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***THE NEEDS OF HIV
POSITIVE PATIENTS AND
THEIR FAMILIES***

BY

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Submitted in fulfilment Social Science in Nursing

Masters in Social Science in Nursing

In the
Faculty of Health Sciences,
School of Nursing
At the


University of the Free State

May 2002

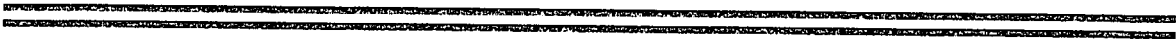
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I declare that the dissertation submitted for the degree, Magister social Sciences in Nursing to the University of the Free State is my own independent work and has not previously been submitted for a degree to another university.

A handwritten signature in black ink, appearing to read "B.S. Ndaba", is written over a horizontal dotted line. The signature is stylized and cursive.

B.S. Ndaba



ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to the following:

- ❖ God almighty for granting me health and time to finish this study.
- ❖ The National Research Foundation for sponsoring this venture.
- ❖ Participants in this research, for their openness and co-operation.
- ❖ My colleagues at the Koffiefontein Primary Health Care centre for their support.
- ❖ This specialized Auxiliary Service Officer Mrs. Rebecca Motswahaye for your willingness and enthusiasm during our home visits and in organising the focus group for interviews.
- ❖ Mrs. Elzabé van der Walt, for the timeless, neat typing. Your patience is unimaginable.
- ❖ Ms Hannemarie Bezuidenhout, division of educational Department, Faculty of Health Sciences for language editing and translation.
- ❖ The National, Research Information System personnel in Bloemfontein for their support on current statistical information.
- ❖ The Free State Provincial and local research information systems personnel for statistical information.
- ❖ The infectious Diseases Co-ordinator in Region B, Mrs Simpe on statistical information for the region and the district.
- ❖ Numerous people, not mentioned by name, who in some way have contributed to this study.
- ❖ Dr Lily van Ryn for your guidance on interview skills and communication skills generally.
- ❖ Dr Petro Basson and Mrs. Sarie Honiball, for your clear and firm guidance and exceptional visionary ability in what often felt like overwhelming chaos. I feel privileged to have had this experience under your guidance.
- ❖ My children for their unconditional support and love demonstrated throughout this study.

PREAMBLE

HIV infection is a global problem affecting individuals of all racial groups, socio-economic backgrounds, cultures, sex and age

The statistical information available at all governmental levels shows only a tip of an iceberg, because of the small number of people who present themselves for HIV blood tests. In South Africa, for example projected statistical information at provincial levels is based on the results of antenatal women attending the public primary health care facilities (who volunteered to be tested for HIV) (refer to Figure 1.1).

The aim of the study was to identify the needs of HIV positive patients and their families. A qualitative study was done that captured the unique experiences of the interviewed subjects, by tape-recording the unstructured interviews of both the HIV positive individuals and their family members. Purposive sampling was done from the attendance register, with the assistance of the primary health care centre personnel and specialized Auxiliary Officer at Koffiefontein. Subjects participated voluntarily in the research, after signing an informed consent form. The sample comprised both adult males and females. Saturation was reached after interviewing four patients and three members of their families. Giorgi's method of data analysis was used (See Appendix II)

Identified needs were classified into themes/constituents and groups using activities of daily living as described by Uys (1999). The groups were further categorised into major categories according to Maslow's hierarchy of needs.

Under the physiological needs, the needs identified included nutrition, sleep, rest, respiration, exercise, water and hygiene. The emotional support, empowerment and financial support form the pillars for the safety and security needs. In the love and belonging needs category, the communication and self concept needs of subjects were identified. The self-esteem and self-actualization needs revealed

the needs for emotional support, understanding and compassion towards the HIV positive individuals and their families.

HIV infection affects not only those who have the virus, but also those who irrationally fear infection, those who are at risk of being infected (who fear infection), friends, families, professionals and volunteer care givers, and neighbours of HIV infected individuals alike. The elderly are also included, because this disease affects their children who are economically active.

HIV infected individuals are normally taken care of by their relatives during their final stage of the disease (AIDS). On their death the elderly take care of their children. Where there are no relatives the children may be taken to orphanages, hospitals and for foster caring.

The disease per se is a multifaceted challenge that needs a multi-disciplinary approach from grass roots level to the highest authority in the country to fight against its spread (intersectoral collaboration).

People living with AIDS and their families need understanding and compassionate community members to support them emotionally, thereby removing the burden of the stigma associated with this disease.

OPSOMMING

HIV-infeksie is wêreldwyd 'n probleem wat 'n inpak maak op die lewens van individue van alle rasse-groepe en socio-ekonomiese agtergronde, ongeag kultuur, geslag en ouderdom.

Die amptelike statistiese inligting wat beskikbaar is, dui maar op die punt van die ysberg, omdat so min mense hulself aanmeld vir bloedtoetse om te bepaal wat hul HIV-status is. In Suid-Afrika, byvoorbeeld, word statistieke op provinsiale vlak gebaseer op die resultate van toetse gedoen op swanger vroue wat die primêre gesondheidsorgfasiliteite besoek, en hulself vrywilliglik laat toets vir HIV.

Die doel van die studie was om die behoeftes van HIV-positiewe pasiënte en hul gesinne te bepaal. 'n Kwalitatiewe studie, wat die unieke ervaring van die proefpersone met wie onderhoude gevoer is, vasgeê het, is uitgevoer. Dit is gedoen deur ongestureerde onderhoude wat met beide die pasiënte en 'n familielid van elk gevoer is, en op oudioband geneem is. Doelbewuste steekproefneming is gedoen uit die bywoningregister van die primêre gesondheidsorgsentrum of Koffiefontein. Die hulp van die personeel van die sentrum en die Spesialis-Hulpdienswerker is hieroor ingespan. Die proefpersone het vrywillig aan die navorsing deelgeneem nadat 'n vorm vir ingeligte instemming geteken. Die teekproef het beide die mans en vroue ingesluit. Versadiging is bereik nadat onderhoude met vier pasiënte en drie familieledes gevoer is. Giorgi se metode is vir die data-analise gebruik (vgl. Appendix II)

Geïdentifiseerde behoeftes is in temas en groepe ingedeel volgens daaglikse aktiwiteite deur Uys (1999). Die groepe is verder gekategoriseer volgens Maslow se behoeftehiërargie.

Onder fisiologiese behoeftes is voeding, slaap, rus, respirasie, oefening, water en higiëne aangespreek. Die behoefte aan emosionele ondersteuning, bemagtiging en finansiële ondersteuning vorm die boustene van die kategorie oor veiligheid en sekuriteit. In die kategorie van liefde en om te behoort, is kommunikasie-en-

selfkonsepbehoefte aan emosionele ondersteuning, begrip en deernis teenoor die pasiënte wat HIV-positief toets en hul families na vore gekom.

HIV-infeksie het nie net 'n invloed op die lewens van die persone wat die virus opgedoen het nie, maak ook op diegene wat 'n irrasionele vrees het vir infeksie, diegene wat die risiko loop om geïnfekteer te word (wat infeksie vrees), vriende, gesinne, professionele en vrywillige gesondheidswerkers en bure van HIV positiewe persone. Bejaardes word ook getref, want die siekte tas hul kinders, wat ekonomiese aktief is, aan.

Persone wat HIV –geïnfekteerd is, word deur hul familieledede versorg gedurende die finale stadiums van die siekte (VIGS). Indien hulle te sterwe kom, moet die bejaardes na hul afhanklikes (kinders) omsien. Indien daar geen familieledede is nie, kan dit gebeur dat die kinders na kindershuis of hospitale verwys word of in pleegsorg geplaas word.

Die siekte per se is 'n uitdaging met vele fasette en 'n multidissiplinêre benadering, met insette vanaf grondvlak tot op die hoogste vlak (intersektorale samewerking) word benodig om die verspreiding daarvan te bekamp.

Mense wat VIGS het sowel as hu gesinne het 'n gemeenskap wat begrip en deernis toon nodig om hulle emosioneel te ondersteun en daardeur die stigma wat aan die siekte kleef, uit te wis.

INDEX

	PAGE
CHAPTER 1: Problem statement and background	
1.1 INTRODUCTION.....	1
1.2 PROBLEM STATEMENT.....	2
1.2.1 Prevalence of HIV.....	2
1.2.1.1 Global overview.....	2
1.2.1.2 South Africa.....	3
1.2.1.3 The Free State.....	4
1.2.1.4 Koffiefontein area.....	6
1.2.2 Effects of HIV infection on individuals and their families.....	8
1.2.3 Key issues and needs related to illness.....	8
1.3 CONCEPTUAL FRAMEWORK.....	10
1.4 DEFINITION OF CONCEPTS.....	11
1.5 AIM OF THE RESEARCH.....	13
1.5.1 The objectives of the research.....	13
1.6 RESEARCH DESIGN AND METHOD.....	13
1.6.1 Population and sampling.....	14
1.6.2 Data collection.....	14
1.6.3 Pilot study.....	15
1.6.4 Data analysis.....	15
1.6.5 Ethical considerations.....	15
1.6.6 Validity and reliability.....	16
1.7 CHAPTER OUTLINE.....	16
1.8 CONCLUSION.....	17

	Page
CHAPTER 2: Philosophical grounding of the study	
2.1 INTRODUCTION.....	18
2.2 THE PHYSIOLOGICAL NEEDS.....	19
2.3 SAFETY AND SECURITY NEEDS	19
2.4 NEEDS FOR LOVE AND BELONGING	20
2.5 SELF-ESTEEM NEEDS	20
2.6 NEEDS FOR SELF ACTUALIZATION	21
2.7 CONCLUSION	22
CHAPTER 3: Research design and methods	
3.1 INTRODUCTION.....	23
3.2 AIM AND OBJECTIVES.....	23
3.2.1 Aim of the research.....	23
3.2.2 Objectives of the research.....	23
3.3 RESEARCH DESIGN AND METHOD	24
3.3.1 Population and sampling	25
3.3.1.1 Target population.....	25
3.3.1.2 Sample and size	25
3.3.1.3 Sampling criteria	26
3.3.2 Data collection	26
3.3.2.1 Interviews.....	26
3.3.2.2 Interview process.....	28
3.3.3 Pilot study	29
3.3.4 Data analysis	29
3.3.4.1 Content analysis	29
3.3.4.2 Transcribing interviews	31
3.3.4.3 Method of coding	31
3.3.4.4 Data filing system	32
3.3.5 Ethical considerations.....	3

	Page
3.3.5.1 Consent for the research	32
3.3.5.2 Voluntary participation	33
3.3.5.3 Privacy and confidentiality	33
3.3.6 Validity and reliability/trustworthiness	33
3.3.6.1 The truth value/credibility	34
3.3.6.2 Applicability/transferability	35
3.3.6.3 Consistency/dependability	35
3.3.6.4 Neutrality/confirm ability.....	36
3.3.7 Belief value	36
3.3.8 Triangulation	36
3.3.9 Literature control.....	38
3.3.10 Conclusion.....	38

CHAPTER 4: Literature review

4.1 INTRODUCTION.....	39
4.2 THE IMMUNE SYSTEM.....	39
4.2.1 Infection of the T-cell by HIV.....	41
4.3 HIV TRANSMISSION.....	41
4.3.1 The fluids and other usual means of transmission ...	42
4.3.1.1 Sexual secretions	42
4.3.1.2 Blood contained in needles or other instruments	42
4.3.1.3 Mother to child transmission	44
4.4 RELATIONSHIP BETWEEN MASLOW'S HIERARCHY OF NEEDS AND HIV INFECTION	46
4.4.1 The relationship between Maslow's hierarchy of basic human needs and HIV infection with regard to HIV positive individuals.....	46
4.4.1.1 Physiological needs	47
4.4.1.2 Safety and security needs	48

	Page
4.4.1.3 The love and belonging needs.....	51
4.4.1.4 The self-esteem needs	53
4.4.1.5 The self-actualisation needs	56
4.4.2 Relationship between Maslow's hierarchy of needs and HIV infection with regard to the families	57
4.4.2.1 The physiological needs	57
4.4.2.2 Safety and security needs	58
4.4.2.3 Needs for love and belonging	59
4.4.2.4 The esteem needs.....	60
4.4.2.5 The actualisation needs.....	63
4.5 CONCLUSION	64

CHAPTER 5: Data analysis

5.1 INTRODUCTION.....	65
5.2 FINDINGS.....	65
5.2.1 The physiological needs	65
5.2.1.1 Nutritional needs.....	66
5.2.1.2 Need for well-being.....	69
5.2.1.3 Activity and stimulation needs	72
5.2.1.4 Internal homeostasis needs.....	74
5.2.1.5 Elimination needs	75
5.2.1.6 Hygiene needs.....	76
5.2.2 Safety and security needs	77
5.2.2.1 Biological safety.....	77
5.2.2.2 Pharmacological safety.....	80
5.2.2.3 Environmental safety	81
5.2.3 The needs for love and belonging	81
5.2.3.1 Communication needs/assertiveness	82
5.2.3.2 Self-concept needs.....	85
5.2.4 Self-esteem and self-actualisation needs	85

	Page
5.2.4.1 Emotional support.....	86
5.2.4.2 Compassion and understanding.....	89
5.3 CONCLUSION	90

CHAPTER 6: Conclusion and recommendations

6.1 INTRODUCTION.....	91
6.2 RESEARCH RESULTS.....	91
6.2.1 The needs of the patients	91
6.2.2 The needs of the family	92
6.2.3 Physiological needs	93
6.2.3.1 Recommendation	93
6.2.4 Safety and security needs.....	93
6.2.4.1 Recommendation.....	94
6.2.5 The love and belonging needs.....	94
6.2.5.1 Recommendation.....	94
6.2.6 Self-esteem and self-actualisation needs.....	95
6.2.6.1 Recommendation.....	95
6.3 SUMMARY.....	95
6.3.1 The research problem and literature review	95
6.3.2 The study.....	96
6.3.3 The results	97
6.3.3.1 The physiological needs	97
6.3.3.2 The safety and security needs.....	97
6.3.3.3 The love and belonging needs.....	97
6.3.3.4 Self-esteem and self-actualisation needs.	97
6.4 THE LIMITATIONS OF THE STUDY	97
6.5 CONCLUSION	97
BIBLIOGRAPHY	99

	Page
APPENDIX I: Research questions	109
APPENDIX II: Interviews.....	112
APPENDIX III: Application for consent to perform research.....	142
APPENDIX IV: Consent for the research	144
APPENDIX V: Consent form for the subject participants	146

LIST OF FIGURES

	Page
FIGURE 1.1: HIV prevalence in pregnant women attending public antenatal clinics, by province, South Africa, 1999.....	4
FIGURE 1.2: Percentage HIV/AIDS positive cases in different districts of the Free State.....	5
FIGURE 1.3: Health districts of the Free State	7
FIGURE 1.4: Conceptual framework.....	10
FIGURE 2.1: Maslow's hierarchy of needs.....	18
FIGURE 3.1: Crano and Brewer's modified flow diagram for sampling for needs of HIV positive patients and their families	27
FIGURE 4.1: Infection of a T-cell by HIV.....	40
FIGURE 5.1: Physiological needs	66
FIGURE 5.2: Safety and security needs	77
FIGURE 5.3: The needs for love and belonging	82
FIGURE 5.4: Self-esteem and self-actualisation needs	86

CHAPTER 1

Problem statement and background

1.1 INTRODUCTION

Advanced technology, the scientific knowledge explosion coupled with epidemic, pandemic and endemic episodes of catastrophic and uncontrollable diseases, are all characteristics of the modern era.

One such a disease is Acquired Immuno-deficiency Syndrome (AIDS) which is caused by the Human Immuno-deficiency Virus (HIV). HIV is cited as one of the six killer diseases in South Africa (Vial, 1998:22). The World Health Organization cites it amongst the top 10 deadliest diseases in the world (DENOSA, 1998[a]:58).

Although campaigns world-wide have been initiated to equip communities with the necessary and relevant knowledge against this "dragon" disease, ignorance is still the human being's greatest enemy regarding HIV (Collins, 1992:39).

Some communities and individuals still do not regard AIDS as real, but as a disease of certain categories of the community, and therefore turn deaf ears to all educational programmes in this regard. What is required, is expressed well in the following quote:

"AIDS is not who you are, but what you do. We need to replace:

- Promiscuity with monogamy*
- Fear with courage*
- Ignorance with education*
- Sensationalism with the truth*
- Victimization of people with humanity*
- Ostracism of people with compassion*
- Criticism with empathy" (Gustaffson, 1988:15)*

1.2 PROBLEM STATEMENT

In this study the word "HIV positive" will be used to refer to both HIV infection and AIDS. AIDS and its concomitant problems are a reality, as is explained in the following discussion of HIV prevalence.

1.2.1 Prevalence of HIV

An overview at various levels proves the seriousness and prevalence of this infection.

1.2.1.1 *Global overview*

Global estimates of HIV infection in 1997 are that nearly 16,000 people (adults and children) are infected with HIV daily, and that 5,8 million people were newly infected with HIV in 1997, and 5,4 million in 1999 (Galloway, 2001:30). Of the infected, 5,2 million were adults, and 2,1 million of these adults were women; 590,000 were children above 15 years of age (DENOSA, 1998[a]:3; Richter & Heywood, 2002:47). Currently there are 33,6 million people who are living with HIV, 70% of these are in the sub-Saharan Africa(William, 2000:14).

A joint report released by the World Health Organization and the joint United Nations Programmes on HIV/AIDS revealed that death due to AIDS reached a record of 2,6 million during 1999, and that new infections continued uncontrolled, with an estimated 5,6 million adults and children world-wide becoming infected (DENOSA, 2000[b]:26;Richter, 2002:4). The groups most vulnerable to this disease are females, aged 15-34 years, and males aged 25-44 years (DENOSA, 1998[a]:32). The age groups affected are of childbearing age, economically productive and the leaders of tomorrow. If they do not work due to illness, the economy of their families may be affected as well as that of the state. Their premature death resulting from HIV infection may lead to a society composed of very old citizens and young children.

1.2.1.2 South Africa

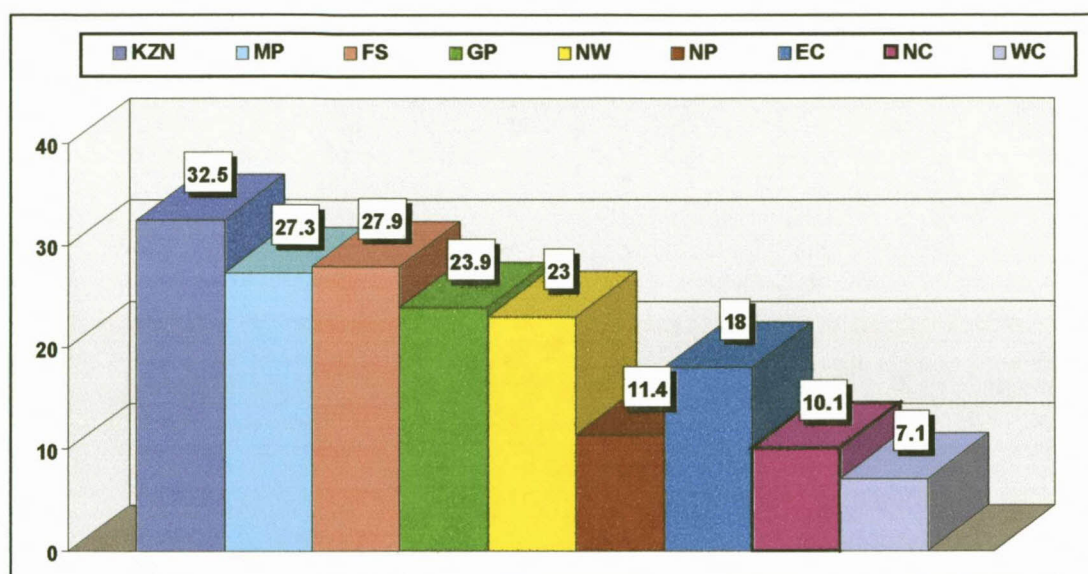
In 1999 estimations were that up to 1,700 to 1,850 new infections in men, women and children occurred daily in South Africa (Financial Mail, 2000:6).

According to Health minister Dr Manto Tshabalala-Msimang (Southern Africa report, 2000:7), roughly one in ten South Africans are infected with HIV, and that an estimated 4.2 million people in South Africa were infected with HIV at the end of 1999(Ala, 2000:8).

A country-wide survey was conducted in the years 1997 and 1998 comparing HIV prevalence by province. Based on 17,000 (Southern Africa Report, 2000:7) blood samples screened for HIV antibodies, it was estimated that 22.8% of the women attending antenatal clinics of the public health services nationally were infected with HIV by the end of 1998. This represented a 33.8% rate of increase in the prevalence level of HIV infection since 1997. In 1999 the prevalence increase was 36.5% which was at 7.1% rate compared to an increase rate of 5.2% in 1998 (Southern Africa Report, 2000:7).

The statistical information for 1998 on HIV infection prevalence rate rated KwaZulu-Natal as the most affected province with 32.5%, followed by Mpumalanga with 30%, and the Free State with 22.8% (Ntsaluba, 1999:4). The 1999 statistical information reflected the following findings per province: HIV prevalence in pregnant women in KwaZulu-Natal remained constant at 32.5%, in Mpumalanga it had dropped from 30% to 27.3%, in the Northern

Province it remained at 11.4%. On the other hand there was an increase in all the other provinces with the Free State rating second with 27.9% (Allen, Simelela & Makubalo, 2000:10). In Figure 1.1 these statistics are depicted graphically.



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

FIGURE 1.1: HIV prevalence in pregnant women attending public antenatal clinics, by province, South Africa, 1999 (Allen, Simelela & Makubalo, 2000:10)

HIV prevalence was slightly higher in the 30-34 year old and the 35-39 year old groups and slightly lower among teenage girls (Southern Africa Report, 2000:7; Richter & Heywood, 2002:4).

1.2.1.3 *The Free State*

For several reasons the data collected in the Free State regarding AIDS and the effects thereof on individuals and their families, are insufficient, due to confidentiality, victimization and Stigmatization associated with HIV infection. Figure 1.2 depicts the HIV prevalence rate at district level in five districts in the Free State (Department of Health of the Free State, 1999).

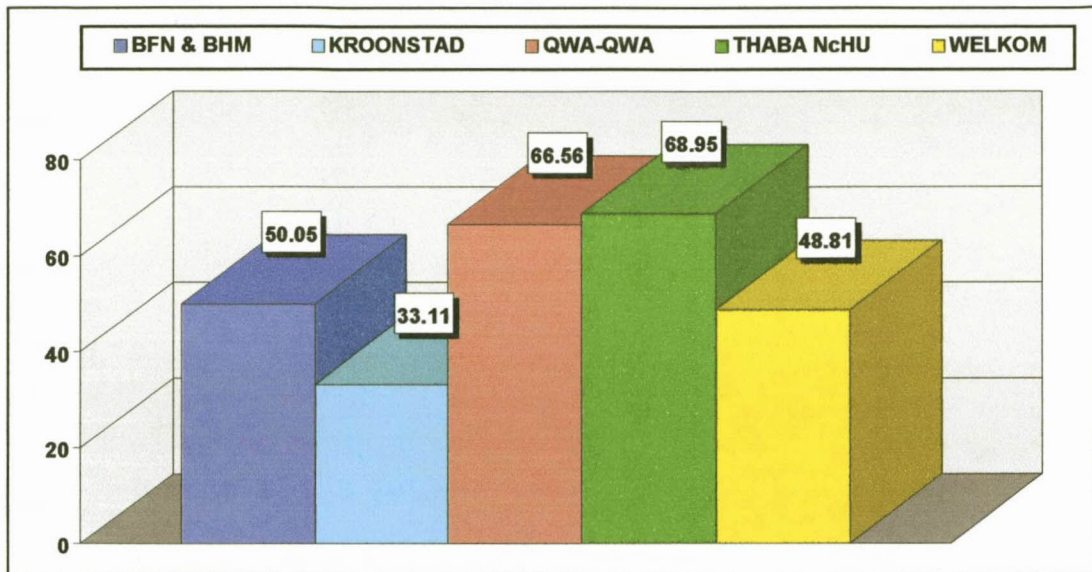


FIGURE 1.2: Percentage HIV/AIDS positive cases in different districts of the Free State (Department of Health of the Free State, 1999)

Of the 14,374 blood samples taken in the health care facilities, as indicated in Figure 1.2 Thaba Nchu had the highest prevalence of 68.95%, followed by Qwa-Qwa with 66.56%, Bloemfontein and Bethlehem 50.05%, Welkom 48.81% and lastly Kroonstad with 33.11%.

This implies that HIV infection is highly prevalent in the Free State and that rural settlements have a higher incidence compared to urban and semi-urban settlements.

The national statistics for the years 1997 and 1998 rated the Free State in third position of the nine provinces. The statistics for the year 1999 rated it second (see Figure 1.1). There has been a tremendous increase in HIV infection from 22.8% to 27.9% of those tested in 1997 and 1998 (Allen *et al.*, 2000:10).

The national research results are based on blood tests done on antenatal female patients only. This could mean that the statistical information for the Free State and other provinces, is not a true reflection of the AIDS epidemic. In the Free State factors like migratory labour, because of the mines found in the province,

need to be considered and therefore a higher incidence might be possible than reflected in national statistics (Evian, 1995:9; Whiteside, 1998[b]:6).

Of the 14,374 blood samples taken in the Free State health facilities for HIV testing, 6,727 (46%) were HIV positive (Department of Health of the Free State, 1999:1). The Department of Health, Information and Research Centre, Bloemfontein gives a much higher prevalence than the national research statistics (see Figure 1.2).

1.2.1.4 Koffiefontein area

This study will concentrate on the Koffiefontein area in the Free State (see Figure 1.3). The selected area is a rural, multicultural area and is characterized by high migratory labour rates, which could be a factor associated with a high HIV infection rate. The selected area represents a part of the Free State where little research has been done on the topic researched.

In unpublished statistics for the year 1999 obtained from the primary health care clinic on HIV infection in Koffiefontein, more than 80% of the HIV positive patients were adults aged between 20 to 50 years; the death rate due to HIV infection is estimated at 43% (Infectious Diseases Co-ordinator Region B: 2000).

Because of the incidence and the increasing rate of HIV infection, this study will deliver a valuable contribution to the management of HIV positive people.

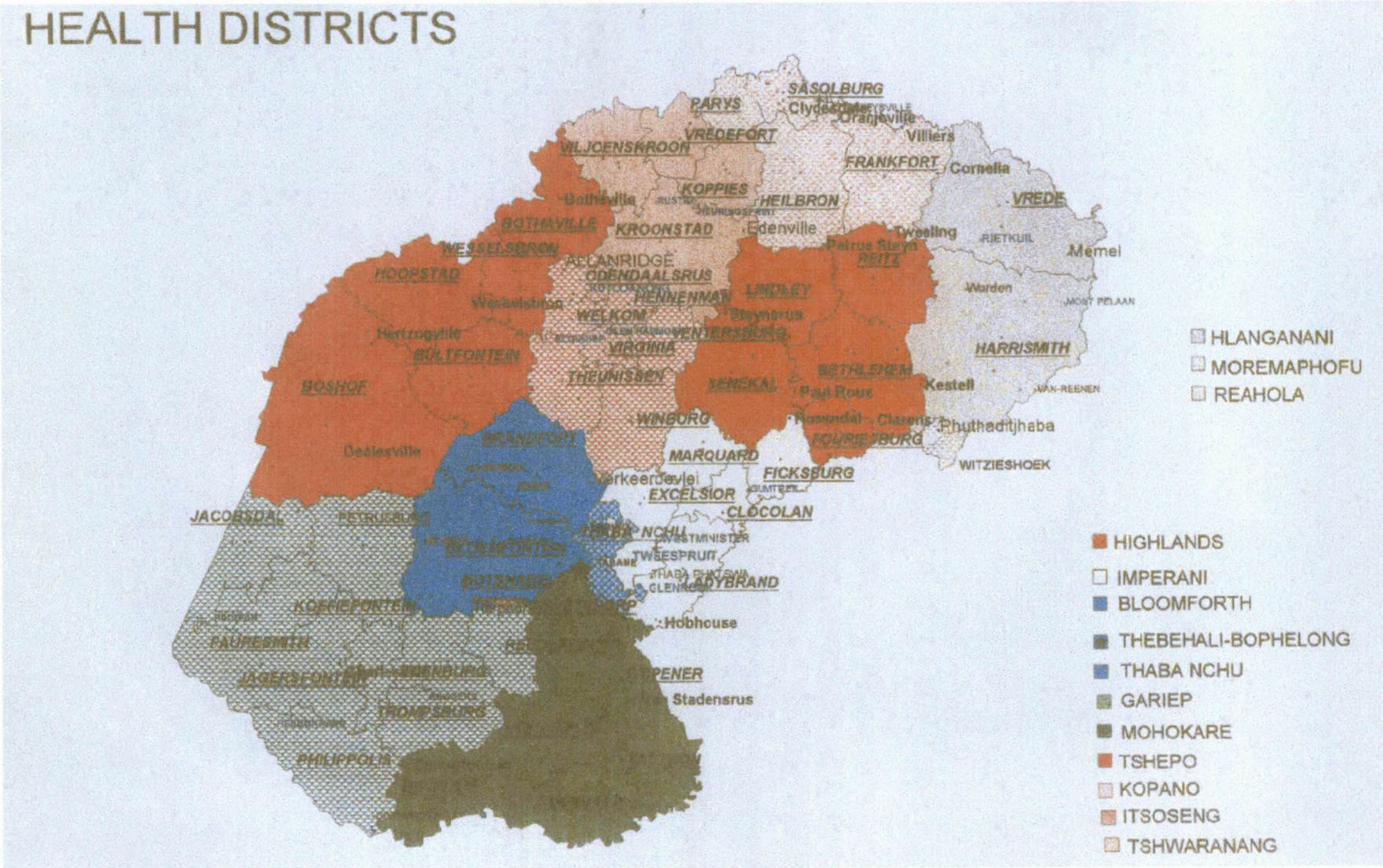


FIGURE 1.3: Health districts of the free State

1.2.2 Effects of HIV infection on individuals and their families

HIV infection is an incurable disease for which no immunization is available. The rapid increase in its incidence rate is aggravated by its mode of spread, which is direct contact with a HIV infected person's secretions as sexual fluids and blood.

An individual who is HIV positive needs support so as to have a positive outlook on life and taking initiative in applying measures to maintain the immune system at average levels to sustain maximum body functioning and not to spread HIV. When patients have full-blown AIDS, they need to be assisted to die with dignity. It is therefore of major importance to look critically into the needs of these individuals. The nurse's role in the comprehensive health care system is vital in this regard (Gustaffson, 1988:14).

The effects of HIV infection on HIV positive subjects and their families will be discussed in Chapter 4 on literature review.

1.2.3 Key issues and needs related to illness

Gorman *et al.* (1989:4-6) identified six key issues affecting a patient's response to illness as self-esteem, body image, powerlessness, hopelessness, loss and guilt. Central to these is an individual's self-esteem which is the personal judgement of the individual's own worth (Gorman *et al.*, 1989:4).

Gorman's issues link with Maslow's hierarchy of needs (see Chapter 2) and because patients experience these needs in general, this could also be the case with HIV positive patients. In Maslow's hierarchy of needs, unmet physiological needs will leave an individual in a state of powerlessness, hopelessness with guilt feelings due to a loss to an individual's body image. In this devastated situation an individual's self-esteem becomes lowered.

According to Maslow the needs at the lower levels of the hierarchy must be satisfied first before an individual becomes aware of the needs at higher levels, for example, an individual who has been starving for more than three days will only

concentrate on getting food. Unless the hunger is satisfied nothing will occupy the mind except hunger and food (Morgan, King, Weisz & Schopler, 1989:299). This could have an influence on identifying own needs by HIV positive patients and their families.

Illness and disability influence self-esteem, because goals may need to be altered or abandoned (Gorman *et al.*, 1989:5). If the self-esteem basis is firm, an individual may adapt and accept the illness state positively, however, if the self-esteem basis is conflicting, the sick person may react aggressively and negatively (Gorman *et al.*, 1989:5). This type of behaviour is also experienced by HIV positive patient (see 1.2.2.4).

Maslow's hierarchy of needs will be used as the philosophic basis, whereby needs of HIV positive patients and their families will be categorised (see Chapter 2).

1.3 CONCEPTUAL FRAMEWORK

Concepts of value for this study include the needs of HIV positive patients and their families (see Figure 1.4).

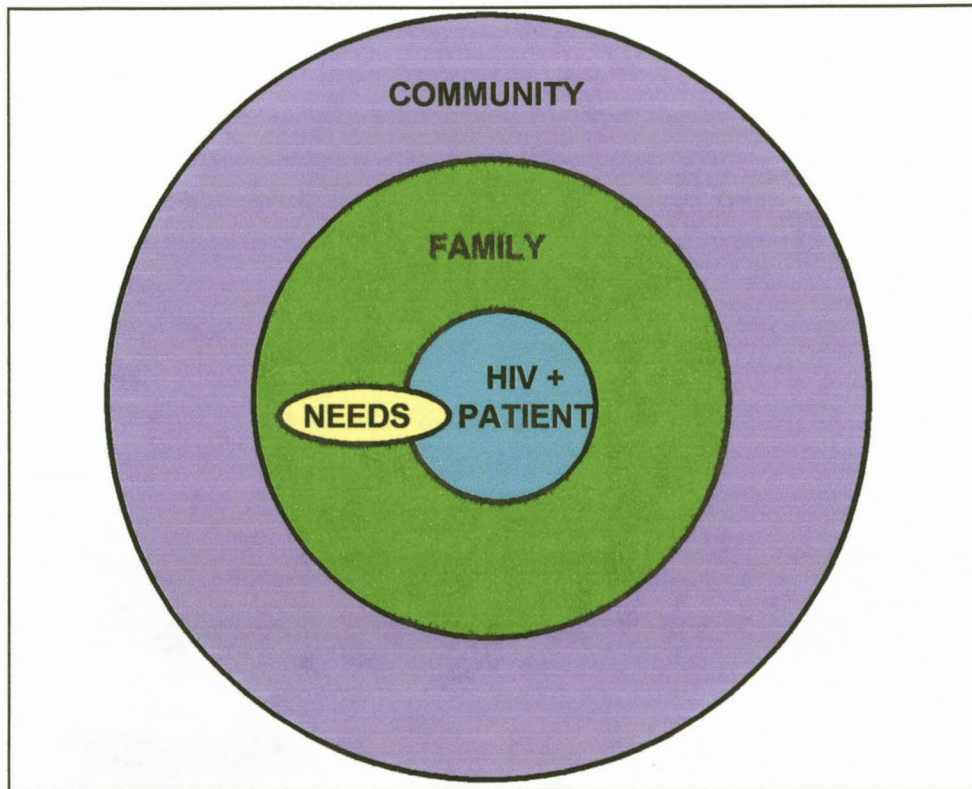


FIGURE 1.4: Conceptual framework

A HIV positive patient forms part of a family which forms part of a community. As HIV infection creates needs in the patient who is a member of a family, this will directly also create needs in the family. Needs experienced by both the patient and the family will influence the community to which they belong.

The broader community needs were excluded from this study, because these fall outside the boundaries of this research, but forms part of the conceptual framework, as a family and the community cannot be separated.

1.4 DEFINITION OF CONCEPTS

For the purpose of this study, the following definition of concepts will apply.

HIV

The Human Immuno-deficiency Virus (South Africa No. 1479, 10 December 1999) is a causative organism of AIDS. The virus belongs to a group of viruses known as retroviruses, meaning that it is capable of replication by making DNA out of RNA – “the blue print for genetic replication” (Winiarski, 1991:11).

HIV positive patient

An HIV positive patient is an individual in whose blood the Human Immuno-deficiency Virus antibodies are detected through a specific test aimed at the identification of the particular virus (Vlok, 1996:600).

AIDS

The word AIDS is the acronym for Acquired Immuno-deficiency Syndrome (South Africa No. 1479, 10 December 1999) a disease process characterized by many and different symptoms, indicating the depletion of a person's immune functioning. The condition is acquired – meaning that the individual is not born with it. The person must be infected by HIV (Winiarski, 1991:11).

Need

A need refers to something without which one believes one cannot live; something perceived as essential, not as a luxury (Coventry & Nixon, 1999:340).

Family

A family is two or more members related in blood and or marriage and functioning as a primary unit of socialization (Tseng & Hsu, 1991:1).

Community

A community is a group of people living in the same area or within a territorial boundary, sharing the same norms and values, and having the potential of interacting with one another (Dreyer, Hattingh & Lock, 1997:104).

Experience

Experience refers to knowledge and skills gained through a practical involvement in an activity or event (Coventry & Nixon, 1999:176).

Problems

A problem refers to something difficult to deal with or understand; something to be solved or dealt with (Coventry & Nixon, 1999:406).

Effects

Effects are defined as responses to stimuli (Hargie & McCartan, 1986:53).

Coping strategies

Coping strategies are ways and means of facing reality and problems when an individual is in a particular situation. Coping is a way of dealing with change and responding to pressure (Wright, 1993:37).

Support systems

These are groups of people with common fears, problems and anxieties formed for the purpose of airing views and feelings (Wright, 1993:186).

1.5 AIM OF THE RESEARCH

The aim of this research was to identify the needs of HIV positive patients and their families in the community.

1.5.1 The objectives of the research

This research had the objectives to:

- (i) identify the needs of the HIV positive patient,
- (ii) identify the needs of this HIV positive patient's family,
- (iii) make recommendations to the district and the regional health management teams based on the results of the research.

1.6 RESEARCH DESIGN AND METHOD

A qualitative study was performed. This type of research captures experiences as lived by the subjects in a natural environment (Leininger, 1985:94).

An exploratory, descriptive study, contextual in nature, was conducted, exploring and describing needs of HIV positive patients and their families.

Lengthy unstructured interviews (Bailey, 1987:193; Omery, 1983:57) were held with subjects who are HIV positive and their family members. Interviews with HIV positive subjects were done separately from interviews with family members, thereby respecting the subject's privacy and sustaining confidentiality and a trust

relationship. Transcription of interviews was done by the researcher and then analysed.

1.6.1 Population and sampling

In unpublished statistics for the year 1999 obtained from the primary health care clinic on HIV infection in Koffiefontein, more than 80% of the HIV positive patients were adults aged between 20 to 50 years (Infectious Diseases Co-ordinator, Region B:2000).

The population included all HIV positive adult subjects and their families in the Koffiefontein and surrounding areas. Blood relations such as mother, father, brother or sister were considered as family. Purposive sampling was done from the attendance register, with the assistance of the personnel in the primary health care centre in Koffiefontein and a Specialized Auxiliary Officer. Saturation was reached after interviewing seven subjects.

1.6.2 Data collection

Data collection was done by recording the unstructured interviews on tape with both HIV positive subjects and their family members.

Because the description of the experience under study was naïve, the researcher asked the subjects to describe their needs related to being HIV positive or living with a family member who is HIV positive. Probing as a communication technique was used to let the subjects verbalise their experiences and needs gradually in an unbiased way (Omery, 1983:56).

HIV positive patients:

"What needs do you have that are related to your HIV positive status?"

The family member:

"What needs do you have now that you have a HIV positive member in your family?"

1.6.3 Pilot study

A pilot study had been conducted to test phrasing, paraphrasing and the use of neutral probes, before conducting the actual study.

1.6.4 Data analysis

Data analysis was done by analysing and coding according to Giorgi's method (Omery, 1983:58). Each subject's description was read, identifying transitions or units in the experiences called constituents. Redundancy in the units was eliminated by the researcher, clarifying the meaning of the remaining units by relating them to each other and to Maslow's hierarchy of needs. The researcher reflected on the given constituents, still identified in concrete language of the subjects and transformed them into the language of science, using the activities of daily living as described by Uys (1999) to integrate and synthesize the insights into a descriptive structure within the levels of Maslow's hierarchy of needs (cf Chapter 2).

1.6.5 Ethical considerations

The research protocol was submitted at the University of the Free State to the Faculty of Health Sciences' Ethics Committee and the School of Nursing's Research Committee for ethical consideration and approval, respectively.

Formal introduction of the researcher to the subjects was done by the Specialised Auxiliary Service Officer at the primary health care centre at Koffiefontein.

An informed consent form was signed by all subjects who participated in the study voluntarily, and confidentiality was ensured throughout. No physical tests were done that could cause bodily harm. Subjects were informed that they might not benefit directly from this study and might withdraw if they wished.

1.6.6 Validity and reliability

The researcher was trained to conduct interviews and was evaluated for proficiency in this skill by two experts. The validity and reliability of the data analysis of this study were ensured by applying coding according to Giorgi's method whereby the truth value, appropriateness, consistency, neutrality and belief value (Comery,1983:58) also (see paragraphs 3.3.6.1 to 3.3.6.5). Interview transcripts and tapes were sent to a specialist in this field to verify coding and classification of categories.

1.7 CHAPTER OUTLINE

Chapter 1	Problem statement and background
Chapter 2	Theoretical grounding of the study
Chapter 3	Research methodology
Chapter 4	Literature review
Chapter 5	Data analysis and findings
Chapter 6	Conclusion and recommendations

1.8 CONCLUSION

AIDS is a reality. Health care providers, communities and service providers in other sectors (governmental and non-governmental) should join hands to curb the spread of this disease. HIV infection affects individuals of all age groups, sex and social status alike if ignorant of good health and self-care behaviour.

The statistical information given in this chapter gives an overview on the extent of prevalence rate and incidence rate of HIV infection and AIDS.

In this chapter the problem was stated and a philosophic grounding for the study will follow in Chapter 2.

CHAPTER 2

Theoretical grouping of the study

2.1 INTRODUCTION

The theoretical grounding of this study is based on Maslow's hierarchy of needs. These needs are integrated, with no distinct stratification.

Maslow's hierarchy of needs is used in this research as the foundation on which the needs of HIV positive patients and their families in the community were identified. The hierarchy has a broader base, which tapers at the top (see Figure 2.1). The needs appear in this order, from lowest (broader base) to highest (tapered top), with physiological needs first and self-actualisation needs last (Morgan *et al.*, 1989:298).

The needs at the lower level are basic and necessary for daily living as will be outlined in the following discussion. The tapering apex indicates that only few individuals attain satisfaction of needs at that level.

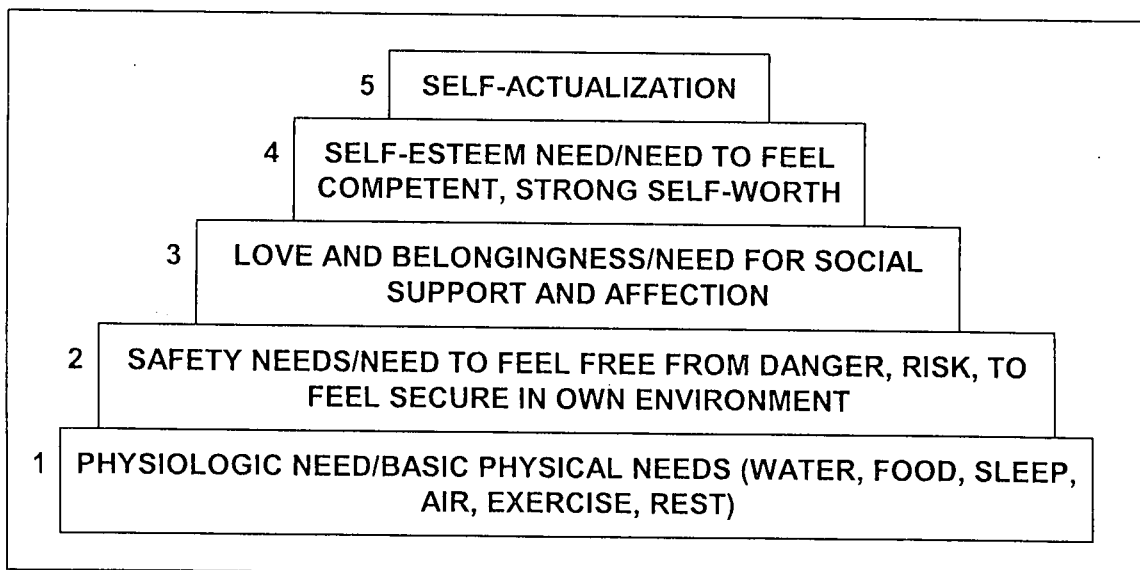


FIGURE 2.1: Maslow's hierarchy of needs (Morgan, King, Weisz & Schopler, 1989:298)

2.2 THE PHYSIOLOGICAL NEEDS

These needs predominate in the motivation of human behaviour and drive the mechanisms towards maintenance of homeostasis. They involve the regulation of the respiratory, nutritive and excretory functions, as well as the maintenance of the water content of tissues, adjustment of body temperature and the operation of numerous protective mechanisms (Perko & Kreigh, 1988:29). Therefore nutrition, oxygen, water and elimination needs predominate other needs in the higher levels (Smith, 1981:152).

These needs are powerful; unless satisfied, they dominate the conscious mind. For example, if persons are obliged to restrict fluid intake for therapeutic reasons, thirst will absorb their thoughts. During this period they are not likely to be too concerned about the hygienic conditions of the environment. As soon as their thirst is quenched, they become aware of other needs, now they may be disturbed by the absence of privacy (Morgan *et al.*, 1989:298; Smith, 1981:152).

2.3 SAFETY AND SECURITY NEEDS

If the physiologic needs are satisfied, the concern for safety emerges. Each individual has needs for sameness, sureness, familiarity, order, trustworthiness, consistency and reliability in life. Usually an individual receives such assurances first from the family, then from associates, and finally from the larger world or society (Perko & Kreigh, 1988:29; Howe, 1995:42).

Certain situations may disrupt this sense of security, for example in cases of loss of a parent or breadwinner, the family members may feel insecure and unsafe and this may affect the psychological aspect. Homeless people especially youth are prone to engage in prostitution (unsafe sex) as a means of earning money and food as well as intravenous drug use (sharing needles) thereby exposing themselves to HIV infection (Beattie, Gott, Jones & Sidell, 1993:179).

This level of needs is therefore addressed by the source of income of an individual and family, as well as the relations within the family, that is, the pampering and encouragement received during development (Gorman *et al.*, 1989:299).

2.4 NEEDS FOR LOVE AND BELONGING

Every individual of all ages at all levels of wellness desires the companionship and recognition of others. Many people travel through life seeking to find love and a sense of belonging (see paragraph 2.3). A person must have company. Somehow, wherever individuals are, they need to belong. Belonging gives individuals assurance of a secure place in the environment around them (Burnard, 1991:41). Every individual desires affection, warmth, kindness and consideration in human relationships. Loving and belonging involve both giving and receiving and are built on a foundation of gratified safety and physical needs. An individual needs the acceptance and the companionship of others, and in turn shares potentials, and compassion as well as the individual self with those who display love (Whitfield, 1989:19).

It is positive to recognise that human beings grow and mature by being loved and wanted (Whitfield, 1989:203; Gorman *et al.*, 1989:299).

A sound source of income and effective coping strategies, especially in times of stress form a firm basis for good relations within the family and among friends and communities (Perko & Kreigh, 1988:152; Morgan *et al.*, 1989:298).

2.5 SELF-ESTEEM NEEDS

As people develop, they come to desire the approval of others regarding their words or actions. They find that when others give their approval, they feel good and that the opposite occurs when they receive disapproval. Persons' strength and confidence are expanded as they come to know their self worth and their capabilities. Each time they experience success in any tasks that are important to

them, their valuation of themselves increases. Early in their lives they are helped by others to build their self-esteem. Gradually, as they mature, their need for the approval of others in their daily actions lessens. They perform because they are operating out of themselves, their values, their work, their responsibility and their world (Morgan *et al.*, 1989:298; Howe, 1995:36).

On the other hand, a low self-esteem is characterized by the feelings of guilt and shame from not meeting the norms and values of one's family and community (Whitfield, 1989:44). Self-esteem and feelings of guilt are among the six key issues identified by Gorman *et al.* (1989:4-6) affecting a patient's response to illness.

2.6 NEEDS FOR SELF-ACTUALIZATION

The last need identified by Maslow is considered the ultimate in personal achievement. When individuals are self-actualised, functioning at optimum capacity is reached. Goals of identity, direction, realisation and fulfilment have been achieved. They are in a state of being fully themselves, and at peace with their individual selves, such serenity is felt also by those who have contact with them (Morgan *et al.*, 1989:601).

A person's own development and contribution to the individual's own world, helps to shape either a positive or negative image of self, that is "who he is". A self-actualizing individual is capable of living with successes and failures (Howe, 1995:74).

The self of the individual is constantly in a state of becoming, and a state of becoming implies growth and change and is closely linked with the communication process. A self-actualizing person feels very capable, very alive, very happy and usually very grateful (Morgan *et al.*, 1989:602). To address the needs discussed above the following questions were asked from the HIV positive subjects and their families:

The question asked from the HIV positive subjects was:

"What needs do you have that are related to your HIV positive status?"

The question asked from the subject's relatives was:

"What needs do you have now that you have a HIV positive family member?"

The use of neutral probes helped the researcher to address all the levels in Maslow's hierarchy of needs.

2.7 CONCLUSION

In times of stress and illness individuals and families normally focus on their lowest levels on Maslow's hierarchy of needs. On overcoming a stressful situation, individuals become aware of the needs at a higher level and try to organize and adapt themselves accordingly. Hence the broader base of the hierarchy indicates that the majority of people, because of stressful situations, will not attain needs in the higher levels.

The nurturing an individual received during the early developmental stages influences an individual's achievements and success. Coping as a mechanism in stressful situation is a learned behaviour. That is why two individuals faced with the same stressor, will react differently. A sound base and satisfaction at the lower levels of needs are necessary for individuals' growth towards emotional maturity (Perko & Kreigh, 1988:152).

CHAPTER 3

Research design and methods

3.1 INTRODUCTION

The design and methods of this research involved exploring and describing the needs of HIV positive subjects and their families in the community. A detailed description of how this was done is discussed in this chapter. The purpose of lengthy unstructured interviews was to encourage the subjects to communicate their deep-seated encounters related to being HIV positive or having family member who is HIV positive in a relaxed and unhurried atmosphere (Bailey, 1987:193).

3.2 AIM AND OBJECTIVES

3.2.1 Aim of the research

The aim of the research was to identify the needs of HIV positive patients and their families in the community within Maslow's hierarchy of needs.

3.2.2 Objectives of the research

This research had the objectives to:

- (i) identify the needs of the HIV positive patient,
- (ii) identify the needs of this HIV positive patient's family,
- (iii) make recommendations to the district and the regional health management teams based on the results of the research.

3.3 RESEARCH DESIGN AND METHOD

A qualitative study, which, according to Burns and Grove (1993:27), is a systematic, subjective approach used to describe life experiences and give them meaning, was performed to capture experiences as lived by the subjects in a natural environment (Bailey, 1987:193; Krefting, 1991:215).

Personal experience of the researcher and the philosophic background of this research (see Chapters 1 and 2) formed the basis on which the design and method of this study were based.

An exploratory, descriptive study, contextual in nature (Babbie, 1992:286), was conducted, exploring and describing the needs of HIV positive patients and their families. In accordance with Burns and Grove's (1993:30) description, the descriptive, inductive approach was used in this study to understand the comprehensive response of the human being, not just understanding specific parts or behaviours (Omery, 1983:57).

According to Bailey (1987:193) unstructured interviews provide a relaxed and unhurried atmosphere that is not stressful to the respondent and this is conducive to remembering forgotten points. Therefore unstructured interviews were conducted with HIV positive subjects and their family members to uncover their deep-seated experiences related to their positive HIV status or having a family member who is HIV positive. Interviews with HIV positive subjects were done separately from interviews with family members, thereby respecting the subjects' privacy and sustaining confidentiality and a trust relationship, because of the active part played by the researcher in the data gathering. Transcription of interviews was done by the researcher as soon as possible after interviews in a private environment.

3.3.1 Population and sampling

3.3.1.1 Target population

The population included all adult HIV positive subjects and their families in the Koffiefontein and surrounding areas.

3.3.1.2 Sample and size

Purposive sampling was done which involved the conscious selection by the researcher of certain subjects or elements to be included in the study (Burns & Grove, 1993:246). The target population was adult (for effective communication) HIV positive subjects and their family members. Blood relations such as mother, father, brother and sister were considered in families. Gender, cultural background and educational levels were not considered for stratification in this study. All participants for the study were selected from the attendance register, through the assistance of the personnel in the primary health care centre in Koffiefontein and a specialized Auxiliary Service Officer (SASO). Four subjects (HIV positive) and three family members were interviewed. Only one family member was chosen by each HIV positive subjects who was approached by the researcher. Seven subjects agreed to participate. Saturation was reached after interviewing these four HIV positive subjects participants and three family members (one from each HIV positive subject participant's family). An informed consent was obtained from all subject participants before commencing with the interviews. Subjects wishing to withdraw either before or during an interview were allowed to do so. Coventry and Nixon (1999:45) define saturation as to fill or supply completely or to excess. In this study saturation in sampling was reached when no new information could be detected from interviewed subjects.

3.3.1.3 Sampling criteria

The subjects had to be residing in Koffiefontein or surrounding area (see Figure 3.1). The selected area is a rural, multicultural area characterized by high migratory labour rates, which could be a factor associated with a high HIV infection rate. Both adult males and females were interviewed. The subjects had to be knowledgeable about their HIV status. One or more members of the patient's family had to be knowledgeable about HIV status of their family member. Subjects had to participate voluntarily in the study, after signing an informed consent form (see Appendix V). The patients in this study were not classified according to the phases of the disease, willingness and voluntarism of the subject participants were considered.

3.3.2 Data collection

The data collection of this research was done through tape-recording of lengthy unstructured interviews, and contextual and behavioural observation of both HIV positive subjects and their family members by the researcher. The purpose of unstructured interviews was to encourage the subjects to communicate their deep-seated encounters related to being HIV positive or having a family member who is HIV positive.

3.3.2.1 Interviews

Lengthy unstructured interviews were conducted. Each conversation was tape-recorded. The subject participant's home or the clinic office environments were used, if the subject so wished to ensure confidentiality. For confidential reasons some participants preferred to be interviewed at the clinic before or after being attended to for minor ailments. Others preferred the home environment for interviews.

SAMPLE FOR NEEDS SURVEY OF HIV POSITIVE PATIENTS AND THEIR FAMILIES

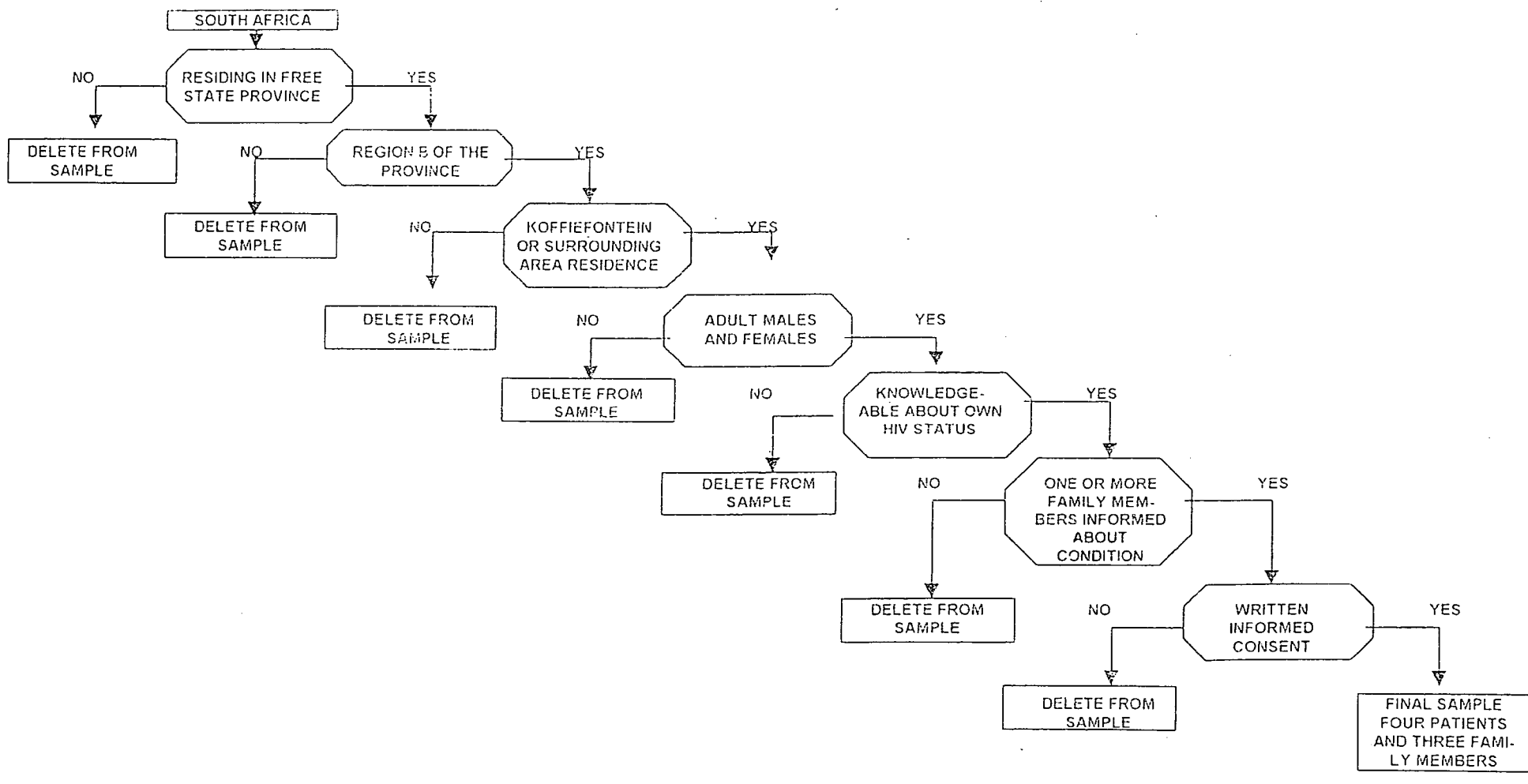


FIGURE 3.1: Crano and Brewer's modified flow diagram for sampling for needs of HIV positive patients and their families

3.3.2.2 Interview process

❖ Greeting

Formal introduction of the researcher to the subjects was done by the specialised Auxiliary Service Officer (SASO) who is a field worker in Koffiefontein and surrounding area. After a reciprocal introduction, the researcher was left alone with the subjects. Interviews with HIV positive subjects were carried out separately from interviews with their family members. After the researcher had explained the purpose of the research, the subjects were given time to consider it, by asking questions. When questions had been answered to the satisfaction of both parties, subjects either consented to participate in the research or declined to do so. The use of the tape recorder was explained, some subjects declined after this explanation. The declining subjects were allowed to do so. Some family members were visited at home, but those who wished to come to the clinic were allowed to do so. Some family members were visited at home, but those who wished to come to the clinic were allowed to do so and the appointment times were discussed and scheduled with them. Subjects requiring counselling or other services were afterwards referred to a counsellor or a specialist in the field concerned.

❖ Questions

The questions were asked using the language most understandable to the subjects. Languages used included Xhosa, Sesotho, English and Afrikaans (See Appendix I)

The following question was asked during interviews to:

HIV positive patients:

"What needs do you have that are related to your HIV positive Status?"

The family member:

"What needs do you have now that you have a HIV positive member in your family?"

Unstructured interview questions were asked to allow a wide range of options to subjects as to how (and to what) to respond. Communication techniques like probing, paraphrasing, clarifying, testing discrepancies, maintaining a neutral position, summarizing and closing were used (see appendix III) to clarify unclear answers (Bradley & Edinberg, 1990:107).

3.3.3 Pilot study

Before the research was embarked on, a pilot study was conducted. Two adult HIV positive subjects were interviewed to test the researcher's interview skills. These two patients were excluded from research. This was done to verify the following:

- feasibility of the study
- phrasing and paraphrasing of the interview questions to gain in-depth and reciprocal understanding of the subject's needs.

The researcher had to undergo training on interview skills before embarking on the actual research following a pilot study.

3.3.4 Data analysis

3.3.4.1. Content analysis

Giorgi's method of data analysis as described by Omery (1983:57) was used. According to Omery, Giorgi described five steps of data analysis procedure. These steps are discussed below:

- (1) The researcher reads the entire description of the experience to get a sense of the whole (Omery, 1983:57). In this research a transcription of the total description of the needs given by the subject participants was read by the researcher after transcribing the recorded data.

- (2) The researcher reads the description again more slowly, identifying transitions or units in the experience, called constituents. Such units are discriminate, together making up the whole meaning of the experience (Omery,1988:57). In this research these constitutes were identified as words and phases used by the subject participants to describe their daily activities (Uys, 1999) which were perceived as needs.
- (3) The researcher eliminates redundancies in the units, clarifying or elaborating the meaning of the remaining units by relating them to each other and the whole (Omery, 1983:57). In this research, redundancies in the units were eliminated by relating them to each other and to Maslow's hierarchy of needs.
- (4) The researcher reflects on the given constituents, still identified in concrete language of the subject and transforms that concrete language into the language or concepts of science (Omery, 1983:57). In this research, the given constituents (in the subjects' language) were reflected by the researcher and then transformed into language or concepts of science using activities of daily living. (Uys, 1999).
- (5) The researcher then integrates and synthesizes the insights into a descriptive structure of the meaning of that experience The final product is then communicated to other researchers for critique (Omery, 1983:58). At this point the researcher integrated insights from all of the interviews into a total description of the needs of HIV positive subjects and their family members. The description was then shared with other researchers for critique.

3.3.4.2. Transcribing interviews

The first task in analysing interview data is to become extra –ordinary familiar with data (Field & Morse, 1990:97). As soon as possible after completion of the tape-recorded interviews, the tapes were played and replayed so as to familiarize the researcher with the content of each interview before transcribing it. Questions, voice tones and non-verbal responses were noted.

It was not possible to analyse a tape without a written transcript. The tape is therefore transcribed word for word either by the investigator or a typist (Field & Morse, 1990:97). In this study the recorded interviews were transcribed by the researcher, noting all exclamations and emotional expressions as well as any gaps or pauses, and these as stated by Chadwick, Barh and Albrecht (1984:242) were indicated as follows (pauses were indicated by using a series of dots and gaps by using a dash). A generous margin on both sides of the page permitted the left margin to be used for coding by identifying units in experiences, called constituents or categories and the right margin to be used for comments regarding the content (see Appendix II) using the scientific language.

3.3.4.2 Method of coding

At this juncture the researcher is able to recognize persistent words, phrases, themes or concepts within the transcribed data. The task becomes one of identifying these words, passages or paragraphs for later retrieval by using a highlighting pen, using a different colour for each major category (Field & Morse, 1990:99).

In this study this was done as follows: Persistent words, phrases and concepts were identified and coded through underlining with different coloured pens. Major categories were written in the margins (see Appendix II). Using individual's activities of daily living (Uys, 1999), the researcher was able to relate these activities into themes and groups under the major categories of Maslow's hierarchy of needs (see Chapter 2). Data was sorted by copying the relevant

passages onto cards (manual sorting), after eliminating redundancies. The data was grouped into major categories using Maslow's hierarchy of needs (cf Chapter2).

3.3.4.3 Data filing system

Concepts or quotes were copied onto the record cards and sorted into the various categories. Each category of cards was put in a separate envelope and labelled according to the selected category, for quick retrieval when needed.

3.3.5 Ethical considerations

3.3.5.1 Consent for the research

The research protocol was submitted to the Faculty of Health Sciences Ethics Committee and the School of Nursing's Research Committee at the University of the Free State for ethical consideration and approval respectively. The ethics committee of the university gave consent for the research.

Consent from the area of study was sought from the district management team, the local authority and the clinic personnel of Koffiefontein, through written applications that were replied before commencing with the research (see Appendix IV) validating the consent for the research.

Formal introduction of the researcher to the subjects was done by the Specialised Auxiliary Service Officer (SASO).

3.3.5.2 Voluntary participation

The researcher explained the purpose of the research to subject participants. The risk and benefits involved in the research were discussed with the subjects.

Subject participation was voluntary. Each participating subject signed an informed consent form in the presence of the researcher and a witness (who was knowledgeable about the subjects condition) for this purpose the SASO member was used as a witness. Subjects were free to decline either before or during an interview.

3.3.5.2 Privacy and confidentiality

Interviews were carried out between the researcher and the subject. No names were used during interviews.

The recorded interviews were transcribed by the researcher to ensure sworn confidentiality. Transcribed interviews were identified by numbers to maintain confidentiality.

During the research period all the records and the cassettes bearing the information on the research were kept locked in a safe place to which only the researcher had access.

On completion of the study, all the records used during the research were destroyed by the researcher, including the recorded information on the cassettes.

3.3.6 Validity and reliability/trustworthiness

Burns and Grove (1993:342) define validity as a concept designating an ideal state to be pursued, but not to be attained. Reliability or precision is the degree of consistency or reproducibility of measurements using physiological instruments (Burns & Grove, 1993:342). The validity and reliability of this study were ensured

by applying Guba's model of truth-value, applicability, consistency and neutrality (Krefting, 1991:215)

3.3.61 The truth value/credibility

Guba and Lincoln (1989:234) refer to truth-value of a given enquiry as the extent to which it establishes how things really are and really work. According to literature truth-value asks whether the researcher has established confidence in the truth of findings of the subjects or informants and the context in which the study was undertaken (Krefting, 1991:215). The data collection method used in this study ensured its truth value whereby tape-recorded unstructured and lengthy interviews were conducted to encourage the subjects to communicate their deep-seated encounters related to being HIV positive or having a family member who is HIV positive. The interviews were conducted on individuals and family members in an environment chosen by the subjects until saturation was reached. This was done to give credibility of the collected data (Krefting, 1991:215).

Verbatim transcription of recorded interviews were done by the researcher as soon as possible after an interview, to note and correlate observed gestures and behaviour to written interviews.

An interview environment was decided upon by the subjects. This was done to allow them to choose a place where they felt comfortable, relaxed and at ease with themselves for a free flow of communication. The interviews took place between the researcher and the subjects concerned. Interviews with HIV positive subjects were held separately from interviews with their family members.

Giorgi's procedure for data analysis was used. This procedure was chosen because it required the researcher to let the experience unfold as it existed for the subject in an unbiased way (Krefting 1991:215). Interviews were conducted in three sessions using the same and or similar subjects residing in Koffiefontein and surrounding areas.

3.3.6.2 Applicability/transferability

Guba and Lincoln (1998:234) refer to this phenomenon as generalizability which can be proven when external validity is met or proved. Fittingness or transferability is the criterion against which applicability of qualitative data is assessed (Krefting, 1991:216). Further argument is that transferability is the responsibility of the person wanting to transfer the findings to another situation or population than that of the researcher of the original study.

In this research sufficient descriptive data to allow comparison is given by the researcher (see chapter 5).

3.3.6.3 Consistency/dependability

Consistency includes inter alia whether the findings would be consistent if the enquiries were replicated with the same subjects or in a similar context. However, the key to qualitative work is to learn from the informants rather than controlling them (Krefting, 1991:216). Field and Morse (1990) further stated that qualitative research emphasizes the uniqueness of the human situation, so that variation in experience rather than identical repetition is sought (Guba & Lincoln, 1998:234; Omery, 1983:57). Dependability of the results of this study was ensured through the unique unstructured interviews which were conducted with HIV positive subjects and their family members whereby subjects verbalised their unique experiences related to being HIV positive or living with a family member who is HIV positive.

3.3.6.4 Neutrality/conformability

Neutrality refers to the degree to which the findings are a function solely of the informants and conditions of the research and not of other biases, motivations and perspectives (Krefting, 1991:216). This was ensured by allocating the researcher to a primary health care centre in Koffiefontein. Fieldwork was done

with the SASO member. There were no prior meetings or arrangements entered into by the researcher and the subjects. Arrangements were made with counsellors for referral of subjects who may require such services and/or other specialised services.

The study was subjected to critical evaluation by two study leaders from the beginning to the end.

3.3.7 Belief value

Abraham Maslow's hierarchy of basic human needs has been used as the philosophical background to this study. The belief system stems from the fact that a human being (individual) be it a patient, or healthy adult or child depends on the physiological functioning of their bodies to maintain homeostasis. Any stimulus disturbing this harmony therefore triggers a need. Such needs are grouped into levels or categories according to the urgency of their satisfaction. Unmet needs cause disharmony.

This is applicable to all individuals who are ill or well. Because of the problems associated with HIV infection, Maslow's hierarchy of needs was seen as most appropriate in this study.

3.3.8 Triangulation

Triangulation is a powerful strategy for enhancing the quality of the search particularly credibility (Krefting, 1991:219). It is based on the idea of convergence of multiple perspectives for mutual confirmation of data to ensure that all aspects of a phenomenon have been investigated. Krefting (1991:215) identified four types used to ensure the credibility of the study through triangulation. Only two types of the four types were applied in this study in the following manners.

(a) Triangulation of data sources

Triangulation of data sources maximizes the range of data that might contribute to complete understanding of the concept. It is based on the importance of variety in time, space and person in observation and interviewing (Kreting, 1991:219).

Before commencing with the actual study, a pilot study was conducted on subjects belonging to the same category as the sample used in the study.

Interviews were carried out per appointment with subjects. The time and venue for the interviews were chosen by the subjects. Statistical information from clinic records, the district co-ordinator's records and the provincial research and information centre was used.

(b) Peer examination

According to Krefting (1991:219) peer examination involves the researchers discussing the research process and findings with important colleagues who have experience with qualitative methods. The research process and findings of this study were discussed with two experts in qualitative research who were not actively involved in the research. The interview tapes and transcripts were sent to a specialist for co-coding.

3.3.9 Literature control

A comprehensive literature study was carried out on the findings of other researchers in matters related to the topic under study. This was done on completion of interviews and transcriptions thereof to void any biases by the researcher.

In qualitative research, the purpose and timing of the literature review vary, based on the type of study to be conducted. Phenomenologists believe the literature should be reviewed after data collection and analysis, so that the information in the literature will not influence the researcher's objectivity (Burns & Grove,

1993:142), the purpose of literature study being to compare and combine findings from the study with the literature to determine current knowledge of a phenomenon. This same method was applied in this study.

3.3.10 Conclusion

In this chapter the research methodology was described. In Chapter 4 the literature that was studied, is discussed.

CHAPTER 4

Literature review

4.1 INTRODUCTION

A discussion on the immune system of human bodies and the mode of transmission of the Human Immuno-deficiency Virus will be given in the following paragraphs.

A human body should be in homeostasis for it to function at its optimum level. A disturbance of any degree, in any system, at any level of body functioning therefore may result in a deficiency of one or more needs.

4.2 THE IMMUNE SYSTEM

The immune system protects human bodies against invasion by micro-organisms including HIV, and other micro-organisms. Winiarski (1991:12) states that immunologists believe that the immune system also protects humans from mutant cells that continue to proliferate becoming neoplasms or tumours.

He further identifies two branches of the immune system:

- The B-cells which are produced in the bone marrow and in turn produce humoral immunity; and
- The T-cells, which are produced in the lymph nodes and in turn produce cell mediated immunity.

The T-cells are further classified into five types, each with specific functions interchangeably, in immunity.

- The natural killer T-cells act against infection, others act against tumours.
- The T-helper cell or T₄-cell, currently known as CD-4 for the specific surface molecule, which acts as a "dock" for HIV.
- The T-suppressor cell, which "cools down" the immune response when the threat seems over.
- The monocytes – macrophages identify and destroy foreign bodies and produce antimicrobial substances and antiviral interferon.

The Human Immuno-deficiency Virus (HIV) targets the above-mentioned T-cells, especially the macrophages and the circulating CD-4 cells.

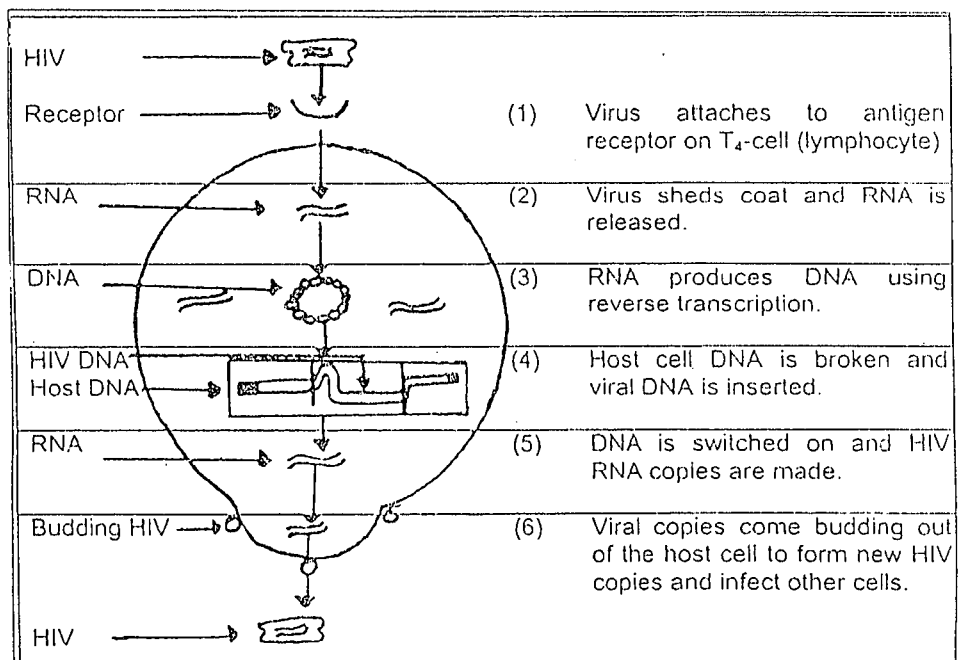


FIGURE 4.1: Infection of a T-cell by HIV

4.2.1 Infection of the T-cell by HIV

The human Immuno-deficiency Virus on entering the human body, attaches to the antigen receptor on T-cell (lymphocyte) (see Figure 4.1). Then the virus sheds its coat to release RNA. Through the process of reverse transcription the released RNA produces DNA. At this stage the host cell (T₄ – cell) DNA is broken and the viral DNA inserted. The DNA is switched on and HIV RNA copies are made through replication (Winiarski, 1991:13).

The viral copies come budding out of the host cell to form new HIV copies and infect other cells through the same process, thereby reducing the number of T₄ – cells in the body – the body's defence mechanism becomes embarrassed.

A Human Immuno-deficiency Virus (HIV) infected person falls easy prey to HIV and AIDS –related opportunistic diseases, like certain cancers, direct infection of the central nervous systems, the wasting syndrome or a combination of these (Allen, Simelela & Makubalo, 2000:11 Schoub, 1997:3)

The clinical manifestations vary from person to person and depending upon the system susceptible to viral infection – hence the term "syndrome". Depending upon certain factors, for example the virulence of the virus and the vulnerability of the immune system of the host during infection, the incubation period of the virus varies from individual to individual. To some it could be few months and to some it could be a year or more (Whiteside, 1995:12)

4.3. HIV TRANSMISSION

Currently there is no evidence of HIV transmission by insects or by casual contact that does not involve exchange of bodily fluids. Therefore individuals contract HIV by receiving into their bodies the HIV infected fluids of another person (Whiteside, 1995:12; Winiariski, 1991:14).

4.3.1 The body fluids and other means of transmission

4.3.1.1 Sexual secretions

The most common mechanism of HIV transmission is sexual transmission which accounts for 70% to 80% of global infections (Whiteside, 1995:12).

Among heterosexuals transmission could be from the male penis to the female's vagina and *vice versa*. In homosexuals it could be from the male to another male through anal or oral sex and among lesbians, transmission is from female to female through oral and digital contact and exposure to vaginal blood (DENOSA, 2000[a]: 5; Winiarski, 1991:15; Allen, 2000:9).

Anal sex is believed to be most dangerous route for HIV infection, because of increased friction believed to be associated with it, which results in breakage of the mucous membrane, thereby exposing a large surface area of raw tissue to infection (Winiarski, 1991:15).

Having more than one sexual partner without using safe sex methods like condomising, non-penetration and masturbation has proven to be the fastest method of transmitting the Human Immuno-deficiency Virus among individuals (Allen *et al.*, 2000:9; Baleta, 1998:14). A polygamous marriage is a practical example of having more than one sexual partner.

4.3.1.2 Blood contained in needles or other instruments

Globally, prior 1985, when HIV was not isolated and tested for, blood products served as means of HIV transmission. In the 13 years since the introduction of anti-HIV testing in October 1985 there has been only one recognized case of HIV transmission by a seronegative donor in the United Kingdom (Martlew, Carey, Tong, Parry, Belda, Barlow, Chu & Syed, 1999:93).

In 1999 the United Kingdom reported a second case of three patients who were infected after having received blood transfusion in 1996. The report further states

that the donated blood was screened against HIV-infection using states that the donated blood was screened against. HIV-infection using a sensitive EIA method and it was negative, however subsequently the blood showed to contain p24 Ag and HIV RNA by an amplification technique (Martlew et al, 1999:93).

(i) Accidental pricks from contaminated needles

Health care providers can accidentally be pricked by infected needles during procedures or when discarding such needles. Workers at the incineration site may get infected while working with refuse at the dumping site if correct measures are not taken on disposal (Goldberg, Johnson, Cameron, Fletcher, Stewart, Mcmenamin, Coder, Hutchinson & Raeside, 1999:99)

By the end of 1997, there were 95 health care workers who definitely had and 191 who possibly, acquired HIV infection through occupational exposure worldwide, but excluding the USA and Europe. Only 24 of the 286 cases were reported by the investigators (Goldberg *et al.*, 1999:99). The majority of needle pricks occurred amongst nurses. In the United Kingdom, four cases, all female health care workers, were identified as having been infected by HIV while on duty. One surgeon had been reported as having been infected while performing surgery by cutting his gloved finger while incising an abscess (Goldberg *et al.*, 1999:99)

(ii) Sharing of needles and syringes among drug abusers

Among drug abusers, blood infected with HIV may be transmitted from one person to the next, when needles and syringes are shared without taking the precautionary measures to clean and sterilize them after use (Beattie *et al.*, 1993:179). The safest method to syringe and needle use is disposal after use by an individual.

(iii) Tattooing and ear piercing

Tattooing, ear piercing and any procedures involving breaking through the skin may also transmit HIV when the instruments are not sterilized after use between clients (Landau-Stanton, Clements & Associates, 1993:175).

4.3.1.3 Mother to child transmission

"Vertical transmission" from mother to child is the source of infection for 80% of the infected children worldwide. Reported rates of transmission vary from under 20% in some European studies to 60% in a study from Zaire (MacIntyre, 1992:28). In a study conducted by (Marseille, Kahn, Mmiro, Guay, Musoke, Flower and Jackson (1999:803) the findings were that 600,000 babies worldwide were infected with HIV through mother to child transmission in 1997. All the factors affecting the rate of transmission remain unclear, however it is acceptable that:

- more advanced maternal disease,
- low CD4 counts, and
- previous delivery of an infected child are factors associated with an increased risk of transmission to the fetus (McIntyre, 1992:28-29).

Provision of nevarapine to the mother when in labour and a teaspoon of syrup to the baby within 72 hours of birth has been reported to reduce the infection rate by 50% (Southern Africa Report, 2002:4).

The mechanism of infection of the infant has not yet been fully demonstrated. Three possibilities exist namely:

(i) In utero

The virus could be transmitted in utero during pregnancy, where the blood and immunity exchange occurs between the fetus and the pregnant mother- through the placenta (substances that cross the placental barrier) (McIntyre, 1992:29; Maart & Gray, 1997:10).

(ii) During birth

At birth, while the baby sweeps the birth canal, it may become infected by exposure to the infections from the cervical and the vaginal secretions (McIntyre, 1992:29). Studies carried out revealed a higher rate of infection in first-born twins, in a ratio of 2:1 first-born and second-born twins respectively (McIntyre, 1992:29), the possibility being due to longer exposure to infectious cervical and vaginal secretions. This area needs further research.

(iii) Breastmilk

Breastfeeding is considered the best method for feeding babies, especially among Third-world people, as breastmilk contains antibodies, which are passed passively from the mother to the child to fight against infections. However, with the Human Immuno-deficiency Virus that has been isolated from breastmilk and shown to be infectious by this route, great controversy has occurred on this issue (McIntyre, 1992:29). What must be borne in mind is the mother's social and financial stability coupled with what is best for the baby, healthwise, when dealing with breastfeeding and HIV infection (Nduati, John, Richardson *et al.*, 1996:10-11; Kuhn & Stein, 1997:7).

Having discussed the mode of transmission of HIV, it is vital at this point to look into the relationship between HIV infection and Maslow's hierarchy of basic human needs.

4.4 RELATIONSHIP BETWEEN MASLOW'S HIERARCHY OF NEEDS AND HIV INFECTION

A discussion regarding the HIV positive individuals will be followed by that of their families (see 4.4.2).

4.4.1 The relationship between Maslow's hierarchy of basic human needs and the HIV infection with regard to HIV positive individuals

HIV infection has a tremendous emotional and psychological impact on all individuals. Lego (1994:4) identified three categories of individuals in relation to HIV infection: the afrails, the worried well, and those who opt for testing.

Presently there is no cure for HIV infection. The rapid increase in its incidence rate is aggravated by its mode of spread, which is direct contact with a HIV infected person's secretions like sexual fluids and blood (Allen *et al.*, 2000:9; Martlew *et al.*, 1999:93).

Although references will be made to Gorman and Dr Kubler-Ross's theories, Maslow's theory on the hierarchy of basic human needs forms the theoretical background in this study. Dr Kubler-Ross identified five stages of the terminally ill patient as anger, denial, bargaining, depression and acceptance, while Gorman on the other hand identified six key issues affecting a patient's response to illness as self-esteem, body image, powerlessness, hopelessness, loss and guilt. Central to these is an individual's self esteem which is the personal judgement of the individual's own worth (Gorman *et al.*, 1989:4). The argument is based on the assumption that with HIV infection one deals mostly with emotions. These emotions normally affect the higher levels in Maslow's hierarchy of needs and gradually, as the illness progresses, all other levels are affected. The three authors address the self and what happens to the self in times of stress and illness. On hearing the bad news an individual reacts through certain emotions that necessitate appropriate interventions by the health care providers (Howe, 1995:78).

4.4.1.1 Physiological needs

These needs form the broader base in Maslow's hierarchy of needs; according to Dr Kubler-Ross's stages of mourning, the needs at this level tally with acceptance stage, which according to Gorman is a state of powerlessness and hopelessness, when the fighting spirit of a patient has diminished (Vlok, 1991: 346; Gorman *et al.*, 1989:4; Lubkin, 1990:93).

(i) Personal hygiene

According to Vlok (1991:346) the stage of acceptance (Dr Kubler-Ross's final stage of mourning) is characterised by detachment and loss of interest in the environment; the patient dozing on and off, and gradually lapsing into a coma as the body functions decline. As interest declines during this stage no attempt should be made to raise the patient except to attend to the functions of the body. The person may need help with personal hygiene, might have wounds which need dressing and care to back and pressure parts because of confinement (DENOSA, 2000:20; Uys, 1999:49; Cullinan, 2001:19).

The health care workers must ensure that the patients are comfortable and that there is always somebody near them attending to their needs and touching them. In a hospital situation the relatives, when present, should be allowed to remain with their loved ones until they are detached from this world (Vlok, 1991:346; Cullinan, 2000:19).

(ii) Nutrition

Nutrition refers to an adequate supply of food nutrients required to keep one alive and healthy (Guyton, 1984:530; Uys, 1999:70). Patients who are infected with HIV should be encouraged to take a balanced diet, enriched with vitamins and minerals. Multivitamin tablets and the African potato can be used effectively to improve the person's health status (DENOSA, 2000[c]: 20; Smith, 1981:152; Uys,

1999:707) Alcohol use should be discouraged, and when identified, follow-up measures in counselling should be made.

(iii) Other infections and HIV

The nature of HIV infection is to lower the body's defence mechanism. All infections, including minor ones should be given immediate attention. Patients should be advised to visit a clinic monthly for general check-up. Sexually transmitted diseases or chronic diseases like tuberculosis (TB) and herpes should be treated as soon as they are detected. The nurse should encourage patients to adhere to TB treatment by encouraging DOTs (Directly Observed Treatment) (Uys, 200:20).

In HIV infected people reactivation of herpes is a major cause of morbidity and death and accounts for about 4.4% adults and 3.8% of children with HIV infection (Virus SA, 1997:1). Both herpes viruses and HIV are associated with lifelong persistent infections and it is therefore not surprising that there is substantial interaction between these two viruses (Virus SA, 1997:1)

4.4.1.2 Safety and security needs

These needs in Maslow's hierarchy of needs are at level two. They basically address shelter and employment, contribution to insurance companies, as well as security and protection against bodily harm (Hartweg 1991:21).

(i) Shelter and employment

Individuals feel safe and secure when they are among those who are close to them, have shelter and are employed. A crisis situation may shift individuals from this homeostasis, thereby affecting their feelings of safety and security and putting

them in a state of helplessness and hopelessness. (Whitefield 1989:129) Homeless people especially youth are vulnerable to involvement in prostitution and intravenous drug use, thereby sharing needles and having unprotected sex, putting themselves at risk of HIV infection (Beattie et al 1993:179). HIV infection, like any terminal illness, represents a drain of personal resources. The effect on resources is felt, because combating the disease costs money. If private doctors are used, the individuals may still have the benefit of medical insurance (while they are employed) (Southern Life, 1998). The HIV positive individuals however, have to find and use their own resources, should they lose their jobs or exceed medical aid limits. This will eventually involve liquidating assets such as pension funds, insurance savings and other holdings. This money is lost to investments (Winiarski, 1991:36; Evian, 1995:8; Booysen, van Rensburg, Bachman, Engelbrecht & Steyn, 2002:11).

(ii) Contribution to insurance companies

There is no magic means, which can be applied to avoid bearing the cost of treatment of AIDS without either increasing contributions to insurance or reducing the benefits. Some insurance schemes are starting to provide different types of death/disability benefits, whereby payments differ for different causes of death such as accidents, dreaded diseases and/or other illness and AIDS related conditions (Evian, 1995:10) (refer paragraph (A))

(iii) Financial burden

Many AIDS related deaths occur. Adult deaths deprive communities of the vitality and skills needed for development, while placing new burdens on children and the elderly to care for one another (Solomon, 1996:15).

Apart from medical costs related to HIV infection an individual's death within a family may cause a catastrophic situation because of funeral costs incurred and

loss of income (Hope, 1995:11; Booysen, van Rensburg, Bachamann, Engelbrecht and Steyn 2002:11).

- **Death of a spouse/breadwinner**

On the death of a spouse, the widow with young children is usually left with no or little income; when the woman is HIV positive too, family support must be sought in case the infection converts to illness. The woman may already have an ill child who needs care and has no partner to share the burden with (Walker, 1991:252; Booysen et al 2002:11)

- **Individuals in training**

In the professional fraternity, if HIV infected individuals are still students, they may be compelled to resign voluntarily, because accumulated sick leave during training can make finishing their studies impossible (Carlisle, 1993:24), thereby ending with them being not professionally qualified and with no income.

(IV) Life expectancy

In the world's nine most affected countries – all of them located in Africa, at least a tenth of the adult population are infected with HIV, a person born between 2000 and 2005 can expect to survive only to the age of 43, instead of to the age of 60 as would have been expected in the absence of AIDS (DENOSA, 2000[a]: 5).

If the incidence rate of HIV infection continues to rise, the average life expectancy in South Africa would be cut down from 63 to 40 in less than 15 years. Many children will be left without parents to cater for their needs (Sunter, 1996:14).

(V) HIV infection and peer pressure

Young people are at special risk to HIV infection, because of peer pressure, developmental risks related to their desire to learn new ways of discovery and learning, including experimenting with sex, drugs and alcohol (DENOSA, 1998 [a]:8).

4.4.1.3 The love and belonging needs

The needs at this level basically are concerned with relationships and are found in the level three of the hierarchy of Maslow's needs. These needs emanate from the fact that a person is a social being born within a family, and who grows and matures in a family (Refer to paragraph 2.3 & 2.4).

(i) Secrecy

Individuals grow and mature through being loved, accepted and cared for unconditionally. Individuals feel confident and valued when loved and accepted unconditionally (Howe, 1995:15). Because of the stigma associated with HIV infection, a study conducted on women and their decisions or choices faced with, in relation to their HIV illness, it was reported that subjects hesitated to tell family member out of guilt because of the pain that they knew it would bring to the family (Regan-Kubinski & Sharts-Hopko, 1995:333; Imber-Black, 1993:34). Guilt as a cause of secrets emanates from the feelings of insecurity – the patients thinking that somehow they have failed to play their roles effectively as children, parents and spouses. (See paragraph 5.2.3.1-(ii)).

(I) Abandonment versus confidentiality

The choice to tell a friend depends on the closeness of the friend to the individual, and whether or not the individual thinks that the friend would accept

that the person is HIV positive, or fear of rejection. This was shown through study carried out on HIV positive women (Wincze & Carey, 1991:146; Regan-Kubinski & Sharts-Hopko, 1995:333). One client in their study's response reads: (telling) "...might *take them out of my life again*" an understanding that confidentiality will be respected as a factor in deciding whether to tell or not to tell (Regan-Kubinski & Sharts-Hopko, 1995:333). (See paragraph 5.2.3.1(iii))

(iii) Scapegoating

Scapegoating or blaming certain categories or groups of people is still prevalent, for example in the United States, Latin America and Europe, where the HIV/AIDS epidemic continues to be blamed on gay men who have been persecuted for being responsible for the epidemic. In some countries, including South Africa, the commercial sex workers are used as scapegoats, while in India, truck drivers are shunned as the likely carriers of HIV (Forsythe, 1999:14).

(iv) Dry sex practice

An alarming practice that is still in use in South Africa – even in this HIV/AIDS era – “a traditional (African) South African sexual practice” – dry sex – aimed at pleasing men, (to fulfil the love and belonging need) whereby household detergents, antiseptics and herbs are inserted into the vagina by the woman before sex, to ensure that they are “hot, tight and dry” (Baleta, 1998:14) A research study on gender violence revealed abuse among commercial sex workers, probably because of the illegal status of secretive nature of their work in South Africa (Wojeicki, 2001:8). This practice is mostly prevalent in KwaZulu-Natal, which is the province in South Africa with the highest HIV infection incidence. Tight competition for clients among commercial sex workers has forced them to resort to this practise ((Baleta, 1998:14). This factor could be associated with the high incidence and prevalence rates of HIV infection in KwaZulu-Natal and in other areas where this practice is still done.

4.4.1.4 The self-esteem needs

These needs at this level deal with the self, that is "who you are". The self-concept is learned and develops throughout life as a result of one's integration with the significant others (family, friends teachers and people in the community who have personal impact on individuals) and the reference groups (those groups in which one has membership or wants to join). Incorporated in a self-concept is self-awareness, whereby individuals are consciously aware of their own feelings, how to handle such feelings, their limitations and strengths, when and how to react to the various stimuli and environments (Bradly & Edinberg, 1990:146; Morgan et al 1986:298).

However, in times of stress and illness, the self-esteems of individuals may be affected adversely resulting in them having low self-esteem that may also affect their self-actualization or awareness. Because of the stigma associated with HIV-infection, people who are infected with this virus have low self-esteems and reduced self-actualizing needs (helplessness and hopelessness according to Gorman's issues) .

As indicated in the literature, psychologically any illness (including HIV infection) may evoke a wide range of emotions like fear, sadness, depression, despair and loss of control (Gorman et al., 1989:4; Vlok, 1991:342). A person with a low self-esteem and diminished self-actualizing needs will present with the above emotions. Each emotion will now be reviewed.

(i) Fear

Fear of the unknown affects one's perception adversely. On being diagnosed with an incurable disease, death-related fear occurs. The most dominant cause of fear with HIV infection is the premature death associated with this disease. The most vulnerable groups affected are usually young and participating actively within their families, at work and in society at large (Masobe, 1992:12). Mothers often fear for their children whom they will leave with nobody to look after them; fear of the

stigma associated with the disease causes many individuals to suffer in silence rather than to communicate their situation to their loved ones (Regan-Kubinski & Sharts, 1995:333).

Many people often are psychologically not ready to accept the nature of their terminal illness when they learn about it for the first time (Vlok, 1991:343; Masobe, 1992:12). The work of Doctor Elizabeth Kubler-Ross and the grieving stages she identified through which the majority of terminally ill patients pass before they die, gives valuable information to enhance understanding the emotional needs of terminally ill patients, including those who are infected by HIV (Vlok, 1991:343).

On learning of their HIV positive status, individuals may react in varied ways. However, the dealings of shock, anger and panic are experienced, together with denial of the news (Lego, 1994:5; Vlok, 1991:343).

Because HIV infection is presently an incurable disease, individuals who are infected with HIV undergo the same stages as those of terminally ill patients as identified by Dr Kubler-Ross. These stages will now be discussed.

(ii) Denial

After individuals have become aware of the terminal nature of their illness, they often cannot believe that their days are numbered. They may seek different medical opinions to verify or deny the diagnosis. (Carroll, 1992:41).

Individuals who have not been told of the nature of their illness, but have become aware of its fatality, may also refuse to accept the implications on a conscious level and therefore avoid discussions of the topics which concern them most. Denial may also play a role in that the person sometimes needs to think of more cheerful things and make bright plans for the future (Vlok, 1991:343; Gorman *et al.*, 1989:110).

The purpose of this stage is an unconscious avoidance to protect the self from painful reality (Gorman *et al.*, 1989:110; Vlok, 1991:343-344). Very few individuals maintain the defence of denial right to the end. Denial usually gives way to the second stage – the stage of anger.

(iii) Anger

Feelings of anger at the unkindness of fate or God, envy of and resentment towards those who are healthy, replace denial. The anger is usually projected to the loved ones, family, friends and health care workers (Lubkin, 1990:93). The individual becomes very difficult to handle, is dissatisfied and demanding, and unless the nature of the anger is recognised and understood, this may cause health care workers and the loved ones to neglect and avoid the patient and his/her aggressive outbursts (Wincze & Carrey, 1991:145; Vlok, 1991:344).

The purpose of this stage is that the person attempts to take control when feeling out of control by attacking and blaming others (Gorman *et al.*, 1989:110; Lubkin, 1990:93). Most adults respond with frustration and anger to their loss of independence and their forced submission to plans for treatment made by doctors in consultation with the family. Unless they are very sick or immature dependent people (patients) like to be consulted and treated like autonomous human beings whose sensibility is recognised (Vlok, 1991:344)

(iv) Bargaining

After anger has taken its toll, many individuals go through a stage of bargaining with God for an extension of life, or for a remission of the illness, or for a few days without physical discomfort in order to attend to some urgent family business or funeral of a friend or relative. Some individuals feel that their lives, work or their ideals have not yet been fulfilled and make promises aimed at propitiating God in return for the gift of life (Barroso, 1996:404; Vlok, 1991:344). In a study carried out on HIV positive individuals it was discovered that a positive outlook and the

will to live were the main reasons for survival. Some individuals described themselves as fighters, or as having a strong will to live (Barroso, 1996:404).

At this stage individuals are usually aware of the nature of their illness and may attempt to change reality by bargaining for more time. This indicates the beginning of acceptance.

4.4.15 The self-actualization needs

Individuals attaining the needs at this level are fulfilled in discharging their duties within their families. An awareness of a disturbance in this feeling may lead to depression.

(i) Depression

In Mosby's dictionary (1998:111) depression is defined as "a mood disturbance characterized by feeling of sadness, despair and discouragement resulting from and normally proportionate to some personal loss or tragedy".

Normally the fighting spirit of individuals will eventually subside as they enter the stage of depression – the stage in which they experience the reality of their great losses.

Depression stems from the anxiety of helplessness caused by the illness and from loss of body image through massive weight loss, eczema, diarrhoea and other HIV infection related signs and symptoms. It is at this stage where individuals often think of their families, especially the care of their children (who will take care of their children when they are no longer there) as well as their loved ones. Because of the nature of the disease and the amount of drugs used, feelings of being a financial burden to their loved ones often pose major problems; these may cause feelings of guilt and eventually lead to depression (Wincze & Carrey, 1991:145; Vlok, 1991:345).

The prime factor at this stage are the persons own anticipated losses of all the things that are precious to them, and separation from their beloved objects. Depressive anxieties may be so acute at this stage that individuals periodically use the defence mechanism of denial to escape from their misery. It is important that individuals be allowed to mourn their losses and that their periods of denial be allowed, however, these must not be encouraged (Shelby, 1995:17; Lego, 1994:6; Vlok, 1991:334). Individuals need their denying fantasies while they are in the process of losing everything they love and should be allowed to express their sorrow as and when they are ready to do so. Only in this way will they be able to reach the final stage of acceptance (Vlok, 1991:345). During this stage the need for an understanding presence and for the human touch overcomes the need for words.

4.4.2 Relationship between Maslow's hierarchy of needs and HIV infection with regard to the families

Families of HIV infected individuals need help with a wide range of issues in coping with the situation like managing the reaction of children to a parent's or sibling's illness or death, future planning for loss and bereavement, and organizing family functioning following loss (Walker, 1991:4).

4.4.2.1 The physiological needs

The catastrophic event (of HIV infection) disrupts family structure and function, resulting in disequilibrium and alterations of the entire system (Snyder, 1986:39), family members may need to change and adjust to new roles including visits to the hospital and or caring for the ill individual in the family ((Snyder, 1986:40) resulting in physical stress because one family member has a terminal disease, the entire family may be in a crisis and thus the target of nursing care.

4.4.2.2 Safety and security needs

(i) Financial implications

Individuals and families feel safe and secure when they have shelters, when their lives are goal-directed, and they have enough income to cater for their needs and their loved ones. HIV infection and AIDS may disrupt such harmony within a family. The economic impact of HIV infection and AIDS is felt by the individual household where the death of a member is a disaster resulting in increased expenditure and a loss of income (Karim, 1995:13); southern Life, 1998). The nature of the disease is characterised by a high morbidity rate whereby available resources will have to be liquidated to defray medical costs (Southern Life, 1998) and by the time of death, the family will have little or no financial resource to cater for the funeral costs. A widow with young children and no income, and who already has been infected with HIV must find family support in case the infection converts to illness (Walker, 1991:252) thereby adding to the financial burden of the already financially crippled family.

(ii) Insurance companies

If the incidence and prevalence of AIDS continue to increase, the insurance companies may find business declining as they cannot write out new policies if all people test positive or are tested for HIV infection. Therefore investments and the national economic status of our country may suffer (AIDS Scan, 1995:13; Southern Life, 1998). All members, including those whose dependants are most in need of financial assistance in the event of a breadwinner's death will need to pay more for benefits, or see a reduction in benefits for the same contribution rate – increased premiums or reduced claims (Moore, 1998:4).

(iii) Productivity

Because the people mostly affected by this disease are economically productive,

a high absenteeism rate due to illness and/or attending funerals and caring for a family member who is crippled by HIV infection will affect the economy of the country adversely (Nursing Times, 1993:24 ; Whiteside, 200:1). These adult deaths will deprive communities of the vitality and skills needed for the development, while placing new burdens on children and the elderly to care for one another (Hope, 1995:11).

(iv) Employers

Where the government carries the burden of health care, AIDS has the potential of using large amounts of the national budget in the department of Health's efforts to improve the health of the people. HIV infection affects individuals who are economically productive, and this has an adverse effect on the employers who must provide in housing and health care facilities in the form of medical aid, which forms part of the employee's package. Costs of recruiting and training replacement staff will also rise. An illness or death of a highly skilled worker will cost a firm more money than the cost incurred in medical care (Karim, 1995:13; Whiteside, 2000:1).

According to Hope (1995:11) estimates of the World Bank in 1993, in terms of direct costs show that in the typical developing country the total medical costs per adult-related death ranges from eight to 400% of the annual per capital income, with the average being about 150% of annual income. It is important, therefore, to assist and empower individuals and families to seek financial advice and to channel their resources appropriately to cover medical and funeral costs.

4.4.2.2 Needs for love and belonging

Love and belongingness enhance emotional growth, progress and development. In terms of stress these needs may increase resulting in a person demanding more attention from loved ones.

(i) Death and alienation

To be loved and to belong give a purpose in life. Family members have a sense of belonging and being loved, because they have one another. However, death usually causes great losses among friends and relatives. Common to all sub-population groups affected by AIDS, is that children die before parents, parents die leaving young children, young lovers unprepared for the death of someone of their own generation, lose a partner and a lover (Hope, 1995:12).

(ii) Family disorganization

Death brings disorganization within the family system. Depending upon the family's emotional structure, individual families with sound emotional structures may utilize the experience of death and bereavement as a dramatic opportunity for growth and change, while, on the other hand, some families with clinging attitudes may seek to substitute the dead person with other family members (Walker, 1991:249).

4.4.2.3 The esteem needs

A self-actualizing family functions harmoniously, and is capable of organizing and reorganizing itself when a crisis strikes. However, when the unexpected has struck the family, for example when one member is infected with HIV there may be a shift from homeostasis to in equilibrium. The family members of an HIV infected person may react in the same manner as the patient on hearing the news for the first time. Shock, disbelief, and denial are the norm until they finally accept the news as no joke (refer to Kubler-Ross's stages of adapting to loss). In this instance the loss would be of a loved one who could have been a breadwinner. The family members will undergo feelings of loss, sadness and helplessness. Grieving is usually done before the patient dies and the actual death may come as a relief to the family (Vlok & Lochner, 1992:526).

(i) HIV infection and children

Although having children proved to have given meaning to the lives of many HIV infected parents, informing the children about their HIV status carried mixed feelings and fears. Sometimes younger children are not informed of their parents' HIV status for fear of them being victimized by their peer groups and adults. Other reasons given for not informing their children included education examinations due to be written. Respondents in an investigation feared that information on the HIV status of parents might be upsetting the children emotionally during examination time (Regan-Kubinski & Sharts-Hopko, 1995:333).

In the Sanlam Report (1993:12) it is alleged that HIV infected toddlers hospitalised for a long period of time are unable to walk, talk or play like other children of their age group, due to lack of strong primary relationships.

Children who are separated from home and family are unable to experience normal socialization, and will grow up feeling uncertain, isolated and stigmatised (Sanlam, 1993:12). This may become a cycle that continues throughout their lives, their feeling uncertain, not able to sustain relationships and jobs, resulting in more isolation and feelings of uncertainty.

• HIV infection and orphans

The most predominant issue in the economy side effects of the pandemic is the number of children who are orphans due to AIDS and those who will lose their parents to AIDS. Estimations are that by the end of the year 2000, 10 million uninfected children world-wide will lose one or both of their parents to AIDS (Hope, 1996:11). KwaZulu-Natal in eight years time will have to provide for half a million children orphaned by AIDS, South Africa, by 2000, will have almost 2 million children orphaned by AIDS (Michael, 1998:8).

- **Orphans and mortality**

AIDS increases mortality in the under five group – both because children are infected, but also because significant numbers will be orphaned and orphans experience higher levels of mortality (Whiteside, 1995:12).

Infants born to HIV infected mothers have a one in three chance of becoming infected, have multiple illnesses and will die before the age of two years. Those who survive the ordeal might be abandoned (Sanlam, 1993:12).

- **Stigmatization**

Social isolation of the family often results from secrets kept regarding the cause of death of a loved one. Children of HIV infected parents are more withdrawn and have more problems to concentrate than children whose parents are non-infected (Forsyth, 1999:8). This may lead to isolation.

Because children often are the victims of stigmatization by peer groups, this may lead to aggressive behaviour and further social isolation (Imber-Black, 1993:344).

Helping others to manage the effects of stigmas is not simple and should be approached with care (Lubkin, 1990:75).

- (ii) Foster parenting**

A study carried out in Zimbabwe revealed that the HIV/AIDS epidemic undermines the willingness of communities to absorb orphaned children. Families were more willing to care for orphaned children if some form of support was offered, for example free education, free health care or food supplements. As first choice for placing orphans, blood relations of the orphan concerned are usually considered (Michael, 1998:8-8).

(iii) Children of HIV infected parents

In a study done on the mental health of uninfected children of HIV infected mothers it was found that the children of HIV infected women may not engage in the "acting out" behaviours that are likely to alert clinicians to the need for psychological intervention. These children are more internalised and less likely to draw attention to themselves, are more withdrawn, depressed and anxious, compared to the children of uninfected mothers, because of a lack of primary socialization which occurs in a family (AIDS Scan, 1998:9).

(iv) Children and abandonment and/or orphanages

Orphaned or abandoned children often experience a great sense of loss, have identity problems, no frame of reference and have not learnt the basic skills of interaction. Children who have been orphaned due to AIDS or are victims of AIDS themselves often grow up in orphanages and hospitals, without the love and warmth of their parents. They have problems in bonding, feel unsafe, insecure, unwanted, unlovable, with unrealistic expectations of how their needs can be met. (Sanlam, 1993:12).

4.4.2.4 The actualization needs

The needs at this level are considered to be in the highest in the hierarchy. A self-actualizing family is fulfilling its functions and responsibilities as a family. However, illness and stress may change the situation drastically.

(i) HIV/AIDS stigma

The stigma associated with HIV infection cost an AIDS activist, Gugu Dlamini her life on revelation of her HIV positive status on television during World AIDS Day in December 1998 (DENOSA, 1999/2000:5). Although the national statistics reflects the highest prevalence rate of HIV infection in KwaZulu-Natal, the community

could not bear such public exposure by a person who came out boldly and divulged her HIV status. The controversy could have been triggered by the differences in the levels of functioning between the victim and those who victimized her (Maslow's hierarch of needs).

On the other hand, a Sowetan HIV positive journalist Lucky Mazibuko, stood up and is running a column called "Just call me lucky", where he comments on confesses and teaches on HIV infection. His voice is heard by thousands and millions of Sowetan readers (Sowetan, 1999:6).

(ii) HIV/AIDS and literacy

A drop in literacy might result in communities where children from AIDS stricken households are taken out of school because their families can no longer afford school fees, or because they are needed to help out at home (DENOSA, 1999[a]: 5).

(iii) HIV/AIDS and religion

The plight of orphans created by the AIDS epidemic will demand of religious communities, ordinary individuals and big business to join hands with the welfare sector in assisting the AIDS stricken families emotionally and in other ways to cope with the demands created by HIV infection (DENOSA, 1999[b]: 14).

4.5 CONCLUSION

In this chapter Maslow's hierarchy of basic human needs, Dr Kübler-Ross's stages of grieving and Gorman's six emotional issues evoked by illness and loss were discussed and applied to the needs of HIV infected individuals and their family members. In chapter 5 the data analysis is described.

CHAPTER 5

Data analysis

5.1 INTRODUCTION

This chapter is a report on the data analysis and findings of the study.

5.2 FINDINGS

Giorgi's method of data analysis as described by Omery (1983:5) has been used, whereby persistent words, phrases and concepts were identified as units called constituents. The raw data was analysed and categorised into Maslow's hierarchy of needs, which forms the philosophical base of this study (cf Chapter). Redundancies were eliminated from the units with the meaning of the remaining units clarified and related to each other using the activities of daily living (Uys, 1999:9). These were further related to Maslow's hierarchy of needs. Each category activities were underlined using a different coloured pen from other categories. Units belonging to the same category were grouped into groups used to classify these units. The researcher then integrated and synthesized the insights into a descriptive structure of the meaning of that experience, in this research this refers to the need of HIV positive individuals and their families using Maslow's hierarchy of needs.

5.2.1 The physiological needs

According to Maslow's hierarchy these needs form the broader base and are essential for patient survival. Nutrition, sleep, rest, respiration, exercise, water and comfort were included (See figure 2.1). The following discussions will be based on categories and description of the findings by the researcher.

In Figure 5.1 the physiological needs are grouped and related themes/constituents and listed.

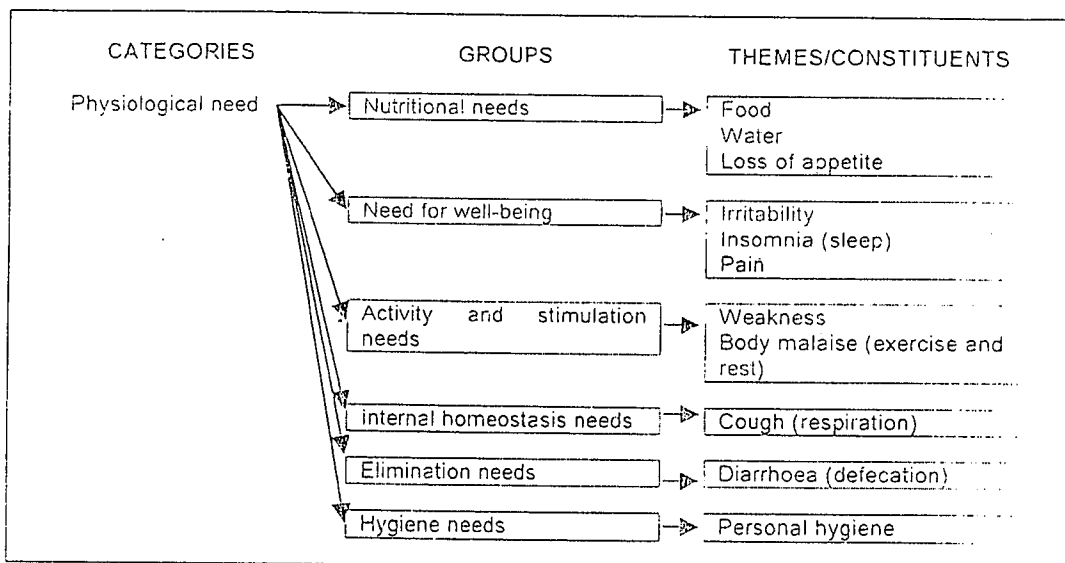


FIGURE 5.1: Physiological needs

Dorothea Orem's theory of self-care Deficit implies that patients are affected from time to time by limitations that do not allow them to meet their self-care needs. These limitations may be due to ill health or age (Hartweg, 1991:11).

On the other hand self-care is described as a learned behaviour from interaction and communication in larger social groups performed deliberately in response to a need by matured individuals (Hartweg, 1991:12). However, illness, including HIV infection, may limit the patient's self-care as will be described in the following paragraphs based on the findings on physiological needs.

5.2.1.1 Nutritional needs

Nutrition refers to an adequate supply of foods that are required to keep one alive and healthy. These foods include carbohydrates and fats, which supply most of the body's energy, and proteins, vitamins, and minerals, which are special chemical compounds needed by the body (Guyton, 1984:530; Uys, 1999:70). There are many factors associated with failure to eat among ill individuals.

Altered metabolism, loss of strength, fear and anguish to mention a few. Loneliness, worry and lack of money may also be implicated (Barckley, 1980:60).

(i) Food

When ill individuals cannot take food or fluids by mouth and where the facilities are available, intravenous infusion may be given or an intravenous hyper-alimentation may be started whereby nutritional fluids are administered through a catheter inserted into the subclavian vein (Barckley, 1980:60; Uys, 1999:70).

On the research carried out among HIV positive individuals and their family members, the researcher identified food, water and a loss of appetite as the needs under nutrition.

❖ The HIV positive individual

All interviewed HIV positive individuals voiced the need for a nutritious diet, and they recommended social assistance in the form of food packs (soups) and grants to cater for this need. This need was also predominant among their relatives, as evidenced by the following quotes. *"I feel guilty when my brother and sister in law have to use their last money for medication instead of buying some food....."* and *"I want to know what I am suppose to eat and not to eat..... sometimes I eat something I am not supposed to."*

❖ The family

Three interviewed family members also voiced the need for a nutritious diet. In two families there were small vegetables gardens at the back of their yards. Financial resources in these families were really lacking. One relative declared *"..... Even when I tell him that you see my brother the only money at hand apparently is enough for food....."*

(ii) Water

Water is essential for maintenance of life, besides oxygen. One can stay alive without food, but without water, survival is limited to days. Water is needed for metabolic processes in the bodies as well as the excretory function of the body that is defecation, urine and expiration (Uys, 1999:72; Smith, 1992:152). The quality of the water used for consumption is important, so as to prevent unwanted diseases including diarrhoea, and other skin infections (Werner, 1978:46). Adequate amount of water is necessary for optimal body functioning.

❖ The family

Although each household had running water, there was a general cry from subjects on the (salty) taste of water used for consumption in the area. Two families reported to be buying water from a nearby farm (from a borehole). *"those who can afford, they buy water from a nearby farm of they bring it when they have gone to Bloemfontein."* Those who could not afford, to buy water, used water as was. Water was also used for personal and environmental hygiene, as well as for the replacement of fluids lost through diarrhoea (home made rehydration fluids). This fluid is made by adding eight levelled teaspoons of sugar and a levelled teaspoon of salt into a one litre of pre-boiled water.

Water is the medium in which waste materials are excreted by the kidneys. Water is essential to keep the faecal matter soft and prevent constipation. Without water, survival is limited (Uys, 1999:72).

(iii) Loss of appetite

Loss of appetite or anorexia is observed by a decreased food intake, a loss of interest in previously favoured foods and usually a temporary weight loss. This condition may be caused by stress, anxiety, unpleasant odours, tastes, pain, and nausea.

❖ The HIV positive individual

Anorexia was identified as a general symptom of three HIV positive individuals *"sometimes I do not feel like eating... if I can have some soup that would be better."* This could probably be associated with the nutritional value of the diet consumed related to financial resources (income). Only one HIV positive patient did not complain about this symptom. The nutritional value of food can be improved by use of multivitamin tablets and the African potato (Labathela) for appetite (DENOSA, 2000:20) and by ensuring a clean mouth by encouraging individuals to care for their oral hygiene and demonstrating the correct method of doing this (Uys, 1999:64)

❖ The family

The three interviewed family members complained of this symptom found in the patients as stated in the following *"we have to check whether she has taken her food or not..."* and *"Sometimes I have to feed him although he fights a lot then."*

5.2.1.2 Need for well-being

Well-being is a relevant term that can only be defined by an individual concerned. However physical well-being denotes an absence of pain or discomfort and living in harmony with one's physical environment (Uys, 1999:206). On the other hand emotional well-being denotes the absence of anxiety, tension, depression and sorrow (Uys, 1999:206).

❖ Irritability

Irritability as a sign originates from the feelings of anger and frustration related to being diagnosed with an incurable disease and the stigma associated with it (Wincze & Carrey, 1991:145). The source of anger must be identified and dealt with through good communication skills.

Two subjects voiced this feeling, which is mostly due to counselling services that are well established in the area, as well as the process of living with the thought that someday they will die from this disease. One respondent even said: *"I have been trying to forget that I am suffering from this condition ... Now all memories have come back. It was better when I was working in Bloemfontein where there is a counselling centre and you share your experiences with people suffering from the same condition as you are... Now ... here... "*

❖ **The family**

This symptom was commented on by one family member: *"Sometimes our brother when (he) is in pain.....he shouts at us and even at the children when they come close to him....."*

(ii) **Insomnia**

Sleeplessness is associated with any condition stimulating the reticular activating centre and thus the brain and muscles too (Rykheer, 1984:76; Lubkin, 1990:111). Worry, anxiety, pain, nervous tension and psychotic brain disturbances are the know causes of an inability to sleep (Vlok, 1988:873; Lubkin, 1990:111).

❖ **The HIV positive individuals**

All subjects complained about this symptom. The inability to sleep was related to thoughts and fear of disclosure of one's HIV status. One subject said: *"I cannot sleep.....thoughts come at night that I am suffering from disease."*

❖ **The family members**

This symptoms also affected the patient's family members. This was caused by thoughts on whether there will ever be a cure for the disease, and whether they

are infected by the virus or not. One family member commented "*I sometimes lie wide awake throughout the night.....*" Sleep inducing measures should be directed first to the removal of the underlying cause (Vlok, 1988:873). Worry and anxiety may be allayed through counselling of both the infected individual and the family. A hot milk may prove effective when taken in the evening before bedtime (Rykheer, 1984:76).

(iii) Pain

Pain is a physical symptom that can be explained by the person experiencing it (Uys, 1999:215; Carroll, 1992:87; Lubkin, 1990:111). Its presence indicates damage to the tissue or threatening trauma (Uys, 1999:215; Carroll, 1992:87; Lubkin, 1990:111). There are certain emotions, which accompany pain, they include anxiety, reactive depression, feelings of guilt, positive acceptance, anger and self pity (Uys, 1999:225). Health care providers should be knowledgeable about these emotions when intervening clients with pain.

❖ The HIV positive individuals

Pain as a symptom was identified among patient respondents with other sexually transmitted diseases like penile ulcers that needed dressing. This was the case with one patient who declared "*.....After dressing I dread going to the clinic.....*" One patient verbalized that "*I have a pain in my right hypochondriac region.....*"

❖ The family

Three family members commented on that, although their patients do not complain about pain to them. They usually identify these symptoms by observing their facial expressions as well as their behaviour, like lying down all the time. Pain related to physical stress and insomnia was identified with all family members. One family member stated that "*my brother would lie in bed for the*

whole day and when you ask him what is the problem.....he will just stare blankly at you....."

Hartweg (1991:21) refers to the physiological needs as the universal self-care requisites, or requirements for action. She listed these as follows (eight were identified, but only five belong to the physiological needs category):

- (i) The maintenance of sufficient intake of air;
- (ii) The maintenance of a sufficient intake of water;
- (iii) The maintenance of a sufficient intake of food;
- (iv) The provision of care associated with elimination processes and excrements; and
- (v) The maintenance of a balance between activity and rest.

The last three belong to higher levels in the hierarchy.

Depending on the level of care needed, the patient may need help with personal hygiene, wound dressing, and care to back and pressure parts (DENOSA, 2000:20).

5.2.1.3 Activity and stimulation needs

Activity and stimulation needs are essential for growth and development. Without sensory stimulation, a person becomes disoriented and confused, while lack of movement results in discomfort, boredom and depression (Uys, 1999:163).

❖ The HIV positive individuals

Body malaise and weakness were common among patient respondents. Many factors could have played a role in bringing about these symptoms. One patient complained that *"My sister-in-law does not want me to help with the household chores. When I start doing something she stops me saying that I am sick, I am not supposed to cook or wash dishes". This behaviour could be associated with fear to contact the disease and ignorance on management of HIV infection.*

However apart from this patient, the remaining three patients were actively participating at home as well as attending religious group meetings and prayer meetings. One even reported using a bicycle or walking to the clinic for review on treatment, although basically this was related to financial constraints.

❖ **The family**

One family member of the bedridden patient commented that: *"When my brother-in-law feels better he usually wakes up and sits in the sun outside".* The others did not comment on this.

(a) Rest

Rest is essential for the sick body by slowing down the rate of metabolism and thus the stress placed on the organs concerned with the vital functions on which life depends (Rykheer, 1984:78). A good bed and a comfortable position are essential for effective rest.

❖ **The HIV positive individuals**

Rest was found to be essential for both the patients and the relatives caring for them. The patients complained of fatigue even on slight exertion of physical effort. One patient said: *".....sometimes I have to stay in bed the whole day. It is an effort to even clean the house....."*

❖ **The family**

The relatives reported that they felt more strain even more in cases where there were children to take care of and when the patient was bedridden, having diarrhoea or vomiting. One family member said that: *"although I am not complaining, however I do feel stress and strain especially that there are children to look after too....."*

5.2.1.4 Internal homeostasis needs

Homeostatis or equilibrium refers to the ability of the body to maintain a constant, stable internal environment by controlling oxygen, carbon dioxide, nutrients, waste products and electrolytes intake and excretion (Uys, 1999:140).

❖ HIV positive individuals and family members

Body temperature, pulse rate and blood pressure as means of maintaining homeostatis were not identified by the subjects, probably because they were not catered for in the study. One family member complained of hypertension triggered by stress. Her quoted verbatim reads. *“Die voelbloed gaan maak jou skaam, you young people do not suffer from this.” She was on treatment.*

(i) Respiration

Respiration involves the breathing in of the atmospheric air rich in oxygen and the breathing out of carbon dioxide laden air from the lungs. The principal muscle of respiration is the diaphragm and intercostal muscles (Guyton, 1984:434). For effective respiration the respiration tract and organs must be clear of infection or obstruction. One patient said: *“cough as a symptom is on and off as well as dyspnoea...”*

All interviewed subjects (Including both patients and their family members) commented on cough as the major symptom and all four patients were on tuberculosis treatment. Coughs were persistent and varied from being productive to non-productive in character.

Dyspnoea and other related signs and symptoms were not observed.

5.2.1.5 Elimination needs

The waste products of the body need to be excreted to maintain a normal internal homeostasis. There are four identified mechanisms to excretion waste material from the body as urine, faeces, expiration and sweat (Uys, 1999:121) the elimination of individuals is affected by many diseases.

(i) Diarrhoea

Diarrhoea is an abnormal increase in the number of stools, which are usually very fluid (Uys, 1999:135). Diarrhoea can be mild or severe, sudden or gradual in onset (Werner, 1978:153). Diarrhoea is a dangerous condition especially in children, because they dehydrate easily. Management of diarrhoea includes bed rest and strict observation of electrolyte balance, food intake, weight and body strength (Uys, 1999:135).

A home made dehydration fluid is used to replace lost fluids, a current recommendation is use of canned fruit juice or flat Coca Cola to supplement loss fluidtroytes (Uys, 1999:135).

❖ The HIV positive individual

This symptom was observed in two patients who went to the toilet more than once during the interview and the remaining two did not complain about it. Diarrhoea necessitated frequent use of the toilet.

❖ The family

In one interview the relative explained the use of the bucket by the patient and the relative having to discard the contents afterwards, to avoid physical strain to the patient caused by getting up and down when going to the toilet and back. Other family members did not comment on this. One family member is quoted as

having said: *"When my brother has diarrhoea, I sometimes make use of a bucket with a lid to avoid him soiling the floor..."*

5.2.1.6 Hygiene needs

Personal hygiene refers to the care of the skin, hair, nails, teeth, oral and nasal cavities and the perineal area (DENOSA, 2000:20;Uys, 1999:49). Healthy and ambulant individuals are capable of attending to their personal hygiene needs. However illness and age (babies) may require such needs to be taken care of by other people, example mother or health care providers.

❖ The HIV positive individual

Interviewed patients in relation to coping mechanisms recalled dependence on others (Their family members) to cater for these needs. All four interviewed patients were able to attend to their personal hygiene.

❖ The family members' views

The three interviewed family members complained of a physical strain related to this need, when their family members are critically ill. Of the three (family members) one commented *"It used to be better when patients were admitted in hospitals... Now they no longer do that"*.

The hygiene needs included bathing the patient, dressing of wounds, attending to the back and pressure parts and oral hygiene of the patient (DENOSA, 2000[c]: 20;Uys, 1999:49).

This is evidenced in the following discussion.

Researcher : *"How do you manage to live with a family who is HIV positive?"*

Client : *"It is not easy, but I am trying as much as I can to keep him clean as well as his room"*

5.2.2 Safety and security needs

The needs depicted in Figure 5.2 are found at the second level of Maslow's hierarchy and they comprise emotional support, empowerment and finance. These three needs form the pillars on which the safety and security needs are based.

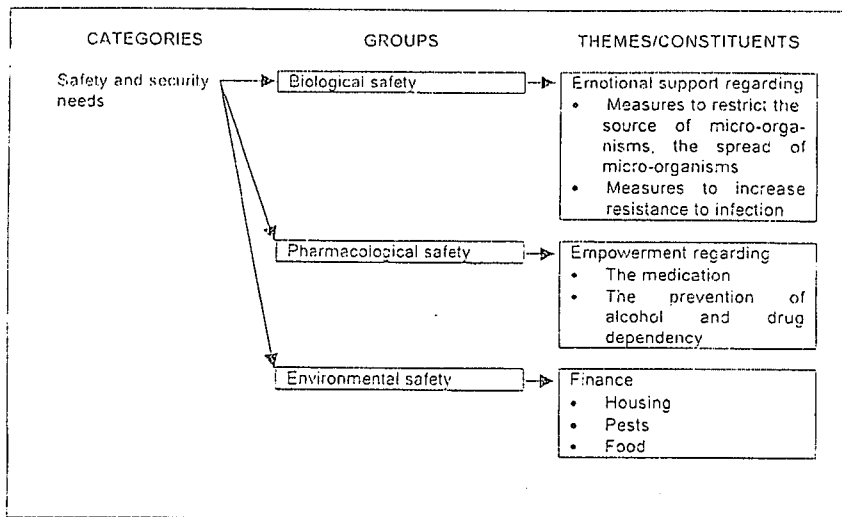


FIGURE 5.2: Safety and security needs

The needs at this level, according to Hartweg (1991:21), entail the prevention of hazards to human life, human functioning and human well being. According to research findings these needs include emotional support, empowerment and finance.

5.2.2.1 Biological Safety

Biological safety involves emotional support regarding measures to restrict the source of micro-organisms, measures to restrict the spread of micro-organisms and measures to increase resistance to infection. Infection means that the body's protective measures have not been adequate to resist the intruding micro-organisms and that the body is reacting to this successful invasion by microbes (Uys, 1999:244).

(i) Measures to restrict the sources of micro-organism

An environmental hygiene plays a major role in this measure. Micro-organisms grow and multiply quickly in warm, damp and dark areas. A well constructed house with adequate lighting system kept clean by adhering to basic hygiene standards (Uys, 1999:245) may limit the number of micro-organisms. The washing of hands with soap and water after using the toilet facilities and before handling food need reinforcement.

A powerful tool to achieve the restriction of sources of micro-organisms is education on health-related matters through guidance and support. Three patients and their family members were found to be lacking knowledge and skills, with only one having limited knowledge regarding the mode of transmission of the HIV virus.

Condoms were supplied by the clinic, but usage was inadequate. One client said: *"After testing positive the clinic sister gave me condoms... but I fear telling my husband to use them because he will ask me where did I get these form."*

One HIV positive individual and her family member thought that mere casual contact or touching food and food utensils would transmit the disease, hence an instance where a patient was denied attending to household chores by the sister-in-law (See paragraph 5.2.1.3).

Another measure to prevent the spread of micro-organisms is to use disinfectants on spilled bodily fluids before attending to and discarding them (Uys, 1999:245). Limited knowledge was identified from three patients' family members regarding the types of disinfectants other than Jik.

Three patients were found to be having more than one sexual partner (One partner in one area and the other/s somewhere else) and not knowing who infected them and when. This is a sad state, as it was difficult to trace contacts.

One patients is quoted as follows: "... my girlfriend with whom I have a child is in Cape Town....another one is in Kimberly."

(ii) Measures to restrict the spread of micro-organisms

The spread of micro-organisms basically depends on knowledge regarding the source of the micro-organism. The two sub-headings (i and ii) are related, one influencing the other either positively or negatively. Two couples had new-borns and the husbands in both instances knew about their HIV positive status long before conception of the babies (bearing in mind the number of HIV/AIDS-related orphans in South Africa) (see paragraph 4.4.2.3[i]). In one example the husband died six months after the birth of the child, and the mother, a young widow suffered from strained relationships with the in-laws. They blamed her for the death of their son. "*When my husband died, his family blamed me for that... I am now staying with my mother....*" Health talks regarding the spread of HIV infection thus need to be given a priority (see paragraph 4.3 and subsequent sub-paragraphs).

(iii) Measures to increase resistance to infection

The immune system plays an important role. To boost immune system immunization programmes and campaigns (Uys, 1999:251) are carried out locally, nationally and internationally. However presently there is no immunization against HIV infection and AIDS.

Some of these measures have been discussed under physiologic needs as nutritional, elimination, internal homeostasis, activity and stimulation and the need for well-being in this chapter (See 5.2.1 and Sub-headings). Touching, listening and a word of encouragement in a non-judgemental manner or attitude can also be used to demonstrate emotional support.

5.2.2.2 Pharmacological Safety

Medications are chemical substances which are used for their therapeutic effect on clients (Uys, 1999:253). To safeguard use of drugs, they are scheduled accordingly, in accordance with the medicines and related substances control act (Act 101 of 1965) (Vlok, 1991:723).

Presently there is no drug to cure HIV infection. Available drugs are still being tested on a voluntary basis by the participants, are expensive and not readily available and accessible to all HIV-infected patients (e.g. AZT) and have significant side effects.

Prophylactic treatment in the form of symptomatic treatment is available, for example tuberculosis treatment and treatment of other AIDS-related diseases.

Alcohol consumption by HIV-infected patients should be discouraged, as well as the use of other drug substances for example cocaine and marijuana, as they lower the resistance of patients further, making them more susceptible to infection (DENOSA, 2000:20;Uys 1999:70).

Drug actions and interactions must be stressed, as well as the use of the correct route of administration of the drug prescribed and the therapeutic levels of various drugs for symptomatic relief (Uys, 1999:251). Researchers have found garlic supplements can cause a potential harmful side effect when combined with a type of medication to treat HIV/AIDS (Riscitelli, *et.,al* 2002:24).

The four patients in this study were on tuberculosis treatment and they all complied to treatment. The relatives of the three bedridden patients ensured the constant supply and compliance to treatment. Verbatim quoted from one relative is as follows: "*My brother is just back from the clinic.... I make sure that he takes his medicines as prescribed.*"

5.2.2.3 Environmental Safety

Environmental safety covers a broader area than biological safety. It includes community environmental safety measures such as population growth, poverty, urbanization, pollution of water, air and environment (Uys, 1999:259) and measures of controlling these health hazards.

Financial support plays a major role in environmental safety. One feels safe and secure when having a roof over one's head. At night, after work, come rain, sun or storms, if one has a shelter one feels safe. The type of a house, whether well constructed or debilitated, has a direct influence on the health of the individuals residing in it (Refer to paragraph 4.4.1.2[i]).

Interviewed subjects were all staying in the sub-economic houses provided by the municipality of the area. Those who could afford to do so, extended them. Two four roomed family houses were extended to seven roomed houses. Environmental health was maintained in the houses visited.

Environmental safety also includes the refrigerators for the storage of food.

5.2.3 The need for love and belonging

The needs at this level basically are concerned with relationships and are found in level three of the hierarchy of Maslow's needs. Hartweg (1991:21) refers to these needs as being necessary for the maintenance of a balance between solitude and social interaction. (See Paragraph 2.3, 2.4 and 4.4.1.3) In this study identified needs include affiliation and assertiveness (in communication) (see Figure 5.3).

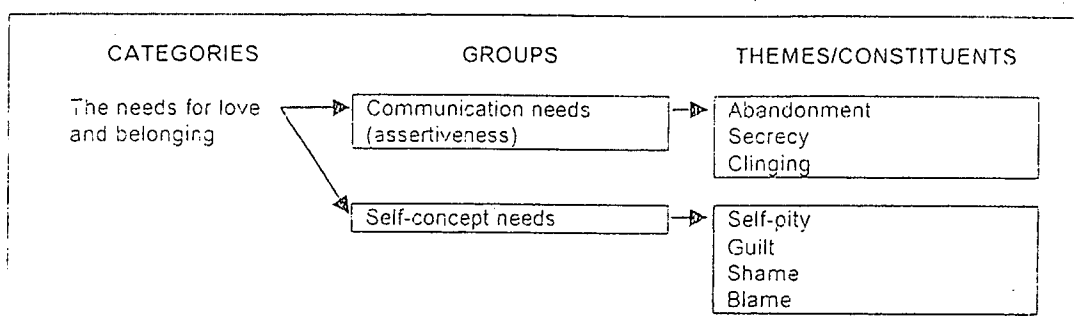


FIGURE 5.3: The needs for love and belonging

5.2.3.1 Communication needs/assertiveness

Communications means the transmission of information, opinion, and intention between and among individuals (Gillies, 1982:468). Man is a social being belonging to a community and a culture group (Rykheer, 1984:73).

A person is born within a family and grows and matures in a family through social interaction (see 4.4.1.3[i]). Any relationship is characterised by communication. Social insecurity and emotional immaturity in times of stress may result in social isolation (Howe, 1995:15). Clear communication means that the information is conveyed effectively between members of the family (Uys, 1999:368).

Communication skills were found to be lacking in both the patients and their families. This could be related to a physical strain among families and fear of abandonment among the patients (refer paragraph 4.4.1.3[i]). Interviewed subjects voiced this feeling when asked about their relationships after having been diagnosed HIV positive. Fear of abandonment by their loved ones and friends resulted in HIV positive individuals keeping their HIV status a secret from those people except their parents or sisters, this is evidenced by the following statement: "if I tell him, you know it yourself that is will not be that easy for me to do so..... maybe that may result in a fight between us."

Health care providers can assist families with poor communications skills by role modelling good communication skills during interviews and counselling sessions (Uys, 1999:369).

(i) Abandonment

The social stigma associated with HIV infection causes fear of being abandoned by one's loved ones. Abandonment is related to the issue of trust and mistrust and this symptom is great among individuals who grew up in troubled or dysfunctional families (Whitefield, 1989:71) In a study conducted by Regan-

Kubinski & Sharts-Hopko in 1995. One client responded, "Telling"... "might take them out of my life again".

❖ The HIV positive individuals

Fear of rejection and abandonment was the deciding factor in informing relatives and loved ones. One participant voiced that: "my partner left me after divulging my HIV status" All other interviewed subject participants had the same complaints (See 4.4.1.3[ii]).

Thus to counter this feeling (fear of abandonment) individuals often mistrust, they shut out their feelings so they do not feel the hurt (Whitfield, 1989:71; Wincae & Carey, 1991:146; Regan-Kübinksi & Sharts-Hopko, 1995:333) Abandoned individuals feel somewhat neglected, lonely and isolated and even rejected (Weisman, 1979:61).

❖ The family members

Of the three interviewed family members, only one member accepted having left her grandson temporarily and went to stay with her daughter in Pretoria and came back after a month. This could have been due to shock on hearing the news for the first time that her grandson was HIV positive. One's patient's grandma verbalised that"... On hearing the news.....left him and went to stay with my daughter in Pretoria....."

(ii) Secrecy

Secrecy in families and relationships emanates from the feeling of shame and guilt. Guilt is the uncomfortable or painful feeling that results from doing something that violates or breaks a personal standard or value, or from hurting another person (Whitfield, 1989:43; Regan-Kubinski & Sharts-Hopko, 1995:333; Imber-black, 1993:344). (See paragraph 4.4.1.3 (i)).

Individuals feel confident and valued when loved and accepted unconditionally (Howe, 1995:15). The stigma associated with HIV infection leads to secrecy in relationships, feeling of guilt emanate from the feelings of inadequacy in performing one's role effectively and the pain the loved ones will suffer on hearing the news. One participant said: "*even my own best friend I cannot tell her myself, she has to forgive me, I cannot.*" The children were the last people to be considered to be informed about the news, the reason being their age and victimization by their friends. True relationships between the patient and the relative informed was another deciding factor, as evidenced in the following statement: "*It is my mother and sister who know about this we have not yet informed my stepfather because he will talk about it to everybody on hearing the news.*" (See paragraph 4.4.1.3. (i) & (ii).

(iii) Clinging

Clinging attitudes emanate from feelings of dependency on others. This is accompanied with emotional immaturity where during the first stage of psychosocial development (Erikson's) the balance between trust and mistrust was not maintained (Brown & Pedder, 1979:53).

Clinging attitudes were observed in two married unemployed subjects: "*who will support me if my husband rejects me*" *Unemployment and a sense of dependency on the breadwinner resulted in them suffering quietly while bleeding inside.* (Refer paragraph 4.4.1.3. (ii).

This was not expressed by their family members.

5.2.3.2 Self-concept needs

The self-concept is a learned behaviour and develops throughout life as a result of one's integration with significant others and the reference groups. Self-awareness is incorporated in self-concept, whereby individuals are consciously aware of their feelings, their limitation and strengths. The self-concept is a prerequisite determination factor for growth towards the two highest levels of the hierarchy (Bradly & Edinberg, 1990:146).

Individuals with an undefined self-concept feel self-pity, have feelings of guilt and shame, and always take blame upon them when relationships fail (Whitefield, 1989:43).

Two of the interview subjects showed these feelings: "If I had stayed in my marriage or at home I wouldn't be in this mess I am today" quoted verbatim of a divorce's response.

5.2.4 Self-esteem and self-actualization needs

Needs at the two higher levels of Maslow's hierarchy were discussed interchangeably as they interested. A positive self-concept is nurtured throughout a person's developmental stages in life (Whitfield, 1989:19). People who grow up in loving and caring families, demonstrate the same assets to others. They set practical and attainable goals, live by certain standards and accept corrections from others and visa versa. Such persons are capable of self-evaluation (Morgan *et al.*, 1986:298; Bradly and Edinberg, 1990:146). They strive for achievement and rejoice in the achievements of others. HIV infection may lower a person's self-esteem and hence the self-actualizing capability. It is therefore important for individuals and families to demonstrate compassion and understanding to their loved ones in times of stress and illness.

In Figure 5.4 self-esteem and self-actualisation needs are grouped and the related

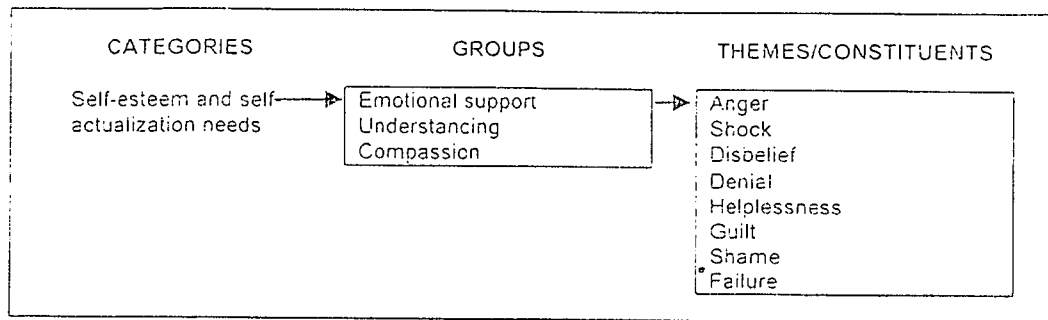


FIGURE 5.4: Self-esteem and self-actualization needs themes are listed

5.2.4.1 Emotional support

Emotional support can be demonstrated through touching, listening and a word of encouragement in a non-judgemental manner or attitude (see 5.2.2.1). Anger, shock, disbelief, denial, helplessness, guilt, shame and failure were themes identified at the fourth and fifth levels of Maslow's hierarchy of needs.

(i) Anger

Feelings of anger are usually projected to loved ones, family, friends and health care workers (Lubkin, 1990:93). The individual becomes very difficult to handle and is demanding (Wincze & Carrey, 1991:145; Vlok, 1991:344). Health care workers should be able to recognise and understand the nature of anger. Most adults respond with frustration and anger to their loss of independence and their forced submission to plans for treatment made by doctors in consultation with their families. Where possible the sick individuals need to be consulted in matters related to their health (Vlok, 1991:334).

❖ The HIV positive individuals

All subjects verbalised having felt anger at some stage on hearing the news. This anger was directed to their loved ones and children, the nurses and anybody who

discussed the topic, and it was related to the feelings of guilt and shame at failing their families, as well as the stigma associated with HIV infection (see 4.4.1.4[iii]).

❖ The family members

Anger displayed by family members it was towards the patients, for example the instances where the grandma left her grandchild (See paragraph 5.23.1).

(ii) Shock or disbelief

Shock or disbelief is related to denial of the hurting news. Individuals react uniquely to unique experiences. Some may react immediately whereas others may have delayed shock. Their behaviour may vary from quietness to aggressive behaviours (Lego, 1994:5; Vlok, 1991:343).

The news was shocking to subjects. Both patients and their family members could not understand how they or their family members contracted HIV infection. One subject said: "*I really do not know how I contracted this virus, because I am a married person.....*"

(iii) Denial

Individuals tend to deny painful feelings pertaining to the nature of the disability of disaster faced with at the particular moment (Carroll, 1992:41). The purpose of denial is an unconscious avoidance to protect the self from painful reality (Gorman et al., 1989:110).

❖ The HIV positive individuals

Subjects expressed varied ways of denial. Two patients consulted a private practitioner on hearing about their HIV status to confirm the diagnosis or to prove that the results were not correct "*I then went to another doctor.... I thought he was*

pulling my leg..." Two patients left their areas of work to go somewhere where they were not known. Two had false hopes and pretended to be suffering from known curable diseases like bronchitis (Refer to 4.4.1.4[ii]).

❖ **The family members**

Interviewed family members could not believe that one of their relatives is suffering from HIV infection. One member said: *"I thought that my brother was going to tell me that he was joking..."*

(iv) Helplessness and worthlessness

Illness and disability may lower an individual's self-esteem resulting in feelings of helplessness and worthlessness, with HIV infection, the disabling nature of the disease, its mode of transmission and the stigma associate with it may lower one's personal worth (Yalom, 1997:111).

Because of the disabling nature of HIV infection, the patients felt helpless and worthless. Although two of the patients were still employed, the remaining two were unemployed. Abscondment from work was the order of the day quoted statement from one patient: *"after hearing the news I left the firm I was employed in I came back home"*. Financial burdens were predominant to all interviewed subjects. Three families depended on old-age pension and children's grants (support from their children's fathers) on separation with their husbands.

A compassionate understanding and guidance are necessary when dealing with HIV positive individuals.

Housewives, who are totally depended on their husbands for the household income, felt trapped in a cobweb from which there seemed to be no escape.

(v) Guilt, shame and failure

Guilt is the uncomfortable or painful feeling that result from doing something that violates or breaks a personal standard or values while shame is the uncomfortable or painful feeling that one experiences when one realizes that a part of them is defective, bad, inadequate or a failure (Whitfield, 1989:44).

❖ The HIV positive individuals

These feelings were the cause of fear of abandonment by their loved ones and they resulted in secrets and strained relationships in may families. One patient verbalised that *".....telling him is another thing my husband usually says that he would commit suicide if he could be diagnosed with this disease."*

❖ The family members

There were no comments on this issue.

5.2.4.2 Compassion ad understanding

Compassion and understanding involves empathic understanding (Yalom, 1997: 50). This necessitates that one understands how others feel and how their actions affect others.

❖ The HIV positive individuals

Two patients reflected anger towards the health care system and the researchers on using them (HIV positive patients) for learning purposes. Three subjects voiced out their dissatisfaction on nurses doing home visits in uniform, they preferred private attire to uniform *"....when neighbours see nurses visiting your home hey start gossiping."*

❖ The family members

One family member commented that *"sometimes my daughter gets angry and shouts at me.... and usually I answer that a sick person does not shout at people....you are freaking your illness."* All three interviews families reflected this need.

5.3 CONCLUSION

The subjects' responses reached saturation after interviewing four patients and three family members and could easily be categorised according to Maslow's hierarchy of needs (see Figure 5.2.1 to 5.2.4). Manual sorting of data was used and this exercise required time and concentration. The needs of both the patients and their family members dove-tailed each other.

CHAPTER 6

Conclusion and recommendations

6.1 INTRODUCTION

In this chapter the conclusion and recommendations are discussed.

6.2 RESEARCH RESULTS

During interviews the following needs were identified:

6.2.1 The needs of the patients

	CATEGORIES	GROUPS	THEMES/CONSTITUENTS
1	Physiological needs	Nutritional needs Need for well-being Activity and stimulation needs Internal homeostasis Elimination needs Hygiene need	Food Water Loss of appetite Irritability Insomnia (sleep) Pain Weakness Body malaise (exercise and rest) Cough (respiration) Diarrhoea (defecation) Personal hygiene
2	Safety and security needs	Biological safety	Emotional support regarding <ul style="list-style-type: none">Measures to restrict the source of micro-organisms, the spread of micro-organisms

		Pharmacological safety Environmental safety	<ul style="list-style-type: none"> Measures to increase resistance to infection Empowerment regarding <ul style="list-style-type: none"> The medication The prevention of alcohol and drug dependency Finance <ul style="list-style-type: none"> Housing Pests Food
3	Love and belonging needs	Communication needs (assertiveness) Self-concept needs	Abandonment Secrecy Clinging Self-pity Guilt Shame Blame
4	Self-esteem needs	Emotional support Understanding compassion	Anger Shock Disbelief Denial Helplessness Guilt Shame Failure
5	Self-actualisation needs	Same as level 4	Same as level 4

6.2.2 The family needs

The needs of the family members were the same as those of the patients with the exclusion of the guilt feelings, shame and failure.

Based on the research and its findings the following conclusions and recommendations were made.

6.2.3 Physiological needs

These needs form the broader base of the hierarchy and are necessary for the survival and performance of basic functions of the body. Unmet physiological needs cause a shift in homeostasis. The level of the shift determines the level of survival. When individuals cannot perform or meet these needs, assistance is necessary and should be given by a second person. These needs include a need for hygiene, nutrition, elimination, internal homeostasis, activity and stimulation, and well being needs (Perko & Kreigh, 1988:29).

6.2.3.1 Recommendation

- (i) Families and communities should be taught basic nursing skills including the protective measures against infection.
- (ii) Social assistance to families in the form of food packs (soups) and/or social grants should be considered to poverty stricken families and communities.
- (iii) Home care nursing facilities should be improved. When home care facilities are improved the individuals and families may learn to take heed of their health needs and take care of their ill family members. This can be done by demonstrating the basic skills during home visits.

6.2.4 Safety and security needs

The needs at this level include a need for biological, pharmacological and environmental safety. Three pillars to maintain these needs were identified as emotional support, empowerment and financial support (Gorman *et al.*, 1989:299).

6.2.4.1 Recommendation

- (i) Communities should be empowered by mastering life skills including skill in the prevention of spread of infection and budgeting, and should participate actively in matters related to health promotion and disease prevention.
- (ii) Health care systems should work hand in hand with the communities they are serving for effective infiltration to the most rural communities.

Knowledge forms a sound base for self-confidence through competence.

6.2.5 The needs for love and belonging

Individuals grow and mature through being loved and belonging to a family, group or organization. Loving involves giving and receiving unconditionally. Conditional love is characterised by poor communication, strained relationships, and broken families. In times of stress these needs are imminent to all individuals, sick or well (Whitfield, 1989:203).

6.2.5.1 Recommendation

- (i) Individuals, families and communities should be taught communication skills (towards assertiveness). Communication is a powerful tool that is used either to build or to destroy relationships. Assertive individuals are able to communicate their emotional feelings to the other individuals without hurting them.
- (ii) Counselling services should be readily available to all. Accessibility includes the distance between the patients' homes and the counselling services' centre, the availability of counsellors, the quality of services rendered and the utilization of the available services by the community members.

6.2.6 Self-esteem and self-actualisation needs

These needs form the highest levels in the hierarchy and comprise emotional support, understanding and compassion.

These needs are a rare commodity. Psychologically matured people attain these levels of needs. Compassion and understanding need a sound and firm base and knowledge of the self. There is more giving than receiving. A sharing disproportion could result in loss and strain when the self-concept is not clearly understood or defined (Bradly & Edinberg, 1990:146).

6.2.6.1 Recommendation

- (i) Social support systems should be available, like therapy groups for the HIV infected individuals and their families. When individuals meet people who have the same problems as theirs, communication becomes free during discussions. This usually promotes a sense of belonging among individuals. This could enhance active participation of individuals in health related matters, and self and community development projects to curb unemployment and poverty.
- (ii) The plight of children's rights and HIV infection needs further investigation. Children who have been orphaned due to AIDS or are victims of AIDS themselves often grow up in orphanages and hospitals without the love and warmth of their parents.

6.3 SUMMARY

6.3.1 The research problem and literature review

HIV infection is a global problem-affecting individuals of all racial groups, socio-economic backgrounds, cultures, sex and age.

The statistical information available at all governmental levels shows only a tip of an iceberg, because of the small number of people who present themselves for HIV blood tests. In South Africa, for example, projected statistical information at provincial levels is based on the results of antenatal women attending the public primary health care facilities (who volunteered to be tested for HIV (refer to figure 1.1).

6.3.2 The study

The aim of the study was to identify the needs of HIV positive patients and their families in the community.

A qualitative study was done that captured the unique experiences of the interviewed subjects, by tape-recording the unstructured interviews of both the HIV positive subjects and their family members.

Purposive sampling was done from the attendance register, with the assistance of the primary health care centre personnel and the Specialized Auxiliary Officer at Koffiefontein. Subjects participated voluntarily in the research, after signing an informed consent form. The sample comprised both males and females. Saturation was reached after interviewing four HIV positive individuals and three members of their families. Giorgi's method of data analysis was used (see Appendix II).

6.3.3 The results

Identified needs were classified into themes and groups using activities of daily living (Uys, 1999). The groups were further classified into major categories according to Maslow's hierarchy of needs.

6.3.3.1 *The physiological needs*

The needs identified in this category included nutrition, sleep, rest, respiration, exercise and water and hygiene (refer to figure 5.1).

6.3.3.2 *The safety and security needs*

This category revealed the emotional support, empowerment and financial support as the pillars for the needs in this level (refer to figure 5.2).

6.3.3.3 *The love and belonging needs*

In this category the communication and the self-concept needs of subjects were identified (see figure 5.3).

6.3.3.4 *Self-esteem and self-actualisation needs*

These two categories revealed the needs for emotional support, understanding and compassion towards the HIV positive individuals and their families (see figure 5.4).

6.4 LIMITATIONS OF THE STUDY

The study did not categorise patients according to the four phases of HIV infection, probably there might be a difference in the needs for the various groups.

6.5 CONCLUSION

HIV infection affects not only those who have the virus, but also those who irrationally fear infection, those who are at risk of being infected (who fear infection), friends, families, professionals and volunteer care givers, and

neighbours alike. The elderly are also included because this disease affects their children who are economically active.

Because of the disabling nature of HIV infection especially during the terminal stage, HIV infected individuals normally come home to be taken care of by their relatives during the final stage of the disease (AIDS). On their death the elderly take care of their children. Where there are no relatives the children may be taken to orphanages, hospitals and for foster caring.

The disease *per se* is a multifaceted challenge that needs a multi-disciplinary approach from grassroots level to the highest authority in the country to fight against its spread (intersectoral collaboration).

People living with AIDS and their families need understanding and compassionate community members to support them emotionally, thereby removing the burden of the stigma associated with this disease.

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APPENDIX I

Research questions

Influence by a limited literature study and Maslow's hierarchy the researcher asked the following questions during interviews to:

HIV POSITIVE PATIENTS

"What needs do you have that are related to your HIV positive status?"

The family member

"What needs do you have now that you have a HIV positive member in your family?"

To ensure that all the subjects understood what was expected of them the questions were translated to the language best understood by the subject concerned.

SESOTHO

Bakoli Ba HIV

Ke li feng nyakoa tsa hau tse bakwang ke hore u na le kokoana hloko ea HIV?

Ua lelapa

Ke li feng li nyakoa tsa hau,joale ha e mong oa lelapa e na le kokoana hloko ea HIV?

XHOSA

Kubaguli besifo ugawulayo

Zeziphi izidingo okanye iitswelo zakho ezibangelwe yinto yokokuba unale ntsholongwane kagawulayo (HIV)?

Kubantu bekhaya

Zeziphi izidingo okanye iitswelo zakho nje ngo kuba omnye wezizalwane zakho enale ntsholongwane kagawulayo (HIV)?

INTERVIEW I

In a clinic office, the time is 09:00. An interview takes place between the grandmother of an HIV positive client and the researcher. The grandmother is aware of the HIV status of her granddaughter. A mixture of languages is used to try and get the same understanding of the purpose of the interview and the required content for the research.

	<p>Researcher: <i>"Nje ngamntu ohlala nomntu onesi sifo, ndicela ukuqonda aphe kuwe okokuba ingaba mhlawumbi zeziphi izidingo okanye iimfuno okanye iingxaki othe wadibana nazo?"</i></p>	
	<p>Client: <i>"Oo, lo omnye "sister"?"</i></p>	
	<p>Researcher: <i>"Ewe."</i></p>	
<p>Love and belonging needs</p> <ul style="list-style-type: none"> • Communication needs 	<p>Client: <i>"Ha-a. Akukho niks."</i></p>	Denial Secrecy
	<p>Researcher: <i>"Akukho niks – ?"</i></p>	
<p>Self-esteem needs</p> <ul style="list-style-type: none"> • Emotional support 	<p>Client: (Shaking her head side ways) <i>"Mhi-hi."</i></p>	Denial
	<p>Researcher: <i>"Akukho mhlawumbi iingxaki othe wadibana nazo ekhaya, nasekuhlaleni onokuthi mhlawumbi undiehazele ngazo?"</i></p>	
<ul style="list-style-type: none"> • Compassion • Understanding 	<p>Client: <i>"Mhi-hi."</i></p>	Denial
	<p>Researcher: <i>"Awuboni zidingo – ?"</i></p>	
<ul style="list-style-type: none"> • Compassion 	<p>Client: <i>"He-e."</i></p>	Denial Secrecy
	<p>Researcher: <i>Akukho nto – ?</i></p>	

Self-esteem
 • Emotional support

• Compassion

Self-esteem
 • Compassion
 • Understanding

Love and belonging needs
 • Communication needs

Client:	(In a low matter of factly voice) Hy is mos buite gelos ."	
Researcher:	"Ndifuna ukuqonda ngokwekhaya into yokuba ekhaya –.	
Client:	"Ee."	
Researcher:	Akukho mhlawumbi izidingo –.	
Client:	"Ee."	
Researcher:	"Mhlawumbi ebantwaneni besikolo nasekuhlaleni."	
Client:	(Puzzled) Uyibeka njani ke ngoku ?"	Shock
Researcher:	"Ndicela ukuqonda ukuba mhlawumbi, nje ngokuba nihleli apha ekhaya –.	
Client:	"Ee."	Financial support
Researcher:	"Akukho mhlawumbi iingxaki neengxwaba-ngxwaba mhlawumbi –."	
Client:	(Shaking head) He-e. Niks nie ."	Denial Secrecy
Researcher:	"Niks nie?"	
Client:	Mhi-hi (emphatically) andifuni kuxoka."	Denial
Researcher:	"Nikisi nje tu-tu-tu?"	
Client:	Mhi-hi ."	Denial
Researcher:	"Nakuye –?"	
Client:	"Nakuye, simphathe kakuhle "	Secrecy

- Self-actualization
- Compassion
- Understanding

- Compassion

- Love and belonging needs
- Self-concept needs

Researcher:	"Nimphethe kakuhle."	
Client:	"Mh."	
Researcher:	"Zange mhlawumbi ikhe imkhathaze -."	
Client:	"He-e, niks. Mna zonke ezizinto mntwanam ndazibeka kuThixo."	Denial Helplessness
Researcher:	"Uzibeke kuThixo."	
Client:	"Ndizawuthini."	Helplessness
Researcher:	"Mh."	
Client:	"Asoze, naye ndimane ndimxelele. (Softly) Ek het hom gesê: 'Man die ding van AIDS maak die mense klaar.'"	Self-pity Fear
Researcher:	"Mh."	
Client:	"Maar ndimane ndimxelel' amazwi am."	
Researcher:	"Mh."	
Client:	"Iyaa."	
Researcher:	"Ngoku ke nje ngokuba uhlala naye phaya, mhlawumbi azikho ezinye izinto mhlawumbi eniye nibethakale kuzo phaya ekhayeni?"	
Client:	"Umenig (Afrikaanse klank) sizinto."	
Researcher:	"Izinto mhlawumbi enibethakala kuzo phaya ekhayeni."	
Client:	"Umeni izinto ezinjani?"	
Researcher:	"Nditsho kuba, uyaqonda into yokuba ukuphila, mandithi ngokuya wayengekaguli umntwana -?"	

Love and belonging

- Communication needs
- Self-concept needs

Self-actualization

- Compassion
- Understanding

Client:	"Mh."
Researcher:	"Nangoku sele egula."
Client:	"Mh."
Researcher:	"Akukho nto mhlawumbi nibethakala kuzo ekhaya."
Client:	"Mh-hi."
Researcher:	"Mh."
Client:	"Nee, andifuni kuxoka, akukho niks, siphila nje ngane siphila."
Researcher:	"Niphila nje ngokube naniphila."
Client:	"Iyaa, laa ndlela sasiphila ngayo iya."
Researcher:	"Okay."
Client:	"Asinamthatha kakubi ..."
Researcher:	"Aninam thatha kakubi."
Client:	"Mhi-hi, ukhuliswe ndim, nam indicela uThixo amphilise umntwan'am."
Researcher:	"Ngumntwana wakho?"
Client:	"Iyaa, ngumntwana womntwana wam."
Researcher:	"Ngumntwana womntwana wakho?"
Client:	"Iyaa, my kind se kind, ukhuliswe ndim."
Researcher:	"Umama wakhe uphi?"

Denial
Secrecy
Shame

Shame
Guilt
Helplessness

Love and belonging needs

- Communication needs
- Self-concept needs

Client:

"Umama wakhe asimazi
nalapho akhona. Akahlali
notata wakhe, bohlukana,
daardie kind hy kom. Babehlala
e Bloemfontein, dis my bloed,
bakhuliswa ndim?"

Abandonment

Guilt
Shame

Researcher:

"Isizathu mhlawumbi
sokungahlali kunye ingaba
uyasazi?"

Love and belonging needs

- Communication needs
- Self-concept needs

Client:

Ba ... bahlukana, bahlukana,
hayi bahlukana, bahlukana,
hayi abazange batshate, he-e,
bahlukana Bathath' umntwana
bamsa kuye. Abazali bomfazi
bathath' umntwana bathi Sy
maar die kind vat' abanamali.
Wamthatha, wandinika
umntwana wakhe. Iyaa."

Abandonment
Guilt

Shame

Researcher:

"Babezekene mhlawumbi
okanye -."

Love and belonging needs

- Communication needs (assertiveness)

Client:

Abazi, hy ken nie dan vir hom,
nayo hy ken nie dan vir haar.
Azange ambone umama
wakhe. Hy ken net vir my."

Abandonment

Researcher:

"Mh."

Client:

"Mhi ... Hy ken net vir my. So
hy is my eie kind."

Researcher:

"Mh."

Self-actualization

- Compassion
- Understanding

Client:

"Ngowam, iya. Uthixo uza
ndipha amandla."

Shame
Helplessness

Researcher:

"Mh."

- Compassion
- Understanding

Client:

"Mh, uza wuyaphi? Sy kan nie
weggaan nie ... Ukhuliswe
ndim."

Helplessness

	<p>Researcher: "Mh ... Kwizinto mhlawumbi ezinje ngento zemali, akukhe mhlawumbi kubekho kubethakala?"</p>	
<ul style="list-style-type: none"> Understanding 	<p>Client: "He-e. (Louder) Uyabona ipeyi yakhe bayithathile na jaar. Bathe baza weer om te doen. Hy gaan hom weer kry."</p>	<p>Anger Irritability</p>
<ul style="list-style-type: none"> Compassion 	<p>Researcher: "Ibi yipeyi yantoni?"</p> <p>Client: "Siekpey. Hy kry mos vallen-siekte. Iyaa, vallensiekte."</p>	<p>Shame</p>
	<p>Researcher: "Mh."</p> <p>Client: "Iyaa, hy kry vallensiekte."</p>	<p>Shame</p>
	<p>Researcher: "Hoe lank is dit toe hy met vallensiekte beval het?"</p> <p>Client: "Vallensiekte, lankal toe hy nog jonk." (Lifting hand to estimate height)</p>	
	<p>Researcher: "Ipeyi le yona uqale nini ukuyifumana?"</p>	
<ul style="list-style-type: none"> Self-esteem needs Emotional support 	<p>Client: "Last jaar. Ek ken nog nie van die jaar nie. Hulle het die hele pey gevat. Babona ukuba sy sal niks doen. Sy val altyd."</p>	<p>Irritability Helplessness</p>
	<p>Researcher: "Ipeyi le yakhe, kuphela kwento mhlawumbi enje ngemali eniphila yiyo apha ekhaya?"</p>	
<ul style="list-style-type: none"> Safety and security needs Environmental safety 	<p>Client: "Nee, sy het sy pey, ek kry ou jaar pey. Hy pey siekte."</p>	<p>Finance</p>
	<p>Researcher: "So kubantwana ohlala nabo ekhaya, ingabe kuphela kwakhe?"</p>	

Love and belonging needs

Client: "He-e, asinguye yedwa. Ndi-
nentombi yam, my eie dogter,
nabantwana bayo ababini. Ek
het net twee dogters, dié eene
is gesterwe."

Researcher: "Iphi yona intombi le eyakho?"

Client: "Ikhona."

Researcher: "Ngaphandle kukamama kalo -
"

Client: "Nee, daar een is my eie kind."

Researcher: "Mhi."

Client: "Iyaa, my eie dogter."

Researcher: "Okay, lo ke ngumzukulwana."

Client: "Iyaa, lo ngumzukulwana."

Researcher: "Ngonyana wakho okanye
ngentombi."

Client: "Iyaa. My seun bly ook by my,
hy bly uit, maar batya
phaya ekhaya, akalali, ulala
ka ntle."

Researcher: "Ngoku aba bantwana be ...,
intombi le yakho yona yenzani."

Client: "Ayinamsebenzi."

Researcher: "Yenzani?"

Client: "Iphelwe ngumsebenzi."

Researcher: "Mh."

Client: "Mhi, hy is maar besig om 'n
ander werk kry."

Researcher: "Ebephangela phi?"

Safety and security needs

- Environmental safety needs

- Environmental safety needs

Finance

- Food
- Housing

Finance

- Unemployment

Safety and security

- Biological safety
- Environmental safety

Love and belonging needs

- Communication needs

Self-actualization

- Compassion
- Understanding

Love and belonging needs

Client: "Ebephangela apha evenkileni. Ngoku amaBhulu emkile."

Researcher: "Mh."

Client: "Ee, ngoku amaBhulu emkile

ene ingxaki utata waba

bantwana wabhubha. Ek

sorg vir hulle, ngabantwana

bam klaar ke ngoku. Toe kyk ek hoe kan hulle lewe."

Researcher: "Ngumyeni wakhe osebenzayo?"

Client: "Mhi-hi, umyeni akanaye, wam-

pha nje abantwana ababini, akafuni nje into ekuthiwa yindoda ..."

Researcher: "Ingaba mhlawumbi ayikho enye into ofuna ukundixelela yona?"

Client: "He-e, my kind ..."

Researcher: "Kwezi zinto ke mhlawumbi besikhe sancokola ngazo."

Client: "Ee."

Researcher: "Mh."

Client: "He-e, daar is geen probleme.

Ek sal maar lewe,

ngumntwana womntwana

wam, met hierdie siekte. Ek

kry my kind jammer, elke tyd

ek dink van hierdie siekte."

Researcher: "Ngoku ekhaya uhlala naye lo mntwana womntwana wakho, nabani omnye."

Client: "Is my kind, my dogter

nabantwana bakhe ababini?"

Finance
Emotional support

Abandonment

Helplessness
Guilt
Shame

Self-esteem
 • Emotional support

Researcher: "Qha?"
 Client: "Umakhulu, **usisi wam uhlala eJaardini by haar eie ronda-wel**. Indoda yam yabhubha. **Ek bly by my eie huis**."

Independence

Researcher: "Mh."
 Client: "Mh."
 Researcher: "Umyeni kadadewenu mhlawumbi?"
 Client: "Wabhubha. Ngoku uhlala yedwa naye."

Love and belonging

Researcher: "Oo."
 Client: "Maar uhlala kum, want die vrou is oud, is gedaan, maar uyaziphekela (softly) uzenzela yonke into, xa uThixo esamphe amandla. Mh."

Helplessness

Safety and security needs
 • Environmental safety

Researcher: "Akaxhomekekanga kuwe?"
 Client: "Mhi-hi, sy pey dan."

Finance

Researcher: "Mh."
 Client: **Utya imali yakhe**."

Finance
 • Food

Researcher: "Okay ... Umzukulwana lo wakho yena akanabantwana?"

Client: (Louder) "Owuphi?"

Researcher: "Lo – umzukulwana wakho."

Love and belonging needs
 • Self-concept needs

Love and belonging needs
 • Self-concept needs

Self-esteem needs
 • Emotional support
 • Compassion
 • Understanding

Self-esteem and self-actualization needs
 • Emotional support
 • Understanding
 • Compassion

<p>Client:</p>	<p>"Nee, ek vat nie die kans, he-e, ndiyamxelela naye as sy swanger word. Nee, sy kan nie 'n kind het nie. Nam ndiyazigulela mntu wabantu. Ndinevoelbloed."</p>	<p>Self-pity</p>
<p>Researcher:</p>	<p>"Unexesha elingakanani unayo?"</p>	
<p>Client:</p>	<p>"Nee, he, lankal, andizi apha ngoba sommer siyahlala apha mntu wabantu. Sometimes uhlale ubusuki bonke, ubuye nangomso. Ngoku ndiyabona ukuba hayi maar mandiyе, noba ndiyohlala phaya akunamsebenzi. Awuboni kuzala nje, kuzala so yonke imihla ... Die voelbloed gaan maak jou skaam. Nina aninayo le nto bantu bajong."</p>	<p>Blame Shame Self-pity</p>
<p>Researcher:</p>	<p>(Laughing) "He-he-he."</p>	
<p>Client:</p>	<p>Iya, aninayo, nijong maan. Niva nje abantu bethetha ngevoelbloed, ngoku aanbeklaring ndiyahamba ngoku imnyama indlela, isibane asikhō, ndingayokuwa phaya. Ene ndinento yokugodola. Mh ingqele ndiyabona ingxamele ukundingena. Nee my kind sisengxakini ... Maar ndiyathetha naba bantwana. Akukho mzali ungathethiyo. Ngaba bantwana, abasimameli ... Siza wuthini?"</p>	<p>Cold Helplessness Guilt Helplessness</p>
<p>Researcher:</p>	<p>"Mhi."</p>	
<p>Client:</p>	<p>"Ene iyabagqiba le nto."</p>	
<p>Researcher:</p>	<p>"Mh."</p>	

Self-actualization
• Emotional support

Client:

Kuyangcwalywe *apha*
eKoffiefontein. Jong kinders,
yingxaki."

Fear
Helplessness

Researcher:

"Mh."

Client:

(Laughing) "Jy sê maar net mh-mh."

Researcher:

"Hayi kaloku ndimamele."

Self-actualization
• Emotional support
• Compassion
• Understanding

Client:

"Ee, die waar beswaar dié siekte. *Inzima le nto, inceda ntoni, and esi sifo awunasifihla dan. As jy het hom, toe het jy hom. Wat doen jy? Uzawuthini? ... Of ndiyaxoka?"*

Helplessness

Helplessness

Researcher:

"Anditsho okokuba uyaxoka."

Self-actualization
 • Emotional support
 • Compassion
 • Understanding

• Emotional support

Client:

"Ee, sinzima esi sifo mntwan'am batsho dan bathi elke dag bathi 'heyi huis toe gaan. Siyabona nje nabantwana bam. Sinzima esi sifo, en xa unaso unaso, uza wuthini? Ene ungabona ayinayeza le nto. Asinalo (emphatically) Siyababona abantu banaso, bayasokola, bahamba emagqirheni, bahamba naphi na. Waar toe gaan hulle? Is swaar met dié siekte. Sizibonela nalapha eThivini. Toe gedaarlik sukkel die mense, is die mense met hierdie siekte, Le AIDS bathetha elke dag ngayo, yonk'imihla. Nob'uvul'iradio bathetha ngayo. Ee, ungayibona nasemzimbeni, ee, inyani, yinyani, inzima ... Awuthethi ngoba ungayazi, uthetha into oyaziyo. Hy is swaar dié siekte ..."

Fear

Helplessness

Emotional support

Empowerment

Fear

Helplessness

Researcher:

"Mh ... Ingaba kwezi ubufuna ukundixelela zonia undixelele ngokwaneleyo na? Akukho nto mhlawumbi uyishiyelelayo ... Het jy al gesê of gaan jy meer sê?"

Client:

"Ja, nee, ek gaan nie meer sê my kind, ek het al gesê. Dit is al."

Researcher:

"Mh."

Client:

"Al klaar, ndiza wuthini ngoku?"

Researcher:

"Uzawuthini?"

Client:	<i>"Ee, ngoba ndithethile, andinayo enye into yokuthetha, ndizathini ngoku torho. Dis al wat ek gesê."</i>
Researcher:	<i>"Hayi ke enkosi ngokundinika ixesha lakho."</i>
Client:	<i>"lyaa, moet ndithethe kakuhle nawe, nawe uthetha kakuhle nabantu, uyacaca ukuba uphuma emzini."</i>
Researcher:	<i>"Enkosi."</i>

KEY

Love and belonging needs

Self-esteem needs

Self-actualization

Safety and security needs

Physiological needs

INTERVIEW II

In a kitchen, in a client's home, an interview takes place between the client who is living with the HIV virus and the researcher. The client is aware of her HIV status.

Researcher:	<i>"Ndicela ukuqonda ukuba njengamnty onentsholongwane ye HIV, ndicela ukuqonda apha kuwe ukuba yintoni iintswelo, okanye izindingo onazo okoko uthe wanesi sifo?"</i>
Client:	<i>"I-HIV?"</i>
Researcher:	<i>"Ee, ndithetha ukuthi mhlawumbi iingxaki okanye iintswelo zakho, okanye iimfuno zakho mhlawumbi, mandiyibeke olo hloblo, zeziphi?"</i>
Client:	<i>"Andazi ukuba ndingathini. Uku (need[er]) kukuthi izidingo, andithi? Utsho ukuthi ndidinga ntoni empilweni yarn?"</i>
Researcher:	<i>"Ewe, empilweni yakho, nasebomini nje generally."</i>
Client:	<i>"Oo, zininzi sisi nje nga nje mhlawumbi ndinabantwana neh?"</i>
Researcher:	<i>"Mh."</i>

Love and belonging needs

Self-pity
Guilt

Love and belonging needs:

- Self-concept needs

Safety and security needs

- Biological safety
- Pharmacologic safety
- Environmental safety

Self-esteem

- Emotional support
- Understanding
- Compassion

Client:

"Yaye izinto ezininzi endizifunayo, ndizidingela abantwana bam ... sendithe maar andazi ilanga lam lizofika nini into enjalo kanje. Maar andingomntu ohlala osoloko ndicingana naloo nto. Mna into endiyicingayo [kukuthi] [ndihlale] [ndifundise] [abantwana bam babe badala] Ndinga [ukuthi ndibakhulise] [bohluleke], noba [ndiyahamba] [ba ndibe ndibakhulisile] ..."
(The ringing phone lengthened the pause.)

Researcher:

"Ubusatsho ke sisi."

Client:

"Ee, hayi kunjalo ke."

Researcher:

"Mh."

Client:

(Softly) "Andazi ke."

Researcher:

"Awazi ukuthini ... Bendisamamele ngela xesha."

Client:

(Louder) "Hayi andithi ndiyatsho ndithi kuwe, [nam ndiyafuna] [ukuthi ndikhulise abantwana] [bam, bahambe isikolo], ngoku ke yeyona nto endiyifunayo leyo, ukuba mhlawumbi bayazihlalela ke bazihlalele."

Researcher:

"Ayikho enye into, mhlawumbi empilweni yakho nje ke yonke?"

Client:

"Hayi, nje ngokuthi ndifeel(er) njani, uyabona?"

Researcher:

"Mh."

Helplessness

Emotional support

Empowerment finance

Anger Self-pity

Physiological needs

- Need for well-being
- Activity and stimulation needs
- Internal homeostasis needs

Client:

"Hayi akukho nto endiyifeel (ayo), umzimba wam uright nje, maar sometimes uthola ukuthi ubabuhlungu ube nexesha eliright, nesifuba ke sisabakhona, futhi ndibuyele ekliniki. Andithi last uyakhumbula ndakuxelela ukuthi ndaphola, and ndaba right ndaphila, ndaphinda ndabuyele emzimbeni wam futhi, ndabuyela eRhawutini ndithi ndiyosebenza. Ndilthe ndifika pha ndaphathwa sisifuba futhi, ndaphinda ndabuya ke ngoku, ngo December ndeza kumama wam, ndaphinda ndabuyela ekliniki."

Pain

Cough

Cough

Researcher:

"Mh."

Physiological needs

- Internal homeostasis needs

Client:

"Ndaqala ndaba right ... Uyakhumbula ngokuya kuqala ndandithe isifuba intoni, ntoni, isifuba ndinaso, nalaa nto yokuthanda ukuvaleka, seyingcono nayo. Ndasendibhetele, ndandithe isifuba intoni, ntoni, saphinda savuka."

Cough

Dyspnoea

Cough

Researcher:

"Ngaphandle kwesifuba nokudinwa, ayokho mhlawumbi enye into?"

- Activity and stimulation needs

Client:

"Iya, ukudinwa ndinako."

Body maleuse

Researcher:

"Mh."

- Activity and stimulation needs

Client:

"But, hayi nje ndingarhaleli ukuhamba or ndingarhaleli ukuya endaweni, mh. Ukuhamba ndihamba, (louder) goed, andihlali, nalaph'endlini."

Exercise

Researcher:

"Mh."

Client:

"Nalokuthi ndifumana daar ukuthi isifuba sam sigcwele, ishort ndizathi yintoni, intloko."

Researcher:

"Iphika."

Physiological needs

- Internal homeostasis needs

- Internal homeostasis needs

Client: "Nalaa nto yokungathi ndiphelelwa ngumoya ayisekho. But all ndingathi ndiright ngoku."

Breathlessness

Researcher: "Nangoku ndandilapha, nalast year, okoko wawusithi ufeeler alright. Uthetha ukuthini xa usithi ufeeler right?"

Client: "Kutsho ukuthi andihluphi niks, behalwe nou, isifuba ke nolukhohlela."

Cough

Researcher: "Utsho ukuthi, mhlawumbi abantwana bakho, ingaba mhlawumbi bafunda amabanga angakanani?"

Client: "Bayitwo, omdala una fifteen years omncinci una leven years. Ufunda seven omdala omncinci ufunda two."

Researcher: "So xa ucinga mhlawumbi, yintoni ekwenza uthi nawe unqwenela ukuba abantwana bakho ubakhulise, bafunde nje ngabanye abantu?"

Safety and security needs

- Biological safety
- Pharmacological safety
- Environmental safety

Love and belonging

- Communication needs

- Self-concept need

- Self-concept need

Self-actualization

- Compassion
- Understanding

Client:

"Ukuthi uma nditsho njalo ndithetha ukuthi ndicela uncedo lokuthi mhlawumbi, ukuthi

mhlawumbi [redacted] undiphe i-advice

[redacted] ukuthi ndiziphilise njani na

kusho [redacted] ukuthi ndingaphum-

[redacted] efela nam ukuphila ixesha

[redacted] elininze. Ee, ukuthi ndi-

avoide ntoni, ndinga-avoidi

ntoni. Naxa (like) mhlawumbi

ndinento endiyityayo

ndingafanelanga ndiyitye. Ene

hore ke phile joang. Nje ngoba

ungusister nje uthi xa ufanele

ukuphila ixesha elide yenza so

yenza so. Nam ngala malanga

(laughing) [redacted] kuya dayiwa manje,

cause nam [redacted] ndiyothuka abantu

[redacted] bayafa, abantu bayafa. Khona

nje kunamaxesha

endiziconsolayo. Okay, yisecret

yonke mos le. Nalaph'elokishini

baya-baya uyazi [redacted] bayandijonga

[redacted] njalo, [redacted] ndingazi bandijongelani,

'Hayi lo [redacted] phela une groot,

siyibiza i-'groot'. [redacted] Phofu xa

[redacted] umnty eright uthi thina Bantu

[redacted] abane TB uthi sine AIDS

Nditshi okay asiyisifo senja, yisifo

ethy thina sonke abantu."

Emotional support

Empowerment

Finance

Fear

Fear

Guilt
Shame

Self-pity

Researcher:

"Mh."

Client:

"Umntu angazixeleli [redacted] ukuthi

[redacted] yena angekhe ayifumane

[redacted] Sonke sizofa yiyo (want)

yisecret yethu sonke apha

emhlabeni. [redacted] Nomntu wakho

[redacted] noba uyafika umxelele ukuthi

[redacted] une TB naye ukuthatha

[redacted] ngokuthi une AIDS."

Anger

Guilt

Researcher: "Xa uthetha ngomntu wakho mhlawumbi, ingaba mhlawumbi uthetha ntoni?"

Client: "Umntu wam?"

Researcher: "Andazi kaloku mna ndive uthetha ngomntu wakho, ingaba mhlawumbi utsho iboyfriend?"

Client: "Hayi; mna andikakabi namntu."

Researcher: "Awukakabi namntu? Hayi bendive into yokuba ulhethe ngomntu wakho."

Client: "Oo, nje ngoba ndisithi somelimes uhlangane nomntu, ndingayazi ke mhlawumbi yena unayo. Andithi bathi thina sine TB sinaso esi sifo sonke yabona, ngoku ndingayazi Andithi nam andicingi ndimxelele ukuthi ndi HIV positive naye akacingi andixelele, siyazi ukuthi sine TB. Ngoku xa efika kum umntu ethi bathi thina sine TB sine AIDS uyavisisa."

Researcher: "Mh."

Abandonment

Denial

Secrecy

Denial

Self-esteem

- Emotional support
- Understanding

Love and belonging needs

- Communication needs

Self-esteem

- Compassion

- Self-esteem
- Emotional support
 - Understanding

Client:

"Xa ndim (consòle[r])
 ndimxelela ukuthi yisifo sethu
 (thina bantu, asiyisifo senja,
 wena ukhathala ngantoni
 (want) lesifo se HIV yisifo
 sethu thina Bantu, sizofa
 sonke yiyo, as long as usese
 young, usajola, sizofa sonke
 yilesi sifo. Andazi
 bayithathaphi le nto, ngoba
 amadoctor wethu awasixelele
 loo nto. Sine TB thina qha
 But mandithi mna andicingi
 ndixelele mntu ukuthi ndine
 HIV, especially aba balapha
 awungekhe uphile nexesha
 elingakanani apha, cause the
 moment luza ngapha uvela
 ngapha seba kugqibile,
 yabona?"

Denial

Anger

- Love and belonging
- Communication needs

Denial

Secrecy

- Self-esteem
- Compassion

Shame

Researcher:

"Bakugqiba njani?"

Love and belonging needs

- Self-concept needs
- Communication needs (assertiveness)

Client:

"Sebathetha ngawe. Even my own best friend, andixolele, ngoba ndiyoyika ukumxelela, uyawisisa, cause ndiyayazi ilokishi yonke izoyazi. Shame andixolele ngoba apha eKoffiefontein, le lokishi en abantu bakhona abathandani and xa ndithi ndizoxelela itshomi yam uyabona, ndithule, yabona ndithi ilokishi izoyazi yonke. Noba sendicinga, bul ukumxelela ngomlomo wam, asinto endingayenza. Ngoba ilokishi izoyazi and mna ndizohlala intliziyo yam ibuhlungu uyawisisa, cause omnye nomnye uzothi uma endibona athi uKholiwe ungamkheleli ngepayinti yakho amanzi, ungamenzeli tiye kwakho une AIDS. So akumnandanga andithi, ndizohlala ndiworried. Kanti apha ekhaya umama wam shame ke undinika olo thando ke nomntwana wasekhaya lo oseRhawutini osebenzayo naye undinika olo thando, xa bethetha nam. Kodwa maar ezi zinto ezi andizicingi and xa ndiphakathi kwabantu sixoxa andibe ndixoxa loo nto. Hesh nxa nam ndiyafakaza ke, kube mnandi, hayi ke kuhlekwe kuphela apho. Andazi ke."

(Softly and sadly)

Guilt
Secrecy

- Communication needs

Self-pity

Secrecy

- Self-concept needs

Guilt

Isolation

- Self-concept needs

Guilt

Self-pity

Researcher:

"Abantwana bakho bona?"

Client:

"Noba uthi uyamxelela naye uxelela umkhozi wakhe e-next door ukuthi ni (share[r]) i-secret yabona, maar awungekhe umxelele i-secret yakho, ngoba nomnye uyaggithisa, nomnye agqithise njalo. Hayi naye umntwana angekhe ndimxelele."

Secrecy

- Communication needs

Safety and security needs

- Biological safety
- Pharmacological safety

- Environmental safety

Researcher: "Ingaba mhlawumbi ayikho enye into onokundixelela yona?"

Client: "Hayi ayikho. **Just nje ndifuna i-advice yokuthi ndenze njani ukuze ndiphile ixesha elide.**"

Researcher: "Kodwa ke okwangoku sisajonge lo meimbi, ndiya kusuka ndikuthumele ekliniki emva koku, okanye kusisi, okanye sisuke sithi emva koku sikhe sixoxe."

Client: "Alraight, ndiyevisisa."

Researcher: "Andazi noba siqibile na ngoku?"

Client: "**Mna ndifuna i-advice yakho.**"

Researcher: "Okwangoku asinakuyixoxa leyo nje ngoba besenditshilo. Ndiza kukuthumela ekliniki okanye emva kokuba siyivalile le ncoko, singancokola. Enkosi."

Emotional support
Finance

Empowerment

KEY

Love and belonging needs

Self-esteem needs

Self-actualization

Safety and security needs

Physiological needs

ENGLISH VERSION

INTERVIEW

Interview

In a client's home in a lounge an interview takes place between the researcher and the client. The client is aware of her condition.

Researcher	"My sister as I have already told you about my visit to you , I would like to hear from you . What came into your mind when you heard for the first time that you are HIV positive.?"
Client	"I never thought that what I was hearing then was the truth, because truly speaking I was not seriously ill when I went to the clinic. I just felt tired, when they examined me they discovered that I have AIDS. They asked whether was I aware that I was sickand that what I am suffering from is contagious. ."They requested to have my blood taken for testing I prayed to God asking him to help me
Researcher	"Mhi"
Client	"..... After six months I had burning micturition and itching around the vulva. I went to the clinic again, They told me that We married women are incapable of controlling ourselves..... Because I knew that I am a married person who does nothing wrong and to be ashamed of I was puzzled, but because it were the sisters who said so I just kept quiet"
Researcher	"Did they just howl at you, without you having done or said anything to upset them?"..... I mean on the day your blood was taken did they tell you why it was taken? "
Client	"He-ke On the first day they said it is like women to do things that are wrong..... I never answered them..... I kept quiet "
Researcher	"You just kept quiet"
Client	"When nurses decide for you, what else can you do?..... Except to keep quiet."

Researcher	(changing the subject) " Sisi with whom are you staying at home?"
Client	"With my husband"
Researcher	Does he know about your condition?"
Client	"I cannot tell him, because in reality if I can tell him,..... I do not know what to tell him,..... you know it yourself he will say this and thatA lot of things. No he will never listen to that thing."
Researcher	"What will make him not to listen to that thing?"
Client	"You see sister telling him is another thing (sighing)..... because I know when I tell him, You know it yourself that it will be difficult for me to tell him. Maybe that can cause us to fight."
Researcher	"Mhi"
Client	"Because I used to hear him when gathered as a family, when somebody has died of this, or when there is something on TV,..... He would say that he would commit suicide. I even asked him that how would he feel if he happens to have it I hear from his response that he takes this serious.(changing the subject) Now what I think is that when nurses visit here ,people are watching, and they will want to know why they usually visit me. I think it is better that when I feel sick, I should be the one who goes to the clinic or a doctor, and not that you should always visit me. That makes me to feel emotionally disturbed."
Researcher	"You mean that you should be visiting the clinic?"
Client	"Ee..... When I have a problem I will just go You see.....As you are here now , and the car you came with, attracts people's minds, and you must not put on uniforms, because when people are talking they say that nurses visit people with certain problems including this one. You know people staying in locations moss they talk too much, even if your visit is not for that, they will say that you have visited for that."
	"From what you have just said, you do not want visits by health personnel"

Researcher	"Ee....."
Client	"May you tell me more about this..... I mean your needs related to the disease"
Researcher	"If it were according to me I would be working somewhere..... (standing up to look through the window)..... But my husband would not hear of that, he constantly tells me that he is able to support me.....(sighing) (pacing the floor) He can arrive anytime now and I would not like it if he finds you here "
Client	"As you wish, but one last question from me..... Who else knows about your condition, except you?"
Researcher	"My mother..... I know that my mother will never just talk about this to anyone"
Client	"Mhi"
Researcher	"You know sister it is not nice to have this thing..... I pray to God to give me strength and courage but it is not easy..... I sometimes lie
Client	wide awake throughout the night hoping that something..... I do not know what to say..... Anymore"
Researcher	"Well on that score then I will not trouble you with more questions. Is there anything you would like to ask or to be clarified for you?"
Client	(Irritably) "I told you that this man can come home anytime now"
Client	(Standing up and ready to leave)"Well thank you for everything, should you need further contacts please contact Sisi she knows where to find me"
Researcher	

APPENDIX III
APPLICATION FOR CONSENT TO PERFORM
THE RESEARCH

P.O.Box 246
Sterkspruit
9762
17 June 1999

Tel: (051) 611 0902(h)
(051) 611 0079(w)
Fax: (051) 611 0021

The Town Clerk
P.O.Box 7
Koffiefontein

RE: PERMISSION TO CONDUCT A RESEARCH IN YOUR AREA

Dear Sir/Madam

I kindly request permission/authority to conduct a research in your area.

I am a nursing student under the University of the Free State and busy with my dissertation.

My research topic is on "THE NEEDS OF HIV POSITIVE PATIENTS AND THEIR FAMILIES IN THE COMMUNITY".

I would greatly appreciate it if I could be allowed to perform this study during the third and fourth week of July 1999.

The research proposal has been approved by the research committee of the University of The Free State and presently awaiting approval of the ethic's committee.

Herewith enclosed a covering letter from my promoter.

Yours faithfully

Daliwe Semly Ndaba (Miss)

APPENDIX IV
CONSENT FOR THE RESEARCH



FREE STATE PROVINCIAL GOVERNMENT
HEALTH

Assistant Director: Mrs. N.P. Tshegare, Privatebag X02, Koffiefontein 9986
Tel (053) 2051013, Fax (053) 2050270

FOR ATTENTION: MISS B.S. NDABA

RE: PERMISSION TO CONDUCT A RESEARCH IN OUR AREA.

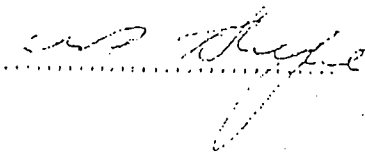
MADAM,

The Region grants you permission to conduct a research in the following towns:-

- Koffiefontein
- Jagersfontein
- Petrusburg
- Jacobsdal
- Fauresmith

We would appreciate it if you can also provide the Region with feedback at the end of your research task.

Thank you
N.P. TSHEGARE
ASSISTANT DIRECTOR
DISTRICT NURSING SERVICES REGION B
99.07.16





APPENDIX III
CONSENT FORM

**UNIVERSITY OF THE ORANGE FREE STATE
SCHOOL OF NURSING**

Informed consent form

PROJECT TITLE: The psycho-, socio- and economical factors affecting HIV positive patients

RESEARCHER: Miss B.S. Ndaba
Tel.: (H) 051-6110902
(W) 051-6110079

The purpose of this research project is to increase health care givers understanding on problems and experiences of HIV-positive patients in a family and community at large. Interviews will be conducted at least three times. Each interview session will not exceed an hour. During the interviews questions will be asked regarding your feelings and problems encountered since being diagnosed as being HIV positive as well as your coping mechanisms to overcome all these. The interviews will be tape recorded, however the information will not be shared with anyone. On completion a report, containing anonymous quotations, will be available to all at the end of the study.

There may be little or no direct benefits to the participants of this study, but there may be changes in services rendered following the completion of this study.

This is to certify that I (print name)
hereby agree to participate voluntarily in the above project.

I understand that there will be no health risks to me resulting from my participation in the research. I, hereby give permission to be interviewed, and for the tape recording of these interviews. I understand that, at the completion of the research, the tapes will be erased. I understand that the information may be published, but my name will not be associated with the research.

I understand that I am free to deny any answer to specific questions if I am not ready to share the information. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

PARTICIPANT

RESEARCHER

WITNESS

PLACE

DATE

IYUNIVESSITHI YEPOHONDO LEFREYISATI

UMXHOLO: Limfuno zabantu abanentsholongwane
ebangela isifo sika gawulayo nezihlobo zabo
ekuhlaleni

RESEARCHER: Miss B.S. Ndaba
Tel.: (H) 051-6110902
(W) 051-6110079

Injongo yolu phando kukuphawula imfuno zabantu abanentsholongwane ekhokhelela kwisifo sikagawulayo nezihlobo zabo eluntwini jikelele.

Ingcombolo nganye eyakuthi yenziwe ayisayikuthabatha ngaphezu kweyure enye. Ngethuba lengcombolo imibuzo eyakuthi inike ubugocigoci malunga nemfuno zakho emva kokuba waziswe ukuba unentsholongwane kagawulayo.

Umatshini wokushicilela uyakusetyenziswa ukuthatha le ngcombolo, kodwa ke obu bugocigoci akukho mntu uyakuthi abazi ngaphandle kwalo mntu uthatha ingcombolo. Xa kugqityiwe ingxelo ebhaliweyo iya kwenziwa. Akusayi kukhankanywa magarna Bantu kuyo. Wonke ubani othathe inxaxheba kolu phando uya kufumano ingxelo leyo.

Mhlawumbi abantu abathabatha inxaxheba kolu phando bangaxhamla kancinane kwiziphumo zalo.

Oku kukuqinisekisa ukuba mna (bhala igama)
Ndivuma ngokuhululekileyo ukuthabatha inxaxheba kolu phando.

Ndigonda ngokupheleleyo okokuba akukho kwenzakala nasikhwasilima endiyakuthi ndisifumane ngokwasempilweni yam xa ndithe ndazibandakanya kolu phando. Ngako oko ndinika imvume yokokuba ndingagocwagocwa ngokuthi kusetyenziswe umatshini wokushicilela. Kwaye ndiqonda ngokupheleleyo ukuba iziphumo zolu phando zingapapashwa, kodwa igama lam alisayi kukhankanywa. Ndiyaqonda okuba ekupheleni kophando amacwecwe okushicilela ayakucinywa.

Ithuba lokuba ndibe nemibuzo ndiliniqiwe, kwaye nemibuzo leyo ipendulwe ngokufanelekileyo nokwanelisayo.

PARTICIPANT

RESEARCHER

WITNESS

PLACE

DATE

U.S. BIBLIOTEK