?

- None
- 1 - 5
- 6 - 19
- 11 - 15
- 16 - 20
- 21 and above

**9. In your opinion, how do clients rate Home-Based Care?**

- Excellent
- Good
- Poor

If "Poor", explain how best home-based care may be improved.

---

---

**10. How likely do you think it is that you may get HIV-infection from your caring role?**

- Very likely
- Likely
- Will never happen

---

**SECTION 4**

---

**SUPPORT SYSTEM**

11. Do you prefer working alone or with others in your role of Home-based Care-giver?

Alone

With others

Give reasons for your answer to No. 11.

---

---

12. The following groups provide you with good support system in your role as care-giver. (Tick all appropriate spaces)

AIDS Counsellors

Social workers

Nurses

Doctors

Members of Non-Governmental Organizations

Other (please state) \_\_\_\_\_

---

**SECTION 5**

---

**13. KNOWLEDGE ON HIV/AIDS**

Indicate how HIV-infection is transmitted from one person to another (Tick (✓) all appropriate spaces)

- |  |                          |
|--|--------------------------|
| Sneezing and coughing                    | <input type="checkbox"/> |
| Sharing eating utensils                  | <input type="checkbox"/> |
| Cleaning vomitus                         | <input type="checkbox"/> |
| Sharing toilet seats                     | <input type="checkbox"/> |
| Prick with used needle                   | <input type="checkbox"/> |
| Unprotected sexual intercourse           | <input type="checkbox"/> |
| Mosquito bite                            | <input type="checkbox"/> |
| Through skin cuts                        | <input type="checkbox"/> |
| Through kissing                          | <input type="checkbox"/> |
| Through tears                            | <input type="checkbox"/> |
| Blood transfusion                        | <input type="checkbox"/> |
| Handling loose stools without protection | <input type="checkbox"/> |

14. How necessary do you think the following practices are, for preventing the transmission of HIV-infection when caring for AIDS clients?

	Very necessary	Necessary	Not necessary
14.1 Hand-washing after contact with the client.			
14.2 Wearing gloves when handling body fluids / excretions.			
14.3 Avoiding re-capping injection needles after use.			
14.4 Covering cuts/abrasions with waterproof covering.			
14.5 use of condoms during sexual intercourse.			

Any other preventive measure(s) (please state) \_\_\_\_\_

\_\_\_\_\_

---

**SECTION 6**

---

**15. FACTORS THAT INFLUENCE PROVISION OF CARE**

How much do the following factors negatively influence the provision of care for people with HIV/AIDS infection?

	Very strongly	Strongly	No influence
15.1.1 Fear of contracting AIDS			
15.1.2 Age of care-giver			
15.1.3 Age of the client			
15.1.4 Lack of resources			
15.1.5 Social stigma			
15.1.6 Your level of education			
15.1.7 Lack of counselling skills			
15.1.8 Concern about personal safety			
15.1.9 Stressful situation			

Other commitments / responsibilities (please state) \_\_\_\_\_

---

---

**SECTION 7**

---

**16. ASSESSMENT OF CLIENT'S NEEDS**

Are clients' needs assessed to meet deficits as the disease progresses?

Yes  No

If "yes" to No. 16, how often are clients assessed?

Daily   
Weekly   
Monthly   
After every 3/12

**17. By whom are clients assessed?**

Yourself   
Doctors   
Nurses   
Other Community Health workers

---

**SECTION 8**

---

**18 AVAILABILITY OF LOCAL COMMUNITY SERVICES**

Spent period of hours with regard to availability of local community services (e.g. clinics)

8 hours - From 07:00 to 16:00   
10 hours - From 07:00 to 18:00   
24 hours - From 07:00 to 07:00 next day

Is there an adequate referral system between:

Home-based care and Hospital care?   
Hospital and Hospice care?   
Home-based Care and Hospice Care?

---

**SECTION 9**

---

**COPING WITH STRESS**

19. As a care-giver have you ever experienced any stressful situations?

If "Yes" to No. 19, kindly state briefly the causes of stress you experienced.

Briefly explain how you coped with stressful situations.

---

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---

**SECTION 10**

---

**20 BENEFITS OF HOME-BASED CARE FOR THE HIV/AIDS INDIVIDUAL**

Nursing a sick individual with AIDS at home has the following benefits:

	<b>STRONGLY DISAGREE</b>	<b>AGREE</b>	<b>DISAGREE</b>
20.1.1 Period of Isolation are never experienced by the client.			
20.1.2 The needs of the sick individual are assessed continuously			
20.1.3 Strict routine with regard to medication time is observed.			
20.1.4 The sick individual is compelled to sleep at specific times.			
20.1.5 Familiar home surroundings prevent fear.			
20.1.6 Boredom of bed-rest is uncommon.			
20.1.7 The individual's dignity and privacy is maintained.			
20.1.8 Complementary treatment i.e. acupuncture, massaging are accessible and available on demand.			
20.1.9 Client's satisfaction with care is low compared to hospital care.			
20.1.10 Individual and the family share moments of happiness, pain and loss			

---

SECTION 11

---

21. **PROBLEMS EXPERIENCED IN HOME-BASED CARE**

Indicate whether the following statements are true or false.

Lack of counselling skills.

True  False

Lack of basic nursing skills.

True  False

Lack of resources i.e. gloves, aprons, funds.

True  False

Unco-operativeness on the part of the client.

True  False

Lack of transport in most areas, especially at night.

True  False

Care-giver, if family member, may be compelled to stop working and take care of the sick individual.

True  False

Fear of contracting the disease

True  False

ANNEXURE 3

**QUESTIONNAIRE FOR SOCIAL WORKERS ON THEIR INVOLVEMENT  
IN HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS**

Dear Colleague

**REQUEST FOR COMPLETION OF A QUESTIONNAIRE FOR RESEARCH PURPOSES**

Kindly complete the attached questionnaire. The purpose of this questionnaire is to collect information on the involvement of traditional healers in treatment and Home-Based Care provided to sick individuals.

Strict confidentiality will be ensured. Please do not write your name anywhere in this questionnaire.

Please answer all questions. There are no right or wrong answers. Your views and opinion are important. Please indicate your answers with a tick (✓) in appropriate spaces and give explanations where needed.

Thank you for participating in this study.

  
L.N. NYEMBE

---

**SECTION 2**

---

**PROBLEMS RELATED TO RELATIVES OF THE SICK INDIVIDUAL**

2.1 Do you experience any further problems with relatives of the sick individuals?

Yes  No

If "Yes" to above, is the problem one of the following? (You may tick (✓) more than one box)

- |  |                          |
|--|--------------------------|
| Lack of family support                               | <input type="checkbox"/> |
| Total rejection by the family                        | <input type="checkbox"/> |
| No visitors allowed for the sick                     | <input type="checkbox"/> |
| Not opening-up and speaking freely about the disease | <input type="checkbox"/> |
| Denial of the disease existence                      | <input type="checkbox"/> |
| Fear of contracting the disease                      | <input type="checkbox"/> |

---

**SECTION 3**

---

**REFERRAL SYSTEM FOR PEOPLE LIVING WITH AIDS**

3.1 In your opinion, is there a good referral system?

Yes  No

3.2 State the type of clients you refer to other professionals

- |  |                          |
|--|--------------------------|
| Patient in need of disability grant                      | <input type="checkbox"/> |
| Those needing legal advice                               | <input type="checkbox"/> |
| Those needing medical attention                          | <input type="checkbox"/> |
| Those needing extensive psychological attention          | <input type="checkbox"/> |
| Family discord or abandonment                            | <input type="checkbox"/> |
| Orphans  | <input type="checkbox"/> |
| The terminally ill with no next-of-kin or friend to help | <input type="checkbox"/> |

3.3 State type of experts to whom you refer AIDS clients, i.e.

Psychologist

AIDS counsellors

Pastors

Support groups ie NAPWA

(National Association for People living with AIDS)

District surgeon

Any other, i.e. hospital / clinic

3.4 In your opinion, what happens to non-referral clients with problems?

They suffer in silence

Present with severe depression

Die sooner than expected

Have a prolonged denial stage

---

**SECTION 4**

---

**INTERVENTION IN REGARD TO AIDS ORPHANS**

4.1 Indicate which intervention(s) are appropriate for AIDS orphans.

Placement in institutions

Foster care

Extended family care

Staying alone with the eldest sibling looking after the  
younger one

Any other \_\_\_\_\_

---

4.2 In your experience, what are the common problems encountered by AIDS orphans?

Exposed to hard labour

Sexual abuse

School dropouts

Become street children

Become malnourished

Rejected by peer group

Live in isolation as a result of the stigma associated  
with AIDS

Any other \_\_\_\_\_

---

4.3 You may give any additional information you want to share on home-based care for people living with AIDS

## ANNEXURE 4

<b>QUESTIONNAIRE FOR TRADITIONAL HEALERS ON THEIR INVOLVEMENT IN HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS</b>
--

Dear Colleague

### **REQUEST FOR COMPLETION OF A QUESTIONNAIRE FOR RESEARCH PURPOSES**

Kindly complete the attached questionnaire. The purpose of this questionnaire is to collect information on the involvement of traditional healers in treatment and Home-Based Care provided to sick individuals.

Strict confidentiality will be ensured. Please do not write your name anywhere in this questionnaire.

Please answer all questions. There are no right or wrong answers. Your views and opinion are important. Please indicate your answers with a tick (✓) in appropriate spaces and give explanations where needed.

Thank you for participating in this study.

  
**L.N. NYEMBE**

**QUESTIONNAIRE FOR TRADITIONAL HEALERS**

---

**SECTION 1**

---

**PERSONAL PARTICULARS**

1. Gender

Male  Female

2. Age group in years

16-25

26-35

36-45

46-55

56-65

66-75

76 and above

3. **EDUCATION LEVEL**

Never been to school

Grade 1-3

Grade 4-6

Grade 7-9

Grade 10-12

Post Standard 10 Certificate / Diplomas / Degree(s) (please state)

---

3.2 Are you registered with *Inyanga* Association?

Yes  No

---

**SECTION 2**

---

**4 EXPERIENCE IN TRADITIONAL HEALING PRACTICE**

4.1 For how long have you practised traditional healing?

1-5 years

6-10 years

11-15 years

Over 15 years

5. Have you ever treated a client with AIDS?

Yes  No

6. If "Yes" to No. 5, state what signs and symptoms the client presents with

---

---

7. How did you diagnose the disease?

---

---

8. In your opinion, was your treatment successful?

Yes  No

9. If "Yes" to No.8, give reasons why you believe that the treatment was successful.

---

---

10. Do you believe in combining traditional medicine with the Western medicine?

Yes  No

11. If "Yes" to No. 10, give reasons

---

---

12. If "No" to No. 10, give reasons.

---

---

13. If your client does not improve on your prescribed treatment, what steps do you take to improve the client's condition?

---

---

14. Do you refer clients to the nearest clinic or hospital?

Yes  No

---

**SECTION 3**

---

15. Is AIDS a curable disease?

Yes  No

15.1 If "Yes" to No. 15, how it is cured?

---

---

---

---

15.2 If "Yes" to No. 15, how do you know when the person has been cured?  
(Briefly explain)

---

---

16. Explain how transmission of infection from one person to another can be prevented.

---

---

---

17. Do you encourage your clients to use condoms?

Yes  No

- 17.1 If "No" to No.17, give reasons.

---

---

18. What methods do you use for healing clients?

Herbs

Holy Water

Animal products e.g. skins, fat

Other methods (please state)

---

---

19. Do you use skin cuts with a razor blade as one of your methods of healing?

Yes  No

- 19.1 If "Yes" to No. 19, what are the risks involved?

---

---

---

19.2 What measures do you take to prevent these risks?

---

---

---

20. Do you work together with health care personnel?

Yes  No

20.1 If "Yes" to No.20, briefly explain how you work together.

---

---

---

21. You may give any additional information you want to share on treating people living with AIDS and the role of traditional healers.

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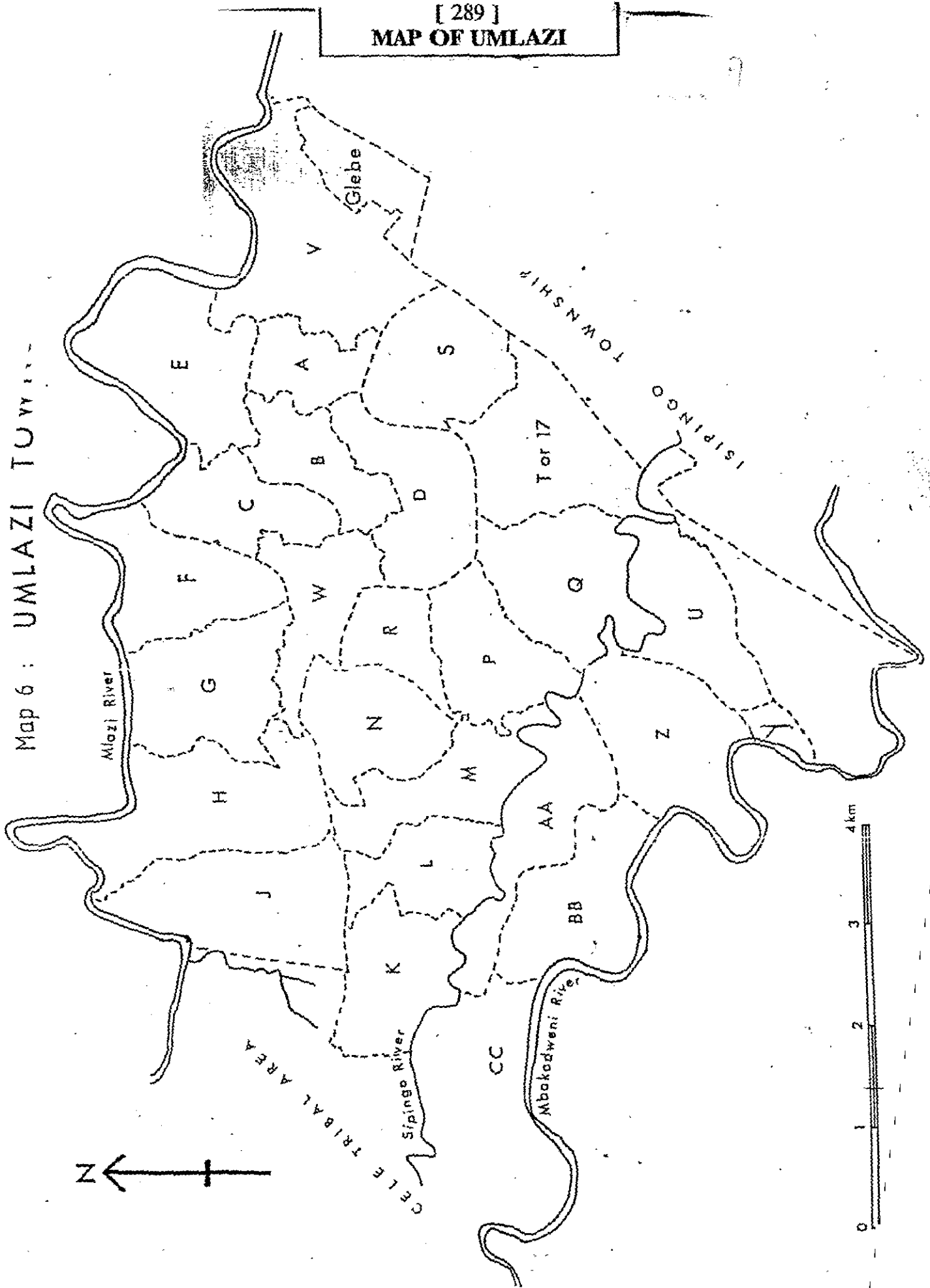
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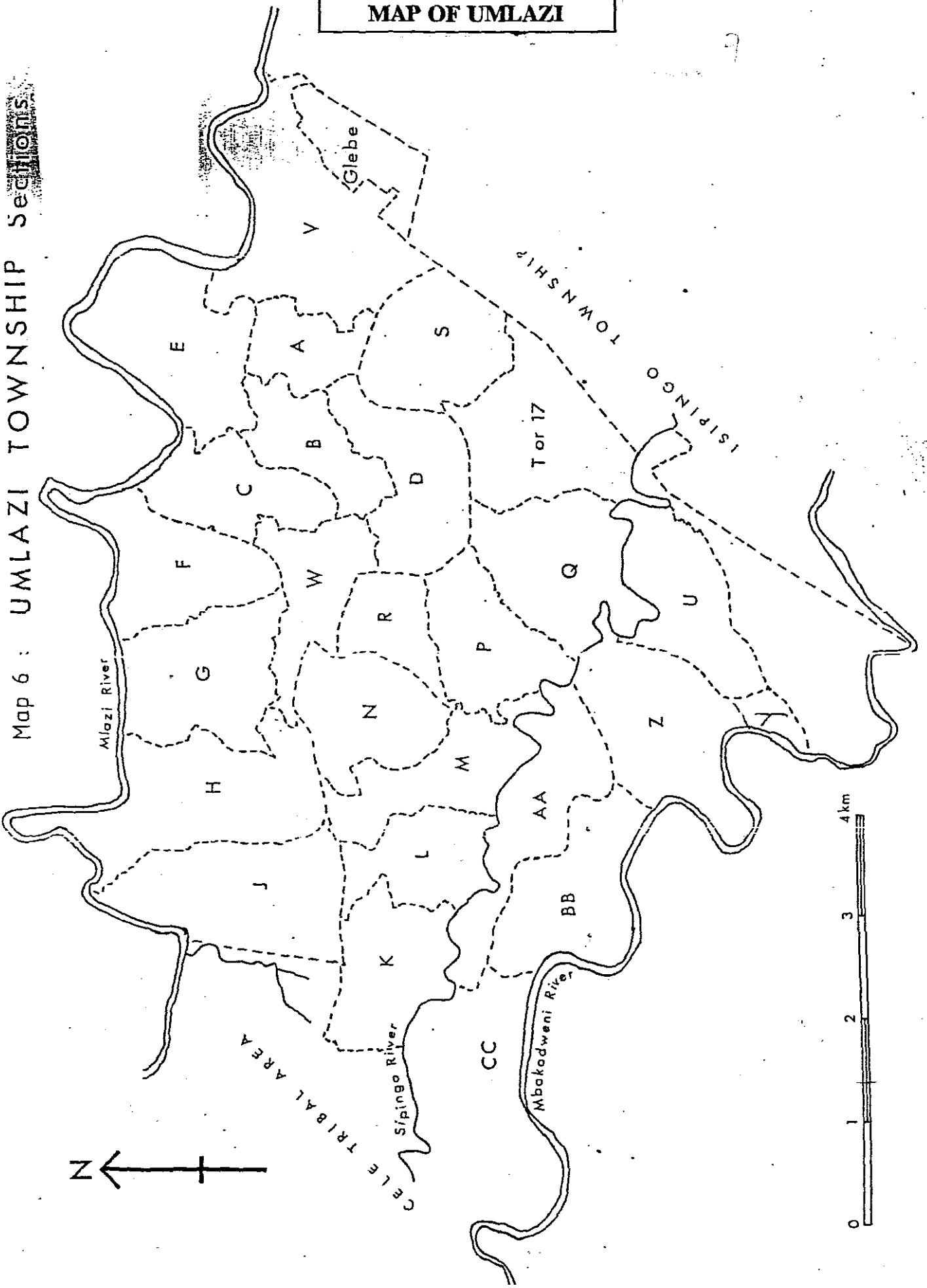
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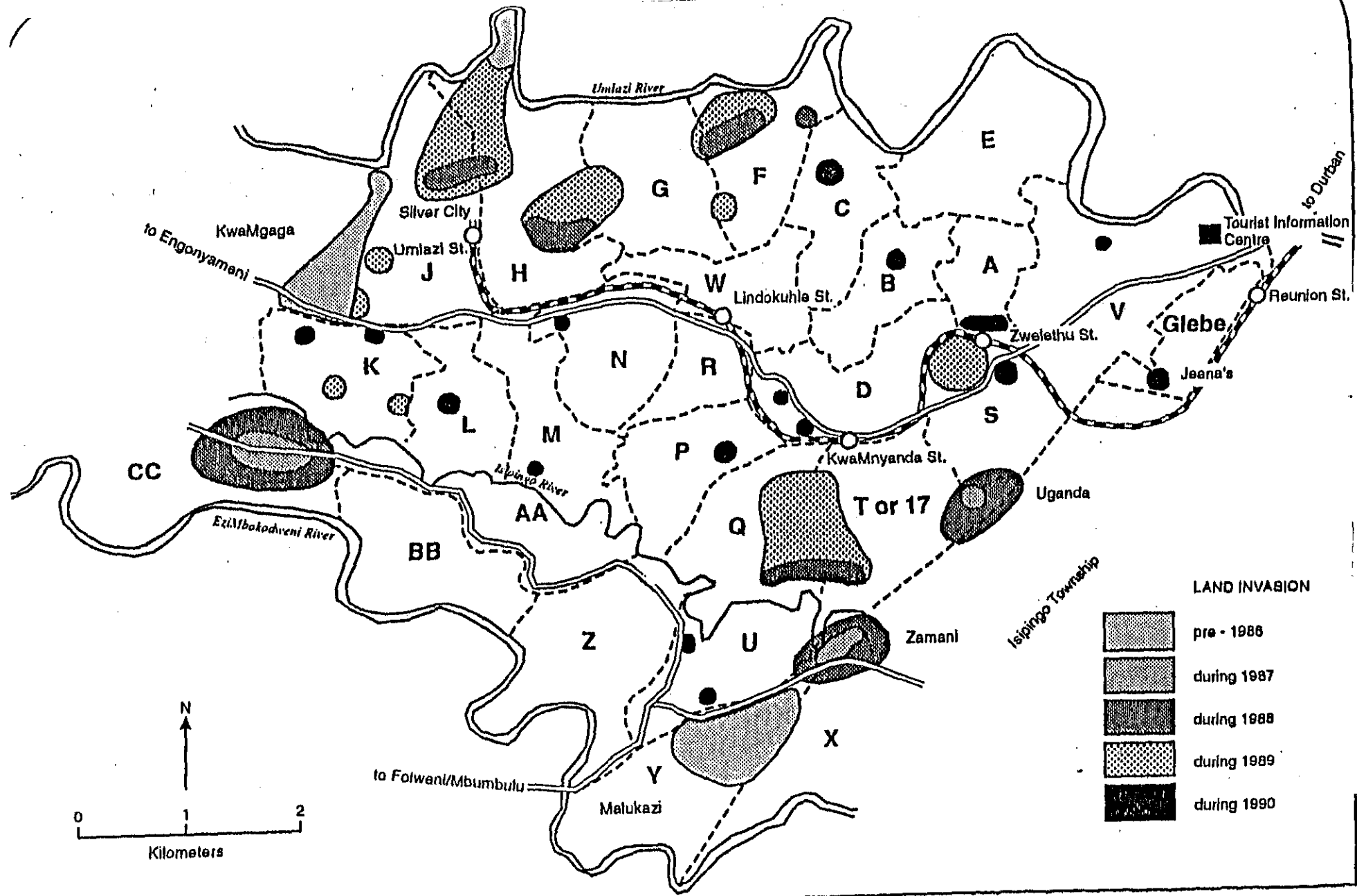
Map 6 : UMLAZI TOWNSHIP



Map 6 : UMLAZI TOWNSHIP Sections



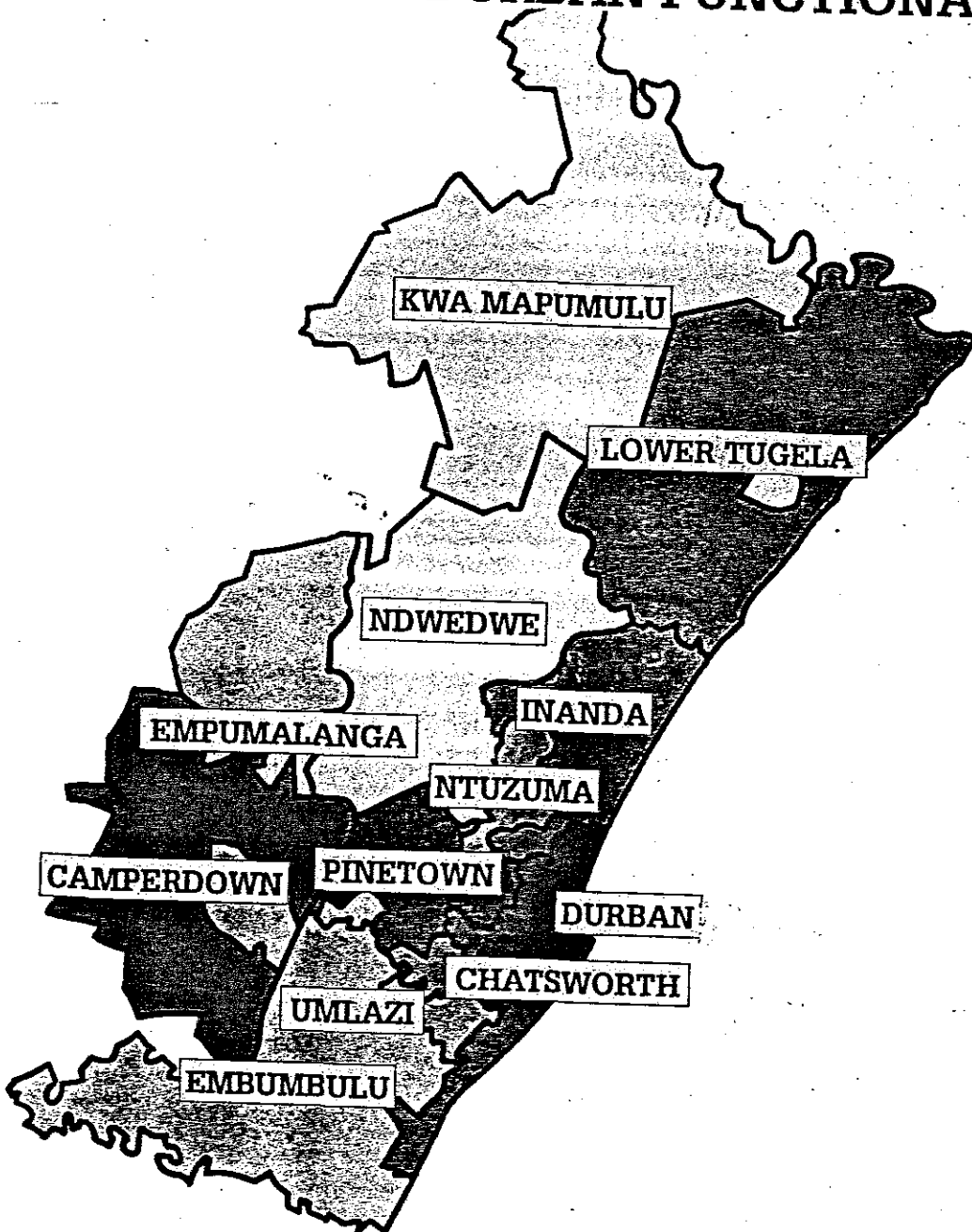
MAP OF INFORMAL SETTLEMENTS OF UMLAZI [ 290 ]



Informal settlements in Umlazi (1987 - 1990)

MAP OF DURBAN METRO AREA REFLECTING  
UMLAZI METROPOLITAN AREA

THE DURBAN FUNCTIONAL REGION



[ 292 ]  
**APPLICATION LETTERS FOR THE STUDY**

V 259 Umlazi Township  
P.O. Umlazi  
4031  
28 August 2000

The Deputy Director of Nursing Services  
Prince Mshiyeni Memorial Hospital  
Private Bag X07  
MOBENI  
4060

Dear Madam

**RE-APPLICATION TO CONDUCT A RESEARCH PROJECT ON HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS TO FULFIL REQUIREMENTS FOR A MASTER'S DEGREE AT THE UNIVERSITY OF ZULULAND (DURBAN-UMLAZI CAMPUS)**

I am a student at the University of Zululand, Durban-Umlazi Campus undertaking a research on the aforementioned topic.

I hereby request permission to conduct this study in your institution. I believe the outcome of the study will benefit the community members as a whole, your institution and the health care system. I will provide you with a copy of the report of the study.

Thank you.

Yours faithfully

  
L.N. NYEMBE (Mrs)

V 259 Umlazi Township  
P.O. Umlazi  
4031  
28 August 2000

The Superintendent  
Prince Mshiyeni Memorial Hospital  
Private Bag X07  
MOBENI  
4060

Dear Sir / Madam

**RE-APPLICATION TO CONDUCT A RESEARCH PROJECT ON HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS TO FULFIL REQUIREMENTS FOR A MASTER'S DEGREE AT THE UNIVERSITY OF ZULULAND (DURBAN-UMLAZI CAMPUS)**

I am a student at the University of Zululand, Durban-Umlazi Campus undertaking a research on the aforementioned topic.

I hereby request permission to conduct this study in your institution. I believe the outcome of the study will benefit the community members as a whole, your institution and the health care system. I will provide you with a copy of the report of the study.

Thank you.

Yours faithfully

  
L.N. NYEMBE (Mrs)

Prince Mshiyeni College Campus  
Private Bag X 10  
**MOBENI**  
4060  
14 April 2000

Umlazi Township Councillor  
**UMLAZI**  
4031

Dear Sir

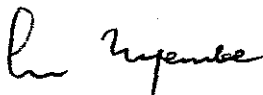
**RE-APPLICATION TO CONDUCT A RESEARCH PROJECT ON HOME-BASED CARE FOR PEOPLE LIVING WITH AIDS TO FULFIL A MASTER'S DEGREE REQUIREMENTS AT THE UNIVERSITY OF ZULULAND (DURBAN-UMLAZI CAMPUS)**

I am a student at the University of Zululand, Durban-Umlazi Campus undertaking a research on the aforementioned topic.

I hereby request permission to conduct this study in your area collecting information from families or individuals with help or any form of assistance to facilitate this study. I believe the outcome of the study will benefit the Community members as a whole.

Thank you.

Yours faithfully



L.N. NYEMBE (Mrs)



Ref. : 18/18/1

2000-09-14

Mrs. Nyembe  
V259 Umlazi  
P.O. UMLAZI  
4031

Dear Madam

**REQUEST FOR PERMISSION TO UNDERTAKE RESEARCH ON HOME BASED CARE  
FOR PEOPLE LIVING WITH AIDS IN UMLAZI**

Your letter dated 28 August 2000 in the above regard refers.

Please be advised that I am not in a position to grant you permission to undertake this research.

I do, however, suggest that you make contact with Ms Nokuthula Dlamini of the Durban Children's Society who has extensive contact with the Umlazi community of 'N' Section through fieldwork. Ms Dlamini is usually to be found at the Zamokuhle Community Hall, N137, Umlazi on Tuesday mornings at 09h30. I would recommend that you work in conjunction with Ms Dlamini for your research. She can be contacted on Tuesdays on telephone 906 5338.

In order to include other areas in the greater Umlazi, you may wish to get in touch with the Durban Children's Society on telephone 312 9313 during office hours to establish contact with the relevant Social Workers.

I wish you every success with your profile towards your Masters Degree.

Yours faithfully,

**COUNCILLOR THERESA MTHEMBU  
MAYOR**

**LETTER FROM MEDICAL SUPERINTENDENT AND  
DEPUTY DIRECTOR OF NURSING SERVICES**

**PROVINCE OF  
KWAZULU/NATAL  
HEALTH SERVICES**

**ISIFUNDAZWE  
SAKWAZULU/NATALI  
EZEMPILO**

**PROVINSIE  
KWAZULU/NATAL  
GESONDHEIDSDIENSTE**

**OFFICE OF: NURSING SECTION : PRINCE MSHIYENI MEMORIAL  
HOSPITAL: SOUTH AFRICA**

<b>Ikheli leposi</b> : P/Bag X07	<b>Fax No.</b> :	<b>Ucingo:</b>
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<b>Imibuzo</b> :	<b>Usuku</b> :	<b>Inkomba</b> :
<b>Enquiries</b> : D.E. Radebe	<b>Date</b> : 18.9.2000	<b>Ref.</b> :
<b>Navrae</b> :	<b>Datum</b> :	<b>Verwysing</b> :

Mrs. L.N. Nyembe  
Prince Mshiyeni College Campus  
Private Bag X10  
MOBENI  
4060

Dear Mrs. Nyembe,

**PERMISSION TO UNDERTAKE RESEARCH ON HOME BASED CARE PEOPLE  
LIVING WITH AIDS IN UMLAZI AND ITS INFORMAL SETTLEMENTS**

- . Permission is hereby granted to you to conduct the above mentioned research on the following conditions:-
- . Information collected will be treated confidentially and for the purpose of your studies.
- . The copy of the final report will be made available to this hospital.
- . PMMH Management wishes you a fruitful period of study.

  
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**Mrs. D.E. Radebe**  
**Deputy Director – Nursing Services**  
**For Chief Medical Superintendent**  
**DER/ssn**

**ZULU VERSION OF QUESTIONNAIRE FOR TRADITIONAL HEALERS**

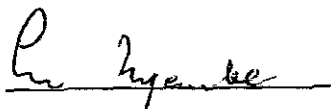
Amaphepha emibuzo abhekiswe kubantu abalapha izifo ngokusebenzisa imithi yeSintu noma labo abalapha abantu abugulela emakhaya ngenxa yegciwane lengculazi.

Sawubona Mhlobo

Ngicela ufunde iphepha leziyalo ngaphambi kokuthi ugcwalise amaphepha emibuzo. Okufanele ukwazi wukuthi zonke izimpendulo osinika zona zizohlala ziyimfihlo njalo. Igama lakho akufanele ulibhale kuleliphepha lemibuzo.

Ngicela uphendule yonke imibuzo. Ngicela unganqeni ukubuza ongakuqondisisi kahle. Imibono yakho ibalulekile. Beka isiphambano kulelo bhokisana ovumelana nalo, okanye chaza kancane lapho okudingeka khona.

Ngiyabonga



**Mrs L.N. Nyembe**

**(Umcwaningi)**

**IMIBUZO**

**ISIGABA SOKUQALA**

**IMIBUZO EQONDENE NAWE**

1. Ubulili

Owesilisa

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Owesifazane

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2. Iminyaka yakho

16 - 25

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26 - 35

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36 - 45

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46 - 55

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56 - 65

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66 - 75

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76 noma ngaphezulu

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3. Izinga Lemfundo yakho

3.1 - Awuyanga esikoleni

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- Ufunde wagcina kwibanga lokuqala

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- Ufunde wagcina kwibanga lesibili kuya kwelesine

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- Ufunde wagcina kwibanga lesihlanu kuya kwelesikhombisa

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- Ufunde wagcina kwibanga lesishiyagalombili kuya kweleshumi

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- Ezinye izifundo ozitholile, chaza

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3.2 Ubhalisiwe yini kwihlangano yezinyanga?

Yebo

Cha

## ISIGABA SESIBILI

### AMAVA NGOKWELAPHA NGEMITHI YESINTU

4.1 Mingaki iminyaka welapha abantu?

1 - 5

6 - 10

11 - 15

Ngaphezu kuka 15


5. Usuke wamelapha umuntu oguliswa yigciwane lengculazi?

Yebo

Cha

Yebo
Cha

6. Uma uphendule kulombuzo ongenhla ngo "yebo" chaza kafushane izimpawu zalesisifo kogulayo.

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7. Yini eyenza uqiniseke ukuthi uphethwe yisifo sengculazi, hayi esinye isifo?

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8. Uma ucabanga indlela owelapha ngayo iyagculisa ngokuba

Nemiphumela emihle

Yebo

Cha

Yebo
Cha

9. Uma ukwelapha kwakho kuyimpumelelo, chaza izizathu ezibangela ukuthi ugqiniseke ukuthi ngempela umuthi wakho unemiphumela emihle.

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10. Ngokwakho ukubona kulungile yini ukwelapha ngokuhlanganisa imithi yesilungu kanye neyesizulu?

Yebo
Cha

10.1 Uma uvuma chaza isizathu sokuvuma kwakho.

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10.2 Uma ungavumelani nokwelapha ngenhlanganisela, chaza isizathu sokuphika kwakho.

11. Uma umuntu omelaphayo engabingcono ngabe uyamdlulisela yini kubahlengikazi, emtholampilo oseduze, esibhedlela noma kudokotela wendawo.

Yebo
Cha

### ISIGABA SESITHATHU

#### UKUCWANINGA NGOLWAZI ONALO NGEGCIWANE LENGCULAZI

12. Ngabe ingculazi iyelapheka iphele nya?

Yebo
Cha

13. Uma uvuma ukuthi iyelapheka, ilapheka kanjani?

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14. Yiziphi izimpawu ezikhombisa ukuthi umuntu welaphekile? Chaza kancane.

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15. Chaza ukuthi igciwane lengculazi lingavikeleka kanjani lingasuki kumuntu onalo liye komunye umuntu.

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16. Ngabe abantu abalaphayo uyabakhuthaza yini ukuthi basebenzise ijazi lomkhwenyana (condom) uma beya ocansini

Yebo
Cha

17. Uma ungabakhuthazi ngokusebenzisa amakhondom (ijazi lomkhwenyane) ngabe yini isizathu? Chaza.

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18. Usebenzisa luphi uhlobo lokwelapha kulezinhlobo ezilandelayo?

18.1 Imithi yesizulu, nezimpande

18.2 Amanzi abusisiwe

18.3 Izinyamazane (amafutha, nezikhumba zazo)

18.4 Ungachaza nezinye izinhlobo ozaziyo


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19. Ngabe uyazigcaba iziguli zakho ngerazor blade uma welapha?

Yebo
Cha

20. Uma usebenzisa nokugcaba, ngabe yiziphi izingozi ezihambisana nalokhu? Chaza.

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21. Ngabe usebenzisana kahle yini nabezempilo (odokotela namanesi)

Yebo
Cha

22. Uma uvuma, chaza indlela enixhumanisayo ekhomba ubambiswano.

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23. Ungachaza nokunye okwaziyo noma okucabangayo okungaba lusizo ngokwelashwa kwengculazi.

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24. Umuntu ongenayo imali kodwa umuntu edinga ukwelashwa ngabe umenza njani? Chaza.

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