NEEDS EXPERIENCED BY PERSONS WITH LATE STAGE AIDS

by

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It is hereby declared that this is my own work both in content and execution.

FRED RABBETS

Needs experienced by persons with late stage AIDS.

Prepared in partial fulfilment of the criteria for a Masters degree in Clinical Psychology through the University of Zululand by: Fred Rabbets, Intern Clinical Psychologist.

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Introduction

This report documents a qualitative description of the special needs expressed by persons with late stage AIDS in the Richards Bay area. A phenomenological research design and methods were employed to impose rigour on this event.

Once the needs of persons with late stage AIDS had been made explicit, these were collated with services rendered or planned through state and welfare structures in the Richards Bay area[1] in an effort to identify salient unfulfilled needs that could be addressed through the establishment of an AIDS Care Centre. This provided important cues regarding the types of services and facilities required at the AIDS Care Centre. Additionally the unstructured interviews employed in the research provided the interviewees with an opportunity to suggest a format of care at the AIDS Care Centre that would be most suitable for them.

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[1] See Appendix 5 for a detailed account of services and facilities providing treatment for persons with late stage AIDS in the Richards Bay area prior to the establishment of an AIDS Care Centre.

Chapter one provides an account of the events preceding and accompanying the research, a brief motivation and definitions of key terms. Chapter two consists of a literature review of models of care for persons with HIV/AIDS as well as recent quantitative and qualitative research regarding the needs of persons with late stage AIDS.

This is followed by an overview of the research design (chapter three), a step-by-step revision of the actual research (chapter four), a summary of the generative themes (chapter five) and an evaluation and summary (chapter six).

Acknowledgements

The following organisations in the Richards Bay - Empangeni area participated in this study:

- the AIDS Training, Information and Counselling Centre (ATICC) in Empangeni,
- ALUSAF (Richards Bay),
- Richards Bay Minerals,
- Mondi (Richards Bay),
- Portnet (Richards Bay), and
- the Richards Bay Coal Terminal.

Their support in making both the research and subsequent establishment of an AIDS Care Centre in the Richards Bay area possible is greatly appreciated.

Impetus for the research and related

events:

Persons with late stage AIDS increasingly requested terminal care from the clinics at companies such as ALUSAF, Richards Bay Minerals and the Richards Bay Coal Terminal in the Richards Bay area during 1994 and 1995. Since these clinics are not equipped to provide palliative care, the heads of the clinics (among them Sr. Van Vuuren at the Richards Bay Coal Terminal Clinic, Sr. Bosch at the ALUSAF Clinic and Sr. Daniel at the Richards Bay Minerals Clinic) indicated to Ms. Potgieter, manager of ATICC (Empangeni), that there was a critical need for a centre in the area to provide comprehensive terminal care for persons with late stage AIDS (or an AIDS Care Centre).

Previous research by Mason and Wood (1994) in the Pietermaritzburg area (regarding the needs of persons with AIDS to be addressed through a drop-in centre) emphasized the necessity for underpinning community intervention of this nature on a valid explication of the needs of the target population. Consequently Ms. Potgieter invited the researcher to draft a proposal for an explication of the needs of persons with late stage AIDS in the Richards Bay area. The overall aim of the proposed research was to provide informed recommendations regarding relevant, valid services and facilities to be provided to persons with late stage AIDS at an AIDS Care Centre in the Richards Bay area.

The research proposal (Appendix 7) recommended a qualitative research design using phenomenological research methods to provide a valid explication of the needs of persons with late stage AIDS in the Richards Bay area. The decision to use a qualitative research design and phenomenological research methods is motivated in detail in chapter three.

The proposed research was approved by representatives of ATICC (Empangeni), the company clinics and other interested parties (such as Dr.

Louis de Klerk from the University of Zululand) at a joint meeting at ATICC (Empangeni) on the ninth of December 1995. The representatives of participating organisations who could not attend the meeting were faxed copies of the research proposal and requested to provide feedback to ensure unanimous support for the proposed research.

On approval of the proposed research, ALUSAF (Richards Bay) provided a grant to fund both the research and subsequent establishment of the proposed AIDS Care Centre. ATICC (Empangeni) administered the funding and execution of the research and the subsequent establishment of the AIDS Care Centre. Due to budgetary constraints (the grant provided by ALUSAF was only available until the thirty first of January 1996) the proposed research had to be completed within the following two months (from December 1995 to January 1996).

On completion of the research, feedback was given at a meeting of the representatives of all the participating organisations at ALUSAF on the second of February 1996 (a complete copy of the generative themes in the original research report presented at the meeting is attached as Appendix 7). At this meeting some of the representatives of the company clinics expressed dissatisfaction with the research results. This stemmed primarily from the fact that the most prevalent recurring need expressed by interviewees with late stage AIDS in the research was a desire to remain distracted from constant awareness of their illness. The researcher proposed activities and facilities at the AIDS Care Centre (as suggested by the interviewees) that would facilitate their distraction to improve their coping. The dissatisfied representatives (who were caregivers providing pre- and post-test counselling at clinics) construed the need for distraction as a form of denial that the persons with HIV/AIDS should be vigorously challenged and confronted with and believed that it should not be accommodated in the format of care at the proposed AIDS Care Centre. The merit of distraction, as a passive form of coping, versus more active coping methods is discussed in more detail in chapter two and five.

Additionally there was criticism regarding the size of the sample used in the research. In line with the use of a qualitative, exploratory research design the sample was limited to twelve interviewees. Some representatives correctly pointed out that this sample was not statistically representative of the study population. The validity and representativeness of the sample used in this exploratory study are discussed in detail in chapter three.

Eventually the research and subsequent recommendations were approved by all the participating organisations and ATICC (Empangeni) commenced establishing the AIDS Care Centre at a disused building provided by Mondi (Richards Bay).

The use of 12 protocols for the original inquiry versus 3 for the current research report.

The generative themes in the original research report resulted from an explication of twelve protocols gained through unstructured interviews during the course of the research. Once the contract research had been completed, the research report, protocols and linguistic translations of the interviews were saved on a fixed disk on a computer as well as on back up copies on stiffies (floppy disks). Additionally full copies of the original research report were available through all the participating organisations.

During July 1996 the researcher was involved in a motor vehicle accident that resulted in permanent damage to the computer and the destruction of most of the back up floppy disks. Consequently the research report, linguistic translations and most of the transcriptions and protocols were lost. Fortunately the researcher could retrieve three of the original protocols from the damaged floppy disks and ATICC (Empangeni) could provide a copy of the original research report.

The original research report did not include systematic references from the generative themes to specific Natural Meaning Units in the explicated protocols. Whereas this was not considered necessary for the report presented to the representatives of the participating companies, it was a requirement for submitting this contract research as a dissertation for a Masters Degree in Clinical Psychology through the University of Zululand. Since most of the original protocols and linguistic translations were destroyed at this point in time, the reference system could not simply be attached to the original generative themes. The only solution was to use the three linguistically translated protocols that could be salvaged to create new generative themes that would then have valid references to Natural Meaning Units and linguistic translations in the protocols.

Consequently the researcher did this and the themes generated from these three protocols are presented under "Generative themes" in chapter six of this report. Fortunately three protocols represent a valid sample in terms of phenomenological research (Kruger, 1988). The use of three of the original twelve protocols to redevelop generative themes served as a validation of the research. The generative themes obtained in this way reflect the same concerns expressed in the same sequence as the generative themes in the original research. The reader can compare this in detail since the original themes are cited in full in the original report contained in Appendix 8. The original sample of twelve protocols and current one of three do, however, have shared limitations and biases discussed in more detail in chapter three and six.

Motivation:

The prevalence of AIDS and circumstances of care in the Richards Bay area:

The health needs of persons with late stage AIDS are particularly important in Kwazulu-Natal where the prevalence of HIV-infection, estimated at 18.23% of a random sample of births recorded during 1995 at hospitals, is the highest in South Africa and the infected population is approaching the syndromal phase of the disease (Directorate: HIV/AIDS and STD Programme, 1995)[2]. During 1994 ten percent of the population of Kwazulu-Natal were estimated to be seropositive for the Human Immunodeficiency Virus (Mason and Wood, 1994).

Additionally developmental and psychosocial issues (such as poverty, entitlement and access to food, medical care, etc.) confound care provision in Kwazulu-Natal and particularly in the Richards Bay area with the already under-served person with HIV/AIDS often receiving inadequate medical and mental health care as well as having limited access to legal resources and facing the likelihood of social stigmatization and isolation with little provision for institutional support or welfare. The plight of persons with late stage AIDS is often very severe in these disadvantaged communities, compelling community intervention to address their suffering (Lindegger and Wood, 1995).

Moreover, despite South Africa's enormous mental health care problems, psychological services are generally a luxury and accessible to the wealthier minority only (Heyns, 1992). The AIDS epidemic has further highlighted this way in which psychology as a profession has marginalized itself from the majority of South Africans and restricted its relevance in a future national health service. The task of meeting the biopsychosocial needs of

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[2] Compared to 1994's rate of 14.35% this indicates a considerable increase of almost 30% per annum.

persons with HIV/AIDS currently generally falls upon nonspecialist health care workers in the Richards Bay area, as elsewhere in South Africa. (Lindegger and Wood, 1995). Unfortunately this often results in inadequate mental health care to persons with AIDS. The counsellor training programmes provided by AIDS Training Information and Counselling Centres and other AIDS-specific programmes have been criticized for being inadequate and inconsequential (Heyns, 1992; Mason, 1993). In itself this necessitates additional efforts at assessing and addressing the needs of persons with late stage AIDS.

While many of these problems stem from the inherent developmental and psychosocial problems in many communities in the Richards Bay area contributing to limited access to medical and mental health care in general, it also reflects the fact that AIDS constitutes much more than a terminal medical disease. It is enmeshed in psychological, social, cultural, political, and economic contexts. In this inquiry, for example, fear of community intolerance often resulted in lack of help seeking behaviour that aggravated medical and mental health problems experienced by persons with late stage AIDS. In terms of the comprehensive nature of the experience of HIV/AIDS, this research as a qualitative, exploratory inquiry is an ideal format for making explicit the holistic impact of AIDS on a person in the Richards Bay area (Temoshok and Baum, 1990).

Prevention versus treatment:

As survival periods from the time of an HIV positive diagnosis continue to increase, there is a growing concern for the quality of the life that has been extended. Thus, while searching for cures for AIDS and methods of prevention and control, it is important that our health and social system develop strategies to facilitate adjustment and enhance the well-being of persons with late stage AIDS (Friedland, Renwick and Mc Coll, 1996).

In the 1980's health professionals focussed on viral studies and learned to treat the numerous opportunistic diseases associated with AIDS. Since then anti-retroviral medications, experience, and increased therapies have increased life expectancy. Scientific treatment has resulted in a course of illness with AIDS, as a life threatening disease, that is similar to chronic illnesses and the mental health, neuropsychiatric, and physiological responses to AIDS have proliferated. This has increased the demand for extended terminal care for persons with AIDS and a better understanding of their needs (Hurley and Ungvarski, 1994).

Moreover, it is self-evident that while there is no cure for AIDS or HIV, social support and counselling as well as preventive measures forms the major focus of helping profession efforts at combatting the disease. Unfortunately there is traditionally an enormous focus on prevention and HIV testing, which only scratches the surface. As long term survival becomes a reality, as interventions for opportunistic infections increase and as prophylactic treatments become more effective, the whole question of the quality of life, coping and the emotional strength of the person with AIDS will demand greater attention (Sherr, 1990)[3]. An in-depth understanding of the experienced needs of persons with late stage AIDS is an essential prerequisite for the development of valid, appropriate counselling programmes to improve their quality of life and ability to cope with the disease (Sliep, 1994).

The argument has been made that the psychosocial needs of persons with AIDS should be no different from those of people with other terminal

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[3] Broomberg, Steinberg, Masobe and Behr (1991) estimate that by the year 2000 there will be more AIDS patients who need hospitalization than there are hospital beds available in South Africa, with a direct cost of between R686 million and R1.2 billion for that year. Obviously at least a large portion of the South African health care system will have to be directed to HIV/AIDS related care at that point and further in the future.

diseases such as cancer, degenerative neurological conditions and Alzheimer's disease that respond equally badly to treatment. AIDS is, however, qualitatively different. Since it is often acquired through drug use, homosexual activity, extramarital liaisons or prostitution it carries a profound stigma. Moreover, persons with AIDS tend to be young and the young do not expect to die. Additionally changes in body image, self-esteem, daily habits, sense of control and general lifestyle due to AIDS can be rapid and precipitous. These changes are usually more dramatic than in people with other potentially terminal diseases in whom decline may be more gradual. Persons with AIDS also generally receive far less psychosocial support from families and friends than persons with other terminal diseases (O'Rawe, Amenta, and Tehan, 1991; Lindegger and Wood, 1995).

Additionally the research is aimed at enhancing the empathic understanding of all health professionals working with persons with AIDS by providing an unbiased description of the human experience of late stage AIDS in all its biological, psychological, and spiritual dimensions. Hopefully this will allay preconceived attitudes and prejudice among both the public and those in the helping profession towards persons with AIDS evident in practice and in recent research (Van der Berg, 1992; Eagle and Bedford, 1992).

Attitudes towards AIDS are particularly important in terms of the role of psychosocial cofactors in disease progression. Research shows a significant correlation between social support, subsequent emotional adjustment and the course of the disease. Social support and emotional adjustment exert a mediatory, stress-buffering effect on persons with HIV/AIDS that can delay the onset of full-blown AIDS and, in cases of late stage AIDS, increase longevity (Temoshok and Baum, 1990; Schlebush and Cassidy, 1993; Miller, 1988; Greznikoff, Grummon, Rigby, Orr, and Procidano, 1994; Ganster and Victor, 1988; Chaung et al., 1989). The protocols and explicated generative themes of this qualitative inquiry (see Appendix 2 and chapter six) support these findings.

A better understanding of the needs of persons with AIDS and the consequent development of better ways to help them cope has preventive implications. Research has shown that the stress induced by having HIV/AIDS prompt attempts to reduce it by engaging in unhealthy behaviours such as unsafe sex and intravenous substance abuse (Thompson et al., 1996). Improving their ability to cope may result in diminished denial and reduce high-risk behaviour that could result in the infection of others or reinfection of themselves (Temoshok and Baum, 1990).

Limited research regarding the needs of persons with late stage AIDS:

Finally, this inquiry was motivated by the limited research involving either qualitative or quantitative studies aimed at uncovering or assessing the needs of persons with AIDS (Berk, Baigis-Smith, and Nanda, 1995; Hurli and Ungvarski, 1994, see also literature review). Thornton and Flynn (1993) mention in this regard:

> *"Resources for the psychological and psychiatric management of people with HIV infection are relatively generous in many pattern I countries, but judging from the disappointingly small number of studies presented at the IXth International Conference on AIDS, little of this work is described or evaluated. The very small number of reports from developing countries which refer to the psychological factors presumably reflects more pressing priorities in these areas of the world".*

In conjunction with improvements in the biomedical treatment of AIDS and its consequent more chronic course, this demands further investigation into the needs of persons with AIDS. The accompanying psychological and psychosocial aspects of AIDS, an area of inquiry that has been neglected - particularly in the third world, forms an intrinsic part of this explication of the comprehensive needs of persons with late stage AIDS.

In emphasizing the importance of psychosocial aspects of AIDS, Schofferman (1988, p. 445; in Hurley and Ungvarski, 1994) states:

> *"...psychosocial issues are so complex that they often dominate the clinical picture of the person dying with AIDS."*

Paradoxically the psychosocial aspects of AIDS are often the most neglected dimension of this illness in its treatment. Interviews with persons with AIDS indicate that, although their medical needs are addressed, their psychological needs are not (Temoshok and Baum, 1990).

Aim

The purpose of this idiographic study is to explicate the needs experienced by persons with late stage AIDS in the Richards Bay area. Their comprehensive needs are then collated with facilities and services available to them in this area. Recommendations drawn from this collation underpinned decisions regarding facilities and treatment to address their unmet needs at an AIDS Care Centre.

Definitions of key terms

In the research, the following are working definitions of key terms:

- A "phenomenological explication" refers to a praxis for making explicit what persons with late stage AIDS can communicate regarding their pre-reflective experience of their comprehensive needs. Pre-reflective experience refers to the data of their awareness; their experienced needs as opposed to their interpreted needs (Edwards, 1991).

- "Needs" refers comprehensively to any wishes or wants persons with late stage AIDS experience. The holistic impact of AIDS (ranging from physical deterioration to psychological and spiritual distress, and the effects of family and community disintegration and intolerance) on persons with late stage AIDS implies that their related needs could incorporate any dimension of human experience.
- "Late stage AIDS" refers to a positive HIV antibody test with a CD4 cell[4] count below two hundred cells per cubic millimetre and/or the presence of an AIDS defining disease. AIDS is the terminal phase of HIV disease and is characterized by signs and symptoms of one or more of a variety of conditions resulting from severe immune deficiency. A CD4 cell count of less than two hundred cells per cubic millimetre usually denotes the stage of severe immune deficiency. Many persons, however, may not develop AIDS defining diseases until their CD4 cell count is well below two hundred cells per cubic millimetre (Pinkey-Atkinson, 1995).

Practically the selected respondents were, where possible, those who

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[4] HIV has an affinity for the immune cells such as CD4 cells, macrophage cells, and dendritic cells. The CD4 cells have critical functions in the control and coordination of the immune response and damage and destruction of these cells ultimately result in impaired immunity with a resultant defect in the protective and healing function of the immune system. The chief marker used to assess immune status in HIV infection is the CD4 cell, also referred to as the 'T4' or 'helper' cell, count. The impairment of the immune system is not an 'all or nothing process', but rather a slow and gradual deterioration often spanning five to ten years. Persons have a range of responses to immune deficiency, some becoming symptomatic earlier than others.

qualified in terms of their presenting symptoms and CD4 cell counts for special care in a terminal comprehensive care centre[5]. For practical purposes in terms of the focus of this inquiry the progression of HIV is divided into the following three phases (adapted from Pinky-Atkinson, 1995), with the research explicating the needs of persons in the late stage of the third and final phase[6]:

I. **Early, asymptomatic phase of HIV infection**: After infection there is usually a history of an initial primary HIV infection reaction, concurring with seroconversion. This initial condition, ensuing four to eight weeks after infection, presents with an infectious mononucleosis type illness characterized by symptoms such as fever, pharyngitis, arthralgia, maculopapular rash, etc. The patient usually remains well and overtly healthy for a long period of time, on average from five to seven years[7] and the CD4 count may remain within the normal limits (five hundred to two thousand cells per millilitre) but usually starts to slowly decrease within the first two to three years after infection.

II. **Mild to moderate opportunistic infections**: Evidence of early immune deficiency, usually starting between five and seven years after being infected with HIV, include herpes simplex and herpes zoster, mouth ulceration, infective skin conditions, delay in healing of some sexually transmitted diseases, mild oral and vaginal thrush, pulmonary

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[5] See Appendix 1 for the Annexure of the Centre of Disease Control (USA) case definition of AIDS. Additionally the criteria established by Mc Cormick, Thomas, Inui, Deyo, and Wood (1991) for patients amenable to terminal care were applied when possible.

[6] See Appendix 2 for WHO staging system for HIV infection and disease (Evian, 1993, p. 91).

[7] In extreme cases this period may vary from three to 15 years (Sliep, 1994). Approximately 80% of HIV infected people will have developed AIDS within 12 years of acquiring the virus (Lindegger and Wood, 1994).

tuberculosis, bouts of short, lasting diarrhoea, and some weight loss may occur. These conditions usually appear when the CD4 count drops below three hundred and fifty cells per millilitre and can typically be effectively treated with patients returning to good health for long periods of time.

III. Severe opportunistic infections - AIDS: As the immune state becomes more dissipated, the above conditions occur more frequently and more severe infections appear. Typical AIDS associated symptoms include pulmonary and extrapulmonary tuberculosis, pneumocystis carinii pneumonia, severe oral thrush, meningitis, severe and lasting diarrhoea, muscle wasting and weight loss, dementia, unexplained fevers and night sweats and eventually caposi sarcoma, toxoplasmosis and various other AIDS related infections.

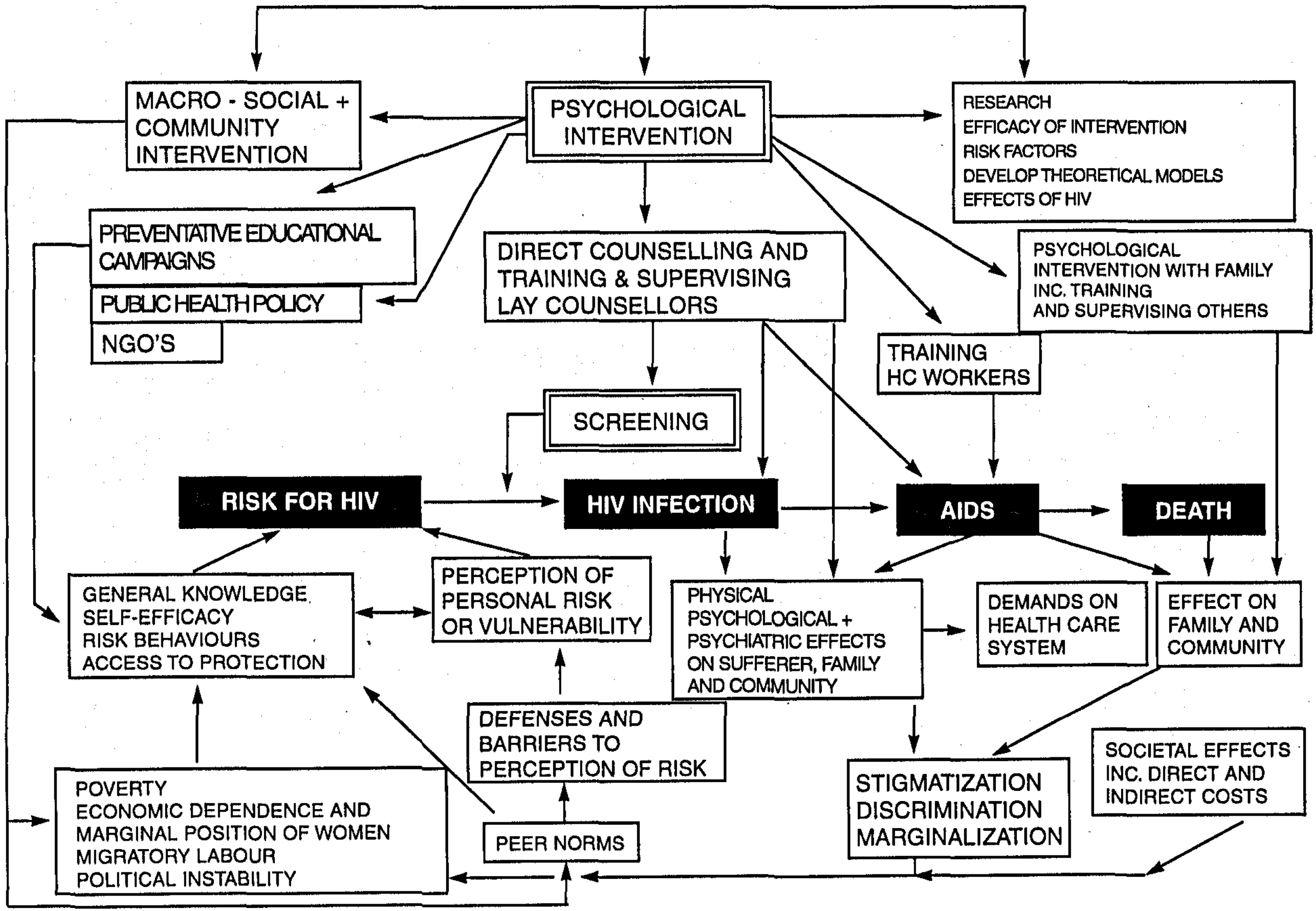
- The "AIDS Care Centre" (ACC.) is regarded, in line with official guidelines, as a comprehensive tertiary care facility for very and terminally ill patients with AIDS. Care and interventions provided at the ACC., as facilities and treatment, should be underpinned by a holistic approach and include biomedical, psychological, spiritual, and alternative care and care providers (NACOSA, KZN, Provincial AIDS Implementation Plan, 1995). The comprehensive nature of the expressed needs of the persons with late stage AIDS made explicit in the generative themes in chapter five confirms the validity of this conviction.

2

Literature review of the psychological sequelae and needs associated with AIDS and models of care:

Consequences of and factors affecting the development of AIDS:

The effects of HIV infection include, as mentioned under "Definitions of key terms" in chapter one, the deteriorating physical and mental health of the person, disintegration of the family and decline of its socioeconomic well being, stress on the community's health services and a deterioration in its economic status (Mason and Wood, 1994). Figure 1 (Lindegger and Wood, 1995, p. 2) illustrates the impact of AIDS on a person and an overview of the factors affecting the development thereof.


PSYCHOLOGICAL INTERVENTION
MACRO - SOCIAL + COMMUNITY INTERVENTION
RESEARCH
EFFICACY OF INTERVENTION
RISK FACTORS
DEVELOP THEORETICAL MODELS
EFFECTS OF HIV
PREVENTATIVE EDUCATIONAL CAMPAIGNS
PUBLIC HEALTH POLICY
NGO'S
DIRECT COUNSELLING AND TRAINING & SUPERVISING LAY COUNSELLORS
PSYCHOLOGICAL INTERVENTION WITH FAMILY INC. TRAINING AND SUPERVISING OTHERS
TRAINING HC WORKERS
SCREENING
RISK FOR HIV
HIV INFECTION
AIDS
DEATH
GENERAL KNOWLEDGE
SELF-EFFICACY
RISK BEHAVIOURS
ACCESS TO PROTECTION
PERCEPTION OF PERSONAL RISK OR VULNERABILITY
PHYSICAL PSYCHOLOGICAL + PSYCHIATRIC EFFECTS ON SUFFERER, FAMILY AND COMMUNITY
DEMANDS ON HEALTH CARE SYSTEM
EFFECT ON FAMILY AND COMMUNITY
DEFENSES AND BARRIERS TO PERCEPTION OF RISK
STIGMATIZATION
DISCRIMINATION
MARGINALIZATION
SOCIETAL EFFECTS INC. DIRECT AND INDIRECT COSTS
POVERTY
ECONOMIC DEPENDENCE AND MARGINAL POSITION OF WOMEN
MIGRATORY LABOUR
POLITICAL INSTABILITY
PEER NORMS

Areas of psychological research on HIV/AIDS:

While most psychological research on HIV/AIDS to date has been concerned with risk factors for HIV and intervention to reduce the hazard of infection, attention is increasingly being given to people afflicted with HIV/AIDS. Within the scope of the general areas of need of persons with AIDS (mentioned in detail further in this chapter) psychological research has addressed three major issues:

- the psychological, psychiatric and neurological sequelae of AIDS,
- the effects of stereotypes about and stigma surrounding AIDS,
- counselling and psychotherapy with AIDS patients (Lindegger and Wood, 1995).

For the purposes of the present study as an explication of the needs of persons with late stage AIDS with a view to developing a relevant format of care, research on the psychological and psychiatric sequelae, needs experienced and coping styles, and counselling and psychotherapy with persons with AIDS is of particular relevance. Therefore the literature will focus particularly on literature regarding these areas of research.

Limitations of psychological research on AIDS:

Within the abovementioned three areas, psychological research on the needs of persons with AIDS have been limited to studies of hospitalized AIDS patients or clients seen in clinics and focussed primarily on men who had sex with men (Snyder, Reyner, Schneidler, Bogursky and Gomez, 1992;

Chaung, Jason, Pajurkova and Gill, 1992; Temoshok and Baum, 1990, Hurley and Ungvarski, 1994). Consequently literature identifying the mental health needs of persons with AIDS in general is severely limited.

Other studies assessed quality of life, quality of care, stress, and patients reactions to their care, which indirectly describe some of the patients' health care needs, but not necessarily those that are unique to the AIDS population (Berk, Baigis-Smith and Nanda, 1995; Mc Cann, 1991, Tolley et al., 1991; Rubin and Wu, 1988; Fournier and Giraud, 1990; Shevach et al., 1990; Benedict et al., 1990; Butters et al., 1993).

Additionally the validity of generalizations about the needs of persons with HIV/AIDS on the basis of studies within different study communities is by definition questionable. Doka (1993, p. 32) states in this regard that the course of HIV/AIDS is different for each individual and is influenced by the actual experience, in terms of preceding psychosocial experiences and preexisting psychological problems. Berk, Baigis-Smith and Nanda (1995) conducted a cross-sectional descriptive inquiry with three hundred and eighty six patients in hospital, outpatient, home care and long term care settings to test for between-setting differences on the Health Care Needs scale for Patients with HIV/AIDS (Berk and Nanda, 1994; Berk, Poe and Baigis-Smith, 1992). The findings of this study supports Doka's (1993) finding by suggesting that there is no consistent trend or distinctive pattern of health care needs in the various settings for persons with HIV/AIDS. The researchers emphasize in this regard that the precipitous changes in physical and emotional health status throughout the trajectory of the disease and the concomitant psychosocial and physiological problems present a challenging complexity of the health care needs of persons with HIV/AIDS that refute generalizations. Accordingly Flaskerud (1992) emphasizes that care and treatment for persons with HIV/AIDS should vary from one setting to another and across diverse clinical manifestations of the disease.

The following studies therefore have limited relevance to the present research as an explication of the needs of a predominantly heterosexual population of persons with AIDS receiving severely limited mental health care. Chapter six contains a critical comparison of the findings of these studies with the present research.

The psychological and psychosocial sequelae of HIV/AIDS, associated needs and coping:

The psychological sequelae of HIV/AIDS and associated needs:

AIDS is a life crisis for the individual. From the moment of diagnosis, persons with AIDS must face the relative certainty of an early death as well as the uncertainty of medical care and treatment options and the overwhelming sense of stigmatization and social rejection. They must also struggle with illness-related fears, such as disability, increased dependence, loss of body control, and pain. Medically, persons with AIDS have to cope with a range of problems from the likelihood of opportunistic infections to central nervous system (CNS) disorders that can include blindness, dementia, and organic mood disorders (Grummon et al., 1994).

Research has shown that HIV/AIDS results in severe enough levels of anxiety to qualify for diagnoses of major depressive episodes, adjustment disorders and anxiety disorders (Lindegger and Wood, 1995). Given the pervasive nature of the continuing stressors that face people with AIDS, it is not surprising that so many appear to be in psychological distress. Symptoms may range from those that are relatively minor, such as apathy, guilt, helplessness, and hopelessness, to severe anxiety disorders, psychoses, delirium, dementia and major depression, sometimes accompanied by suicidal ideation. Additionally there could be pre-existing psychological disorders typical of some high risk groups such as personality disorders with intravenous drug users, anxiety or depressive disturbances in homosexuals and psychoses in psychiatric patients (Grummon et al., 1994).

It has been shown that the amount of psychological distress experienced relates inversely to the progression of HIV/AIDS, with the asymptomatic phase being accompanied by higher levels of distress among persons with HIV-disease than AIDS. This is probably a function of the anxiety surrounding the uncertainty of the implications of being seropositive for the HIV virus (Lindegger and Wood, 1995; Thompson et al., 1996).

Belyaeva et al. (1993) identified the following themes as central concerns expressed by persons on being informed of having HIV in interviews with medical doctors in Russia:

- fear of breach of confidentiality,
- thoughts of the inevitable death due to lack of effective treatment,
- apprehensions regarding the possibility of passing the infection on to loved ones.

Additionally these researchers stress that the most significant emotional problems and needs experienced by persons with HIV are linked to the social implications of their illness (loss of job, being an outcast socially, etc.) and that they are less concerned wit their health. The tendency of persons with HIV/AIDS to experience more distress around the psychosocial implications of their illness than its biomedical aspects does not seem to be a function of the progression of the disease and is evident in the late stage of AIDS (Schofferman, 1988 in Hurley and Ungvarski, 1994; Thompson, 1996). Living with HIV/AIDS possibly results in better coping with these psychosocial concerns and increased acceptance culminating in less anxiety in spite of medical deterioration (Anderson et al., 1991).

Research by Grassi et al. (1995) shows that HIV infected patients have specific psychological and psychiatric needs in comparison with uninfected patients referred with serious illness to a general hospital. Referring doctors requesting a psychiatric consultation judged that there was a higher prevalence of maladaptive reactions to illness in persons with HIV/AIDS than in those who were HIV-negative.

Additionally patients with HIV and related syndromes requested a psychiatric consultation for themselves in a higher percentage than non-HIV patients. This indicates that, unlike those affected by other serious physical illnesses, patients affected by HIV and related syndromes are aware of their serious condition and actively search for psychological help as the perspective of loss, isolation, rejection and death is so strong.

With regard to psychiatric diagnoses, patients with HIV/AIDS were shown to have a higher prevalence of psychoactive substance abuse (mainly opiate) disorder, which represented one of the most important risk factors for HIV in this study in Italy. Patients with HIV/AIDS also reported a higher prevalence of depressive disorder, not otherwise specified, and of dementia than non-HIV patients (see graph 1 and 2). The researchers ascribe the first result to the difficulty in categorizing affective symptoms of patients with HIV/AIDS in criteria consistent with a specific then DSMIII-R diagnosis. With reference to this, Seth et al. (1991 in Grassi et al., 1995) finding abnormal CT brain scan in about 80% of patients with HIV/AIDS with a diagnoses of depression, pointed out that frequently the distinction between organic and functional mental disorders is not so easy. The extensive involvement of the nervous system in HIV infection has, however, been shown in a higher percentage of HIV infected patients reporting more symptoms of generalized cognitive impairment and behavioural problems than in HIV uninfected patients. These symptoms, typical of AIDS related dementia, presents a serious problem for health staff members involved in caring for patients and often leads to requests for specialized help in their management. According to these researchers the symptoms associated with AIDS related dementia correlates with a higher psychosocial service utilization and will probably present a focus for treatment and care at an AIDS Care Centre. In conclusion Grassi et al. (1995) emphasizes that this stresses the necessity of a holistic, biopsychosocial approach to the treatment of persons with AIDS that incorporates collaborative work between psychiatry and other services in a multidisciplinary format.

Chart 1: Primary reason for referral

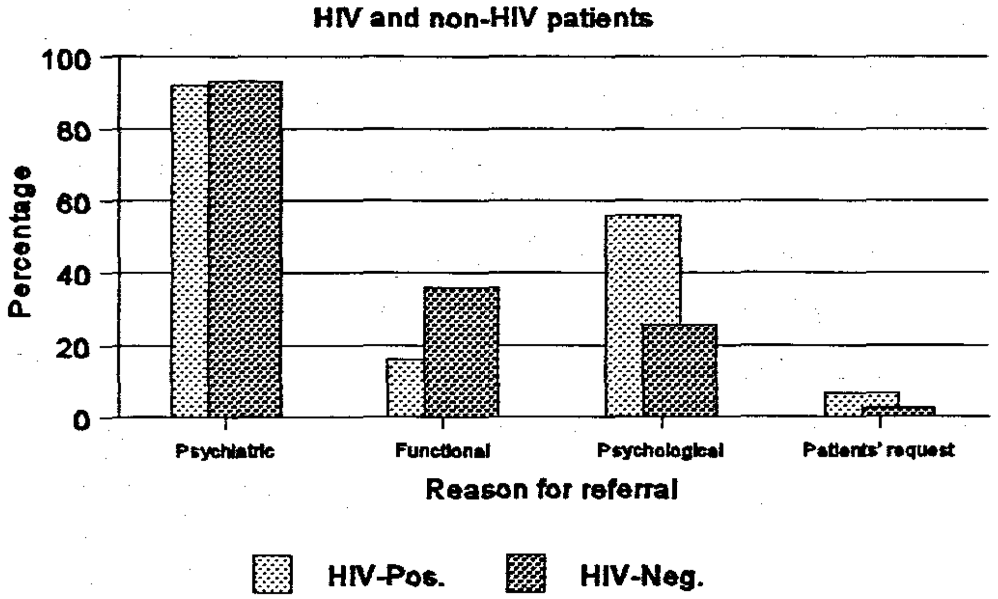
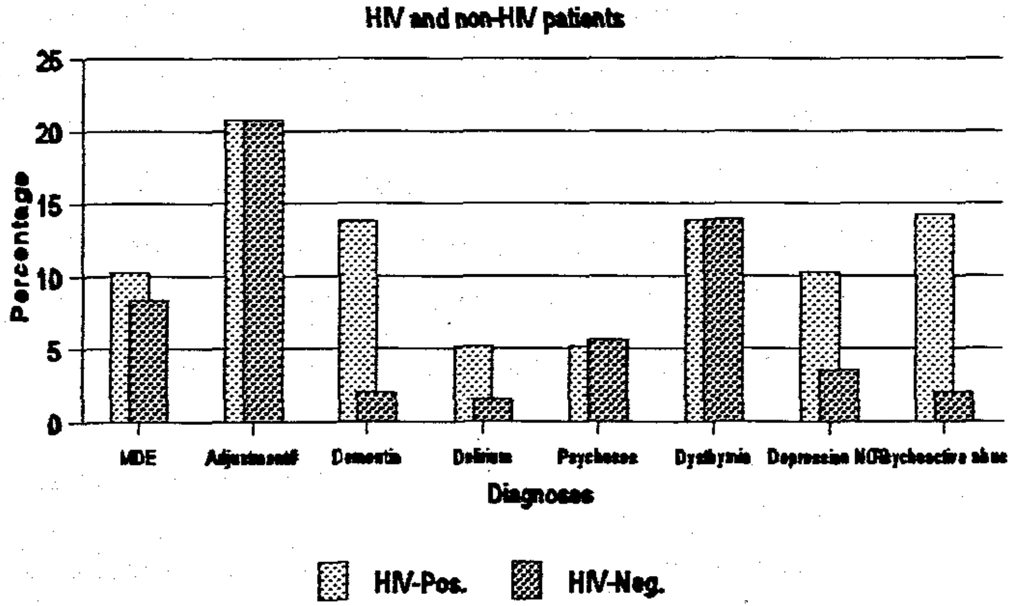


Chart 2: Main DSM3R diagnoses



Hurley and Ungvarski (1994), in support of Grassi et al. (1995) identified memory deficit and depression as the most significant consequences of AIDS on the basis of demographic, psychosocial and physiological data collected from a chart review form on admission of patients to a home care agency in New York (see table 1).

Memory deficit related significantly in this study to inability to manage treatment and resulting medication non-compliance and depression. Memory deficit has also been shown to be significantly related to alcohol abuse and depression during the earlier stages of the disease among HIV seropositive men (Thompson, 1996; Martin, Robertson and Sorenson, 1993).

Additionally this research demonstrates the effects of memory deficit and depression on other health related variables. The researchers point out that caregivers should be alert to the fact that decline in physiological functions controlled by the central nervous system (such as loss of vision, hearing and bowl and bladder control) is often accompanied by related memory deficit, cognitive impairment, depression and other psychological changes. The significant phi coefficients (with phi coefficients of .20 and above considered significant due to the large sample size of N=244 in this study) for depression and memory related symptoms and behavioural limitations or areas of need for care are reported on in tables 2 and 3. Specifically, wandering, bowel incontinence, visual impairment, hearing impairment, difficulty walking, sleep disturbance and bladder incontinence were all related to memory deficit.

The association between memory deficit, depression and related psychological and physiological symptoms is especially significant if one considers that research by Berk and Nanda (1994) indicates that there is no relationship (r = 0.06) between patients' perceived psychosocial needs and their physiological needs *as perceived by nurses*. Both these studies underscores the importance of a holistic approach as the basis for planning care for a population of persons with AIDS. Hurley and Ungvarski (1994) state in this regard that:

> *"A care plan that focuses on the physiological needs and ignores the environmental and mental health needs of clients is inadequate"* (p. 118).

Table 1

Psychological symptoms on admission			
	No. (%) of Cases		
Diagnosis	Women N=75	Men N=169	Total N=244
Memory deficit	20 (26.7)	64 (37.9)	84 (34.4)
Depression	21 (28.0)	46 (27.2)	67 (27.5)
Anxiety	19 (25.3)	46 (27.2)	65 (26.6)
Impaired judgement	11 (14.7)	34 (20.1)	45 (18.4)
Substance abuse	17 (22.7)	27 (16.0)	44 (18.0)
Sleep disturbance	10 (13.3)	29 (17.2)	39 (16.0)
Agitation	7 (9.3)	19 (11.2)	26 (10.7)

Table 2

Depression and related variables (N = 244)			
Related variable	X	ϕ	ρ
Bathing	15.10	.24	.001
Shopping	12.66	.20	.001
Cleaning home	13.74	.23	.001
Treatment management	27.65	.33	.001

Depression and related variables (N = 244)			
Meal preparation	14.32	.24	.001
Medication compliance	46.54	.43	.001
Bowel incontinence	13.98	.23	.001
Bladder incontinence	10.51	.20	.001

Table 3

Memory deficit and related variables (N = 244)			
Related variable	X	ϕ	ρ
Treatment management	21.66	.30	.001
Medication compliance	48.32	.43	.001
Depression	63.99	.50	.001

The psychosocial consequences of AIDS and related needs:

In terms of the psychosocial aspects of HIV/AIDS, stereotypes and stigmatization have emerged as major variables complicating the experience of AIDS and the process of coping and dying with it. AIDS shares many of the features of other terminal diseases, as is apparent from findings discussed in more detail further on, such as the fact that both AIDS and cancer patients who adopt more positive coping mechanisms are likely to survive longer with the disease. AIDS is however separated from other terminal and chronic illnesses by its marginal status in the economy of disease seen in the ambivalent or outright oppositional attitudes of the general public, family members and health care workers towards people with HIV or AIDS (Van der Berg, 1992, Lindegger and Wood, 1995).

Research by O'Rawe, Amenta and Tehan (1991) indicates that one of the most notable experiences of persons with AIDS is social isolation, often extending to isolation from the family of origin. The resulting lack of social support probably correlates significantly with negative coping styles or avoidance and the prevalence of depression and anxiety among persons with AIDS (Lindegger and Wood, 1995).

In addition to the psychosocial burdens common to other terminal diseases, such as adjusting to the diagnosis, preparing for loss and bereavement, providing necessary care and shifting family roles, families and friends of persons with AIDS frequently need help when dealing with fears of infection, with acceptance of the patient's sexual orientation, possible issues of infidelity, and with stigma and discrimination. All of this contribute to additional conflict, need for reconciliation and isolation and distress for the person with AIDS.

Additionally persons with AIDS have to cope with lack of health insurance and inadequate financial resources. This agrees with the general finding that persons with AIDS experience helplessness, guilt, loss of control, denial, anger, depression, anxiety, bereavement due to multiple losses, legal, financial, social and medical problems, loss of income and unemployment and housing concerns. This amounts to loss of control over nearly every aspect of their lives. According to these researchers this contributes to the primary need for increased social support experienced by persons with AIDS.

Needs of persons with AIDS:

Against this background, the comprehensive needs of persons with HIV/AIDS includes the following:

- need for physical and mental health care,
- need for social and economic support,
- need for maintenance of the family's structure and function,
- and need for the maintenance of community stability (Panos Institute, 1992 in Mason and Wood, 1994).

While all persons with HIV/AIDS have the abovementioned needs, a 1992 study in Uganda identified the following five areas of need created by HIV/AIDS in underdeveloped countries:

- basic food and housing,
- income or economic assistance,
- medical care,
- accurate information and health education,
- HIV testing facilities, and

- psychological and social support (Mason and Wood, 1994).

Mason and Wood (1994) identified material assistance and emotional or social support as needs expressed across the continuum of HIV infection and by all persons with AIDS in semi-structured interviews conducted in the Pietermaritzburg area to establish the needs of persons with HIV/AIDS regarding a drop-in centre. Some differences regarding the needs were noted:

- Those respondents who were ill experienced more concern with issues such as child care and medical facilities. They also showed more concern with material needs such as accommodation since they felt that they would soon be forced to leave their families due to increasing needs for medical attention. Correspondingly accommodation emerged as the most serious problem experienced by adults with AIDS in research by Marazzi et al. (1994). Accommodation problems were linked to lack of support and problems experienced by persons with AIDS in their relationships with potential caregivers such as families, friends or spouses.

- Those who were reasonably healthy almost all expressed the urgent need to acquire income generating skills. These were deemed important not only as a means of earning money, but also as a way of gaining direction, meaning and a sense of self-fulfilment in their lives. Linked with this several respondents expressed the desire to become HIV/AIDS educators and counsellors.

- A common need expressed by all the respondents, however, was for friendship and social support.

In terms of activities of daily living, Hurley and Ungvarski (1994) found that 95 % of their male and female sample of adult outpatients with AIDS required assistance with laundry and , 93% needed shopping assistance, and

80% needed help with meal preparation. Fifty four percent needed assistance with both bathing and treatments. Although these are the needs of outpatients in a Home Care service, it should approximate significant areas of required assistance in a terminal care centre since the sample in this study presented with advanced or late stage AIDS. Additionally community based and inpatient services for persons with AIDS would have to be integrated in terms of the fluctuating course of the disease.

In research with adults with AIDS in Home Care by Marazzi et al. (1994) similar needs regarding the activities of daily living emerged. The services most frequently requested were the preparation of meals (75.5% of the sample), household chores (62.5% of the sample) and help with transport outside the home (70.6% of the sample), especially to reach the day hospital.

In this study an analysis of health care services revealed a wide-spread demand for help with personal care (49% of the sample), and nursing (44.6% of the sample), which was mostly satisfied; whereas the need for rehabilitation (50.9% of the sample) was mostly unmet. Social-recreational services and help in the search for an occupation appropriate to their state of health were requested by one third of the sample in this research. Since the latter presents service requirements that are not unique to a Home Care context (such as transport to a day hospital), it should present salient needs in a terminal care centre for persons with AIDS.

Tolley (1991 in Marazzi, 1994) noted that these problems experienced with activities of daily living increased with the severity of the diagnosis.

Coping with HIV/AIDS:

Response to AIDS is an important dimension of the illness itself, particularly since it is a life-threatening illness where the response may have an impact on the outcome (Ross et al., 1994).

Stress associated with response to AIDS may have direct physiological effects, leading to disease onset or a more rapid progression of the illness through suppressing the immune response. In this regard, research by Mulder (1992) indicated that persons with HIV who sought social support, used problem-focussed coping and less denial experience a smaller decline in CD4 cell count than controls. Additionally having HIV/AIDS, as a stressful event, can prompt individuals to attempt to reduce stress by engaging in unhealthy habits or behaviours such as smoking, alcohol use or unsafe sex. To enhance quality of life and emotional well-being for persons with AIDS, it is important to understand the attitudes, behaviours and resources that lead to successful psychological adjustment in the face of the disease (Thompson et al., 1996).

Social support, as "the feeling of being cared for and loved, valued and esteemed, and able to count on others should the need arise" (Friedland et al., 1996, p. 19) has been shown to be an important reinforcer of positive coping with HIV/AIDS. Since coping and social support are considered to be closely linked, coping strategies may, in fact, determine the appropriateness and effectiveness of supports for AIDS patients as they do for others experiencing stress. Whereas social support has been a strong focus of the stress-outcome paradigm within sociological conceptualizations, coping has been emphasized in psychological models of adjustment to illness (Grummon et al., 1994)[8].

The following general trends have emerged from research into coping with

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[8] "Coping" is generally defined in Psychology texts in cognitive-behavioural terms as "the person's cognitive and behavioural efforts to manage the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources" (Folkman et al., 1986, p. 572 in Grummon et al., 1994).

HIV/AIDS. Active coping approaches have emerged as more effective than passive or avoidant approaches. In this regard Folkman et al. (1993 in Friedland et al., 1996), in a sample of 425 HIV-positive and HIV-negative men, examined coping as it related to the assessment of stress. They found that involvement coping was associated with diminished depressive mood whereas detachment coping correlated with increased depressive mood. Reed, Kemeny and Taylor (1990 in Grummon et al., 1994)) found that escape-avoidance coping with AIDS correlated positively with depression, poor psychological adjustment, self-destructive behaviour such as substance abuse and suicidal behaviour. Other studies with persons with terminal illness have shown that denial/avoidance strategies may be most beneficial for short-term adaption, but ineffective or detrimental in the long term since it results in disregard for preventative behaviours, noncompliance with treatment and consequent shorter survival time (Grummon et al., 1994).

Attributional styles leading to the perception of the self as unworthy and undeserving of care due to the nature of HIV/AIDS, its cause and method of contraction and the related tendency to see oneself as responsible for it, as aspects of self-perception, have been identified as factors that reduce active or positive coping ability (Lindegger and Wood, 1995). Research have shown that the coping strategy of accepting responsibility, or self-blame, for one's condition is associated negatively with psychological well-being (Grummon et al., 1994). In this regard a sense of self control and meaning have been associated with a better outcome in terms of coping with HIV/AIDS. (Lindegger and Wood, 1995; Anderson et al., 1991).

With reference to social support versus coping, Thoits (1986, p. 417 in Friedland et al., 1996) has presented an argument for reconceptualising social support as 'coping assistance'; that is the "active participation of significant others in an individual's stress-management efforts". Within this conceptualization it may be possible to integrate models of coping and support with AIDS. Examples of this would be problem focussed coping and instrumental support, emotion focussed coping and emotional support and perception focussed coping and informational support[9]. Of particular interest in terms of social support and coping with AIDS is which particular aspects of social support and health are associated and under what illness and demographic circumstances (Friedland et al., 1996).

Health Psychology has identified diverse aspects of social support (emotional, informational, practical, etc.) with different effects on coping with terminal illness. The buffering hypothesis of social support[10] proposes that the most effective supports are those that are closely related to specific

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[9] "Problem-focussed" coping refers to efforts directed at managing the problems that are causing the distress, whereas "emotion-focussed" coping refers to efforts to manage the accompanying distressful emotions. Specific strategies identified for problem-focussed coping include 'confrontatitive coping' and 'planfull problem solving', while 'distancing', 'escape-avoidance, 'accepting responsibility and 'positive reappraisal' are associated with emotion-focussed coping. Research with chronic illness in community samples has shown that people used more problem-focussed coping in encounters they appraised as changeable and employed emotion-focussed coping in encounters in which they felt that their options for affecting the outcome were limited (Grummon et al., 1994). This indicates that emotion-focussed coping strategies should abound in management of late stage AIDS.

[10] The buffering hypotheses proposes that social support is related to well-being only for persons under stress. Support buffers the pathogenic effects of stressful events, such as having serious illness such as HIV/AIDS, by preventing the initial stressful appraisal or by alleviating physiological, emotional and behavioural stress reactions. By comparison the 'main effects' hypotheses of social support, the alternate model, posits that social resources have a positive influence on people's health irrespective of whether or not they are under strain by shielding them from exposure to certain types of stressors or by fostering good health and morale. In this model social support has a positive influence on health in general and its absence in and of itself implies a stressor in peoples' lives (Grummon et al., 1994, Friedland et al., 1996).

stressors. People with HIV/AIDS have specific stressors to which support can be directed, but they have an added difficulty in that their disease impacts directly on the support they receive. The stigma attached to the disease makes it difficult to gather some forms of support, the high incidence within their social network reduces potential sources of support and the erratic progression of the disease makes it difficult for caregivers to sustain the high levels of support needed. Additionally persons with AIDS are often alienated, both emotionally and geographically, from the natural support groups of their own families and communities (Friedland et al., 1996). Buuren (1992) additionally found that persons with HIV/AIDS often feared rejection or did not want to bother others with their problems and consequently did not disclose their HIV status and experienced an associated lack of social support. This indicates that there is a need for intervention aimed at assisting patients in seeking support and for a general acceptance of HIV disease and a variety of lifestyles to give patients less reason to fear rejection and withdraw from established social networks such as families.

Hays (1989 in Friedland et al., 1996) found that although all types of social support were associated with reduced depression among persons with HIV/AIDS, informational support was especially beneficial for those in the early stages with the disease. Lindegger and Wood (1995) indicate in this regard that behavioural and educational aspects of psychological intervention have been shown to be generally more beneficial to coping than the emotional support provided thereby. A study by Wong-Rieger (1992) evaluating the workshops offering support to men and women from the haemophilia community found motivating factors to be different for men and women with men valuing the acquisition and sharing of information and women the provision of emotional support.

For AIDS and ARC (AIDS Related Complex) groups combined Zich and Temoshok (1987 in Friedland et al., 1996) found emotionally sustaining help was viewed as more desirable, more available, used more often and more useful when used.

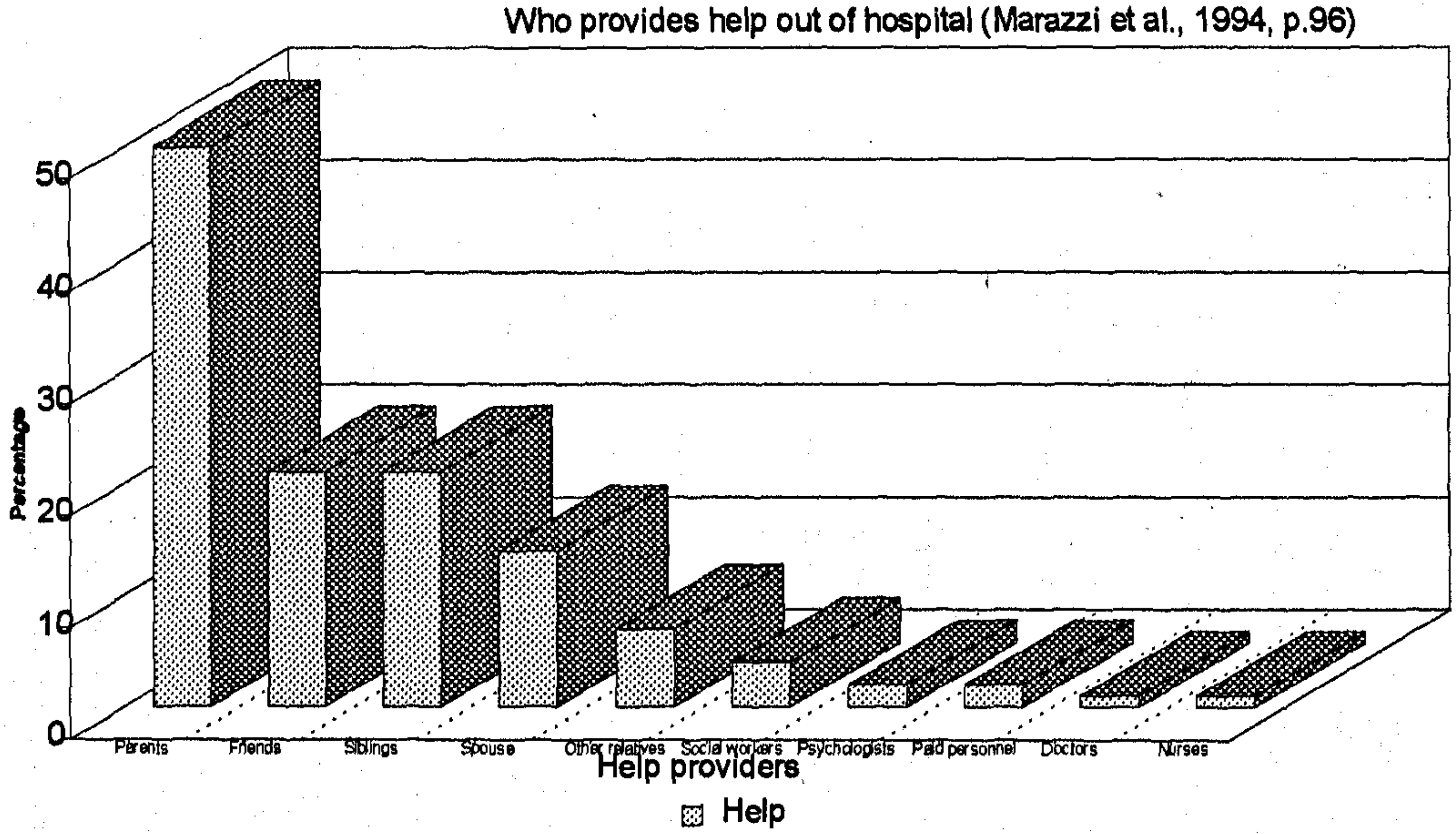
With regard to the source of support, Friedland, Renwick and Mc Coll's (1996) findings corresponds with other research (Folkman et al., 1994; Green 1993; Hays et al., 1990 and Schwarzer et al., 1994 in Friedland et al., 1996) indicating that most support to adult persons with AIDS is provided by partners and close friends compared to the relatively small role played by the family. Turner et al. (1993, in Friedland et al., 1996) found that although family members had the potential to be very helpful they could also be a significant source of harmful social support. There are, however, indications that the importance of social support from family members increase towards the later stages of the disease (Friedland et al., 1996).

Seeley et al. (1993) found in a study in Uganda that the extended family did not in fact provide adequate social support for persons with AIDS, despite the common assumption that it provides social and economic support for its members in times of need in African contexts. In twenty seven out of thirty cases studied there was evidence of limited care. Various reasons were given for this by carers, including lack of food, money, medications and the carer's other family responsibilities and commitments.

In research by Mason and Wood (1994) with unemployed Zulu-speaking adults in the Pietermaritzburg area the family was cited most frequently as the main source of support (mainly material or financial). As also indicated in the research by Seeley et al. (1993), this appeared inadequate and seemed to rest on the condition that their HIV-status remained hidden. The next most frequently cited sources of support (medical and emotional) were clinics and hospitals; followed by the church and support groups. Two of the fifteen selected respondents in this study reported that they received no social support whatsoever. In terms of the most useful means of support, all the subjects in the study were in favour of the development of a centre.

Additionally there was consensus that the focus of the centre should be on income generating activities, material assistance, social support and counselling. Almost all the respondents expressed a desire for the centre to be established in their township in order to ease transport difficulties. This opinion was, however, frequently coupled with concerns with confidentiality. The majority of the respondents expressed the opinion that the centre should cater for all people in need regardless of their HIV-status. This preference seemed to be linked to concerns regarding confidentiality (Mason and Wood, 1994).

Research by Marazzi et al. (1994) provides the distribution illustrated in chart 3 in terms of the degrees of help provided to a population of male and female adult persons with ARC and AIDS in Rome by others. This study indicated that, for personal care and nursing, members of the family played the foremost role, whereas public health services were mostly responsible for physiotherapy.


Who provides help out of hospital (Marazzi et al., 1994, p.96)
Percentage
0
10
20
30
40
50
Parents
Friends
Siblings
Spouse
Other relatives
Social workers
Psychologists
Paid personnel
Doctors
Nurses
Help providers
▨ Help

Care for persons with AIDS:

In comparison with other African countries, South Africa has a greater resource base in terms of its level of economic development, population and per capita income. Additionally South Africa has a four to five year advantage regarding the development of the AIDS epidemic. Nevertheless the prevalence of AIDS/HIV in Kwazulu-Natal is almost two years ahead of the rest of the country with an estimated 10% of the population HIV-positive. This makes it one of the areas with the highest prevalence of HIV infection in Africa and the world (Dr. Zweli Mkhise, Natal Witness, 12 August 1994 in Mason and Wood, 1994).

The increased responsibility that will be placed on particularly hospitals in Kwazulu-Natal is clear. If one considers that the mentioned figures are undereported and that current education and prevention campaigns are ineffective (Jones, 1993), the implications for care becomes overwhelming.

The different models of care which have developed around the world in response to some of the needs mentioned earlier in this chapter are illustrated below with examples from developed countries and Africa (adapted from Mason and Wood, 1994).

Models of oare

Care in developed countries:

Most developed countries around the world have managed to establish a comprehensive range of services for persons with HIV/AIDS. Factors which have made this possible include:

- the presence of established and developed socio-economic infrastructures;

- already existing and comprehensive health and welfare systems; and
- an essentially contained pattern of HIV/AIDS infection.

An examination of the resources in Britain's "National AIDS Manual" (1993, in a London Lighthouse Newsletter in Mason and Wood, 1994) indicates that there are services which offer diverse and specialized HIV/AIDS care to every sector of society. This incorporates drop-in centres, support groups (affording relaxed environments where persons with HIV/AIDS can meet, socialise and receive counselling and information) and AIDS Care Centres established on the Hospice philosophy of care offering accommodation and palliative/terminal care to those who are very ill.

Others offer a combination of the abovementioned care, providing an integrated, comprehensive model of care to the HIV-well, HIV-sick, their partners, families and friends. Most of the services are community-based, having developed from the efforts of those (frequently gay communities) living with or affected by HIV/AIDS. They rely mainly on precarious governmental and private funding, drawing on community volunteers and, increasingly, on other existing community resources (Cain, 1993 in Mason and Wood, 1994).

As far as limitations of care programmes are concerned, Spence (1990, founder of Lighthouse - in Mason and Wood, 1994) argues that

> *"most people living with AIDS are clearly saying that, provided they can be assured of adequate care and support, they would prefer to die at home"* (p. 3).

He indicates that there is therefore an urgent need, in Britain, to develop quality, reliable home support services which are linked with other agencies.

Care in Afrioa:

Jackson (1992, p. 153) points out that many of the problems experienced by families affected by AIDS in Zimbabwe is as much, if not more, associated with economic suffering as with the disease itself. Research by Mason and Wood (1994) with Zulu-speaking adults indicated, in support of this, that material support was a pervasive need expressed by the respondents. Consequently families and communities urgently require assistance with a broad range of primary health and welfare needs. This is a reflection of the situation among Africa's mostly disadvantaged population and these needs have been responded to in several different ways:

Home Based care (HBC):

Increasingly families and communities in Africa have to take care of sick persons with HIV/AIDS at home rather than admitting them to hospital. Home Based Care, in fact, seems to have developed as the primary response to the question of care in Africa due to, among other factors, limited governmental and welfare resources (Mason and Wood, 1994).

Foster (1992, in Mason and Wood, 1994) record some of the benefits of Home Based Care:

- It reduces the pressure on hospital beds. This is particularly important since many hospitals are turning away terminally ill patients due to insufficient facilities.
- It reduces the cost of care for the family and for the state.
- It helps people with AIDS to die with dignity and in familiar surroundings. This is especially in terms of the supportive role of the family and community in African cultures.

- It provides emotional and practical support family members.
- It promotes a holistic approach to care.
- It contributes to community awareness of HIV/AIDS.
- It puts care providers in touch with potential orphans, thus enabling support to be provided prior to a crisis.

The abovementioned advantages does not, of course, consider the very high levels of prejudice and discrimination evident in some African communities against persons with HIV/AIDS. This is aggravated by the absence of or inadequacy of many current information and counselling programmes in these communities. In the present study persons with late stage AIDS had not shared their HIV/AIDS status with partners, family members or the community due to fear of being ostracized or scapegoated. In spite of acute personal distress and isolation they have masked the acute, painful AIDS related illnesses as symptoms of diabetes or other 'inoffensive' conditions. Home Based Care and the possibility of the community discovering that they have AIDS were unacceptable to this sample. Additionally their response could not be ascribed to denial alone, which had to some extent been worked through at earlier stages of their illness in all the cases. Additionally Seeley et al. (1993) found that families in Uganda refrained in a majority of cases from providing adequate support to members with HIV/AIDS due to poverty and other commitments.

Whilst Home Based Care takes many forms these generally fall into three paradigms (Chela and Siankanga, 1991, in Mason and Wood, 1994):

- **A vertical model, where hospital-based teams travel into the community to care for those affected in their homes:**

Chikankata hospital (in Zambia, managed by the Salvation Army) has developed an efficient in- and out-patient service for people affected by

AIDS, funded by international donor organisations. This model has essential similarities with the one currently under development at Ngwelezana Hospital near Empangeni in Kwazulu-Natal. The home-care team consists of a clinical officer, a nurse, an AIDS educator and a driver. Medical, psychological, spiritual and material care (at Ngwelezana Hospital this is restricted to medical care) is provided for patients, their families and their communities. In this way the mobile team at Chikankata hospital is able to provide a continuity of care between existing hospital resources and patients in their home environments. Williams (1990 in Mason and Wood, 1994) observes that instead of evoking fear and stigma, the presence of the team's distinctive yellow Land cruiser has actually fostered community interest and awareness.

- **A horizontal model, where community-caregivers attend to the needs of the affected:**

CONCERN, an Irish NGO working in the Rakai district of Uganda, has established a support network linked to community development. Established women's groups are trained by a village coordinator in basic nursing care, the use of herbal medicines and skills based on traditional problem-solving methods. The care provided is not exclusively for those with AIDS, but for all elderly, ill or handicapped members of the community. Although the care is very basic, the cohesion of the family and the community is maintained. With assistance from CONCERN care givers are also involved in initial income generating activities with those well enough to participate (Mason and Wood, 1994).

- **A combined model, where hospital-based teams support community care-givers in caring for the unaffected. Peripheral clinics or district health centres provide an ideal link between the two services.**

Nsambya hospital in Uganda offers support for a network of small Christian communities which in turn have helped to extend the outreach of the hospital's AIDS programme, and to reduce the burden on the hospital staff as well as lessen the dependency of the community on hospital services.

Those who are ill are admitted to hospital as in- or out-patients, or are attended to at home by the community caregivers. These caregivers attend to all that are in need in the community, paying particular attention to the elderly, the handicapped and those with AIDS. The hospital teams visit patients according to their needs, providing medical care, spiritual guidance and food at each visit. Healthier patients are expected to attend the weekly AIDS clinic at the hospital for support, unless they live too far away (Williams and Tamale, 1993 in Mason and Wood, 1994).

- **Support groups and community centres:**

The AIDS Support Organisation (TASO) in Uganda has developed, among its other various support structures, 'day centres' in Kampala and Masaka. People with AIDS and their families can meet at these centres for information, social and emotional support, counselling and physical and relaxation exercises. Lunch is provided and offers a useful way of demonstrating to friends and families that HIV cannot be transmitted via eating utensils, etc. Also available at the centre are sewing machines which clients use to make sheets for sale and for Home Based Care kits. Several other activities (including making hats, baskets, mats etc) are provided using local and donated material. Places for rest and child care are also available (Hampton, 1991 in Mason and Wood, 1994)

Additionally the AIDS Information Centres in Uganda run "Post-test clubs", which offer support and counselling to HIV-positive and HIV-negative people. These clubs are run by full-time staff members, are open six days a week and include outreach programmes into surrounding communities. The stigma of AIDS has been lessened by opening membership to everyone in the community regardless of their HIV status, and has encouraged many people to return to their communities as agents of change (Mason and Wood, 1994).

In conclusion Mason and Wood (1994) suggests a combined (vertical and horizontal) model of care in South Africa whereby communities in general and families in particular are empowered through existing resources, such as hospitals, to take care of those who are ill. Home-based care, support groups and community day-centres appeared to be most effective sources of care in their research and they recommend and integration of these programmes with child-care initiatives, primary health care and development in order to utilize the inherent strengths of community groups and institutions. The possible role of an AIDS Care Centre within the South African context is discussed in terms of this analysis in the final chapter.

Psyohological intervention with people with AIDS:

The World Health Organisation (WHO) Global Programme on AIDS (GPA) has proposed that HIV-related counselling seeks to promote self-determination, enhance self-confidence, improve family and community relationships and, through them, support the quality of life of those most affected by HIV. Balmer (1991 in Lindegger and Wood, 1995) suggests that the WHO/GPA directions separate counselling objectives into two broad categories: to prevent HIV infection, and to provide psychosocial support to those already affected. The responsibility for the former has generally been assumed by the paramedical profession, whereas that of the latter has largely been assumed by non-governmental organizations (NGO) and groups of people with AIDS. Balmer (1991, in Lindegger and Wood, 1995) argues that there is a need for psychosocial counselling for persons with AIDS which is separate from the medical setting, best situated in the community served. To some extent this has been achieved by the establishment of AIDS Training and Counselling Centres (ATICC's) in many communities in South Africa (Lindegger and Wood, 1995).

Van Dyk (1992, in Lindegger and Wood, 1995) has raised the question of whether counselling is an appropriate form of intervention and support in African settings. Amongst the issues at stake are:

- "Western" concepts of high risk behaviour that do not necessarily correspond with African cultural concepts.
- Differing views of sickness.
- Language differences that may present problems - for example where there are no words for certain objects or concepts such as 'virus', 'condom' or 'immunity'.
- The fact that sex is a taboo subject in many African cultures.

Seeley, Wagner, Kengeya-Kayondo and Mulder (1991, in Lindegger and Wood, 1995) recommends that if counselling is to be an effective form of intervention, it needs to consider the culture in which it takes place. These researchers completed extensive programmes in Uganda and have found that the Euro-American model of person-to-person counselling needs to be adapted to the rural African setting by placing the emphasis on support for the family. The effective holistic approach to HIV and AIDS employed by traditional healers in the Botswana region, that accommodates the context of particular cultural understandings, may in this regard be a prototype for South Africa (adapted from Ingstad, 1990 in Lindegger and Wood, 1995).

Four general trends have emerged from psychological studies investigating psychological counselling and psychotherapy with AIDS patients (Anderson et al., 1991 in Lindegger and Wood, 1995):

- Counselling interventions aimed at helping persons with AIDS establish active control in relation to their disease has been shown to be most effective for enabling coping.
- In addition to psychological assistance to individual AIDS patients the importance of family based intervention has been emphasized (Ackerman, 1989 and Cohen, 1990 in Lindegger and Wood, 1995). Family intervention has been identified as an important therapeutic mode for all persons with terminal illness, but is particularly important with regards to AIDS given the ambivalence surrounding the moral and emotional reactions to AIDS which are likely to complicate the experience of living and dying with the disease and the grieving process. Ingstad's study (1991 in Lindegger and Wood, 1995) supports this finding.
- A direct relationship has been demonstrated between coping mechanisms and period of survival with AIDS (Ross et al., 1994; Thompson et al., 1996; Solomon et al., 1987 in Lindegger and Wood, 1995).

Lindegger and Wood notes that, despite all these findings,:

> "*relatively little research has evaluated the efficacy of various interventions with AIDS patients, and this is an important area for further psychological research*"(Lindegger and Wood, 1995, p. 6).

3

The research design

Motivation: rationale for the use of a phenomenological praxis:

The selection of the research design (as the strategy of research and logic behind it) and research techniques (as the methods used for data generation and collection) for this inquiry was influenced by ethical and practical considerations.

Ethical considerations:

A critical factor that shaped the research design and research techniques was the combination of generative-reflective practice and human science as the postpositivist rationale for community psychological research and action. This approach emphasizes that the only way to provide community-relevant knowledge and consequently appropriate and valid psychosocial intervention is through open dialogue within the study community itself, between researcher and members of the community as well as between research and intervention or praxis and action (Dokecki, 1992, Newbrough, 1992). This corresponds with Paulo Freire's "action - reflection cycle"[11].

A brief comparison of traditional psychological research with the phenomenological method will illustrate the link between the latter and reflective-generative practice as well as the fundamental ethical principles underlying it:

Traditional psychological research seeks causal explanations through the calculative measuring or manipulation of psychological phenomena in order to formulate theory. Phenomenological research seeks to penetrate psychological phenomena, as shared universal dimensions of human experience. This is achieved through bringing the shared prereflective experience thereof to the level of reflective awareness where it manifests itself as psychological meaning. Since phenomenological research involves an explication of shared prereflective experience, it engages the researcher/interviewer in a dyadic relationship with the interviewee, as co-constitutive member in an interpersonal situation aimed at making explicit the shared human meaning of the phenomenon. As such open dialogue between the researcher and members of the study community as reflective-generative practice is am inextricable constituent of the phenomenological method. The heterocentric dyadic relationship of the interview is by definition fundamentally based on caring as the "norm for the rightness or wrongness of all action whatever", or the basis of ethical behaviour, a norm

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[11] "Reflective-generative practises" refers to a relationship between inquiry or research and community characterized by dialogue within the community as the basis for generating community-relevant knowledge to guide appropriate, relevant community intervention (Dokecki, 1992). The principles of Paulo Freire with its emphasis on empowerment, relevance, authentic dialogue, and problem posing are incorporated in a reflective-generative practice (Freire, 1970).

that makes it possible "to define morality by reference to maintaining community in action" (Macmurray, 1961, p. 120 in Dokecki, 1992).

By using more than one interviewee to find the underlying constants or themes that represent universal aspects of the experience of late stage AIDS *for the study population, phenomenological research mirrors the effect of* open dialogue within the community in establishing the shared, intersubjective human meaning of the researched phenomenon for its members (Giorgi et al., 1985; Dufrenne, 1967; Collaizzi, 1973; Kruger, 1988).

Therefore reflective-generative practice and a phenomenological praxis conscientizes the research and subsequent community intervention. Through suspending, as far as possible, all forms of theoretical and experiential bias it emphasizes an understanding of the experienced needs of persons with late stage AIDS. By definition this approach of generating the knowledge on which social intervention is based in the study community forms the basis of an ethical relationship with the target community and minimizes the possibility of imposing invalid and preconceived schemas about their needs on them in the subsequent community intervention through the AIDS Care Centre (Giorgi et al, 1971; Edwards, 1991).

Practical considerations:

As an explication of the experienced needs of the persons with late stage AIDS, as a comprehensive phenomenon, this research demanded a qualitative or exploratory approach. This format for the research design provided the persons with late stage AIDS with the scope to express their conceptualization of the issues at stake as well as their needs as experienced by them. Although quantitative methods would be preceded by a pilot study with a similar aim, there would be the risk of imposing researcher bias on the nature of the researched phenomenon. During a pilot study the researcher would, for example, guide the interviewee according to a hidden agenda in terms of issues deemed relevant to the goals of the research (Oppenheim, 1992). The phenomenological research design resembles a pilot study in explicating the respondents conceptualization of key concepts, but has the additional benefit of imposing rigour on this event through phenomenological research techniques that provides empirically verified and minimally biased results.

The nature of the researched phenomenon (the comprehensive needs of persons with late stage AIDS) and the purpose of the research (creating informed recommendations as to how these comprehensive needs can be addressed in the format of an AIDS Care Centre) necessitated a blending of pilot work and exploratory research for which the phenomenological method is imminently suitable. Researchers such as Temoshok and Baum (1990, p. 12) specifically recommend a flexible approach of this nature to AIDS related research and intervention due to rapid and continual changes in our understanding of the disease and the changing nature of the phenomenon itself. Berk, Baigis-Smith and Nanda (1995, p. 647) mentions in this regard in their research that:

> *"These results question assumptions about the relationship among stage of HIV infection, level and type of health care need, and type of setting and suggest that health system resources and nursing care focus on both the psychosocial and physiological needs of persons with HIV/AIDS* ***using individualized protocols.****"*

Additionally certain characteristics of the target population negated the use of quantitative methods. Issues of confidentiality and anonymity regarding the HIV/AIDS status of members of the target population and its heterogeneity rendered it impossible to draw a statistically representative sample due to the unavailability of a sampling frame. Apart from their shared attribute of having AIDS, the persons with AIDS in the Richards Bay area came from different walks of life and could not be classified or described according to other socioeconomic variables that would provide parameters for the drawing of even an approximate sampling frame.

An overview of the phenomenologioal praxis

Definition

Polkinghome (1989, p. 1247) defines phenomenology as that psychological discipline that seeks to explicate the essence, structure, or form of human experience as revealed through essentially descriptive techniques as well as disciplined reflection. Phenomenological research, then, refers to a praxis for discovering, revealing, describing, and understanding - or explicating - experienced reality. Edwards (1991) states, in this regard, that phenomenology is dedicated to allowing the phenomena of the life-world to reveal themselves in their more original, primordial, and essential form. To "explicate" refers to a process of discovering, revealing, describing, and understanding - or making explicit - what people can communicate regarding their experiences of the researched phenomenon. The phenomenological explication of the needs of the persons with late stage AIDS is therefore a making explicit or uncovering and describing of the essential human needs associated with the experience of having late stage AIDS as the researched phenomenon.

Phenomenological research identifies and explores phenomena through describing human experience[12] since human experience is an essential

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[12] The term "phenomenon", derived from the late Latin "phaenomenon" in turn derived from the neuter Greek present participle "phainomenon" meaning 'to appear' refers to that which appears to a person - i.e. what is experienced by a person - in Kantian philosophy the appearance or experience of an object as opposed to its assumed existence in and of itself,

constituent of human phenomena. Thus the research explores the persons with late stage AIDS experience of their needs from their perspective without imposing bias through interpretation. A precondition for explicating the researched phenomenon is to put one's own presuppositions regarding it on hold.

Sampling

Selection criteria:

Subjects who are pre-eminently suitable for phenomenological research are those who:

- had direct experience of the phenomenon to be researched;
- can articulate and communicate their thoughts, feelings, and perceptions regarding the researched phenomenon;
- express a willingness to be open to the researcher;
- are naive about theories regarding the researched phenomenon - their being untrained increases the probability of their verbalizing the data of their awareness or their original experience of the phenomenon. This prevents undue interference from implicit philosophies of various schools of thought (Giorgi, 1985).

Representativeness of the sample

The representativeness of a sample, and the generalizability of the research results to the target population, in phenomenological research, is based on

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independent of the person experiencing it.

experiential rather than statistical validity.

In phenomenological research representation, like validity and objectivity, is empirically based on direct experience. What we experience as real and valid is by definition so, and generalizable to the extent to which the phenomena are accurately shared.

Therefore objectivity is fidelity to phenomena and not located in measurement and operational definitions as used in traditional social research as criteria for validity. Through employing unstructured interviews characterized by a permissive psychological climate and openness the phenomenological method ensures the faithful and honest articulation by the respondents of their experience of the researched phenomenon. The research results as the themes extracted from these protocols are valid for the target population on the basis of shared experience since phenomena are universal, shared human experiences. Linked to this is the phenomenological premise that experience is not a personal or internal state, but a mode of presence to the world. We are human in unique but also fundamentally similar ways and therefore have essentially similar experiences of shared phenomena. The copies of extracts from the transcribed protocols in Appendix two is a testimony to this basis for validity. Respondents, who do not know each other, spontaneously echoed the same themes as expressions of their needs in terms of the researched phenomenon. This is due to their essential and shared humanity and the experience of AIDS as a shared phenomenon.

Fundamentally traditional social research also relies on this premise for validity through generating valid, measurable definitions and indicators of key researched variables through the unstructured interviews of a pilot study and subsequently developing items for standardized questionnaires from this (Oppenheim, 1992).

Phenomenological research methodology

A phenomenological research procedure was applied in the phases outlined below. These phases correspond with the procedures described by Du Toit (unpublished, 1990), Spiegelberg (1982), Kruger (1986), Stones (1986), and Van Vuuren (1989).

- Phase 1: The identification of the phenomenon.
- Phase 2: The selection of subjects.
- Phase 3: The first person description (interview and protocol).
- Phase 4: Reading the description or protocol.
- Phase 5: Breaking each protocol down into Natural Meaning Units (NMU's).
- Phase 6: Reduction and linguistic translation of the Natural Meaning Units (NMU's).
- Phase 7: Formulating the situated structure for each subject.
- Phase 8: Formulating the general structure (synthesis).
- Phase 9: Discussion: Relating the explicated needs to current theory.
- Phase 10: The research report: an overview, evaluation, and recommendations.

General format for the research procedure

According to Polkinghorne (1989, p. 46) the general format for phenomenological research may be summarized as follows:

- Gather a number of naive descriptions of the phenomenon under investigation through unstructured interviews with persons who are experiencing it.
- This entails asking a sample of the target group (the persons with late stage AIDS) individually the research question ("What are your needs as a person with late stage AIDS?"). This is an unfocussed, highly projective question - "projective" in the sense that the question means whatever the respondent wishes to make it mean, which in turn is the significant aspects of their experience of the phenomenon that the research aims to extract.
- Naturally the research question evokes a flood of information (and, in practice, some denial from persons with late stage AIDS). From the perspective of traditional social research and a pilot study the researcher would then employ "traffic management" to focus the interview on issues deemed relevant to the research in terms of a hidden agenda (Oppenheim, 1992, p. 30). From a phenomenological perspective and in terms of a reflective-generative practice, however, it is important to elicit the respondents' conceptualization of key issues and agenda for the research and subsequent intervention. Therefore the respondent is allowed to set the agenda for the interview. In practice this had the additional benefit of facilitating the ventilation of anxiety associated with the experience of denial and the consequent working through of it.
- Minor modifications to the phenomenological method, due to time and other constraints, are mentioned in more detail in chapter four that deals with a detailed discussion of the actual research.

4

A review of the research

This chapter documents the course of the actual research, including practical problems experienced in applying the research design and research techniques. Where relevant, important principles or problems experienced are illustrated with references to extracts from the protocols cited in Appendix two. The chapter is naturally divided into the practical stages in implementing phenomenological research outlined in the previous section.

Identification of the phenomenon and bracketing of assumptions

It is important to distinguish between the identification of the researched phenomenon and possible definitions thereof. The phenomenon was identified initially in the broadest possible terms (see "needs" under 'Definitions of key terms' in Chapter one). The generative themes in chapter six provides a valid definition of the researched phenomenon as the needs of persons with late stage AIDS in terms of the respondents experienced conceptualisation and understanding thereof (Collaizzi, 1973).

An essential condition for explicating the respondents' experience of the phenomenon is the bracketing of the researcher's presuppositions regarding it. Consequently the researcher interrogated his experience of the phenomenon using phenomenological research methods in a similar way to the actual research. This contributed to increased self-awareness and a putting-on-hold of biases regarding the needs of persons with late stage AIDS.

There were, however, biases and distortions inherent in the setting and format of the unstructured interviews as well as the presence of the interviewer. Naturally a person from a traditionally Zulu cultural background (as all of the respondents were) would not necessarily view being interviewed by a person from a Western cultural background in the environment of a company health clinic as a neutral, permissive experience. Moreover, an unstructured interview is not a normal conversation - it is essentially one-sided requiring possibly a different way of relating to that with which the respondent is familiar.

Practically the persons with late stage AIDS' primary concern with participating in unstructured interviews in a clinic setting with an unfamiliar interviewer was confidentiality. They were especially apprehensive about having the interviews audio taped. In all the interviews they were granted complete freedom in setting the format and method of interviewing. Their apprehensiveness initially inhibited a spontaneous sharing of their needs. Fortunately guarantees of anonymity resulted in this resistance being worked through and them participating spontaneously. All the interviewees preferred the setting of a company health clinic to their homes in the community where they feared breaches of confidentiality more.

Formulation of the research question

As mentioned before, the research question had to be a wide-open, highly projective general question to introduce as little bias as possible in the respondents' subsequent exploration of their needs (Oppenheim, 1992). The question "What are your needs as persons with AIDS?" proved very effective in eliciting an open, spontaneous sharing of their experienced needs. This is both evident in the protocols cited in Appendix Two and in the feedback received from the respondents after the unstructured interviews regarding any possible bias that may have been introduced.

The selection of respondents

Selection criteria and related issues

As mentioned in Chapter Two, direct experience of the researched phenomenon, the ability to articulate this experience, a willingness to be open to the interviewer, and being naive with regards to theories regarding the researched phenomenon are essential criteria for the selection of respondents for phenomenological research. These criteria are discussed in detail in terms of the actual research in the following section.

- ***Direct experience of the researched phenomenon:***

The researched phenomenon is the needs of persons with late stage or full-blown AIDS. Therefore it was considered crucial that the interviewees had to present with the morbid symptoms of late stage AIDS (including Carpossi Sarcoma, pneumonia, AIDS-related dementia, associated venereal diseases, cold sores, diabetes, etc. related to Immunodeficiency) at the time of the interviews to have direct experience of the researched phenomenon.

Consequently they would also be eligible for care in an AIDS Care Centre. Naturally the clinical presentations of acute AIDS varied from respondent to respondent in terms of prominent symptoms. Initially it was thought that CD4-counts could be employed to select respondents on the basis of a cut-off margin since it corresponded with morbidity. It was, however, found that low CD4-counts did not necessarily correspond with the severity of presented symptoms. Several potential respondents with very low CD-counts did not present with any of the acute signs or symptoms of AIDS and were therefore unsuitable for the research.

- ***The ability to articulate their experience of the phenomenon:***

The ability of respondents to articulate spontaneously their needs related to the experience of late stage or full-blown AIDS depended on the provision of a permissive, non-directive psychological climate in the unstructured interviews and their being able to express themselves fluently in English.

An additional obstacle to the persons with late stage AIDS honest sharing of their needs was the phenomenon of denial. Denial of having AIDS presented a barrier to their exploration of their experience of the researched phenomenon. One could argue, however, that the denial and especially the anxiety associated with AIDS is a relevant and valid expression of their experience of having AIDS, as the researched phenomenon. As a coping mechanism for dealing with the experience of having AIDS it represents one of their experienced needs. This need is expressed to some extent as a pervasive desire to remain distracted from thinking about having AIDS - an important generative theme discussed in detail in chapter four.

Moreover, permissively accepting the denial (and not challenging it) resulted in the interviewees spontaneously expressing the underlying anxiety that contributed to it. This resulted in a working through of the denial and acknowledgement of experiencing late stage AIDS. Of the thirteen interviewees selected only one presented with such denial that the interview had to be rejected for the purposes of the research. This interview had to be rejected since the respondent's complete denial made it, by definition, impossible for him to relate his experience of the researched phenomenon (his needs as a person with late stage AIDS).

Language did not present a barrier to the interviewees' articulation of their needs. Of the twelve remaining interviewees only one was not fluent in English and required the use of a translator. The original Zulu interview was audio taped and translated subsequently in whole into English. Since any form of translation and the necessity to conduct the interview through a translator distracts from the authenticity of the protocol, this interview was considered less valid than the remaining eleven.

- ***The unstructured interview:***

Prior to initiating the interview every effort was made to create a situation in which the respondents would feel relaxed and where anonymity and confidentiality could be guaranteed, if required.

For this reason home interviews were avoided since the home environment would not provide a long enough period (sixty to ninety minutes) without interruptions or distractions (Oppenheim, 1992).

Moreover, the sensitive nature of the researched phenomenon, the presence of denial, and the extreme importance attached by the interviewees to confidentiality regarding friends and family knowing about their having AIDS resulted in all the interviewees expressing a preference for not having interviews conducted at home. Conducting interviews at home could have resulted in the introduction of bias among even those interviewees not experiencing any denial due to the expectations of family and friends.

As far as possible settings perceived by interviewees as unpleasant or threatening were avoided. All of the interviewees reported satisfaction about the way nurses treated them at the company clinics (this is evident in the generative themes where it is recommended that staff at the AIDS Care Centre should relate to them in a similar way to staff at the clinics). Additionally offices at the clinics provided an appropriate setting for interviews - it was private, quiet, comfortable and not intimidating. This, in conjunction with the guarantee of anonymity (they were never asked to provide any biographical information) enhanced rapport between interviewer and interviewee.

Having welcomed and thanked the interviewee, after being introduced, the interviewee was seated and put at ease. A standard format of introduction was used in each of the interviews:

> *"We have asked you to participate in this research so that we can benefit from your experiences of having late stage AIDS and insights regarding it. The interviews are entirely private and confidential, your name will not be linked to anything you say here, and I have not been told anything about who you are or where you come from. Furthermore you do not need to provide me with this information unless you want to, in which case it will still not be linked to anything you say. The interviews will be very helpful to us in providing us with better ways to address the needs of persons with late stage AIDS."*

It was decided that the research should be in the format of audio taped unstructured interviews since it has been found that questionnaire completion tend to result in responses of a distant and highly reflective nature. The spoken interview allows the respondent to be as near as possible to their lived experience (Beshai, 1975; Dublin, 1972). Dufrenne (1967, p. 215) mentions in this regard:

> *"In effect, when I speak, I am my speaking; I become one with words. Certainly...to speak puts me at a certain distance from that*

> *of which I speak. But between my consciousness and my speech there is no distance at all: I am in union with the language I use".*

This advantage of the audio taped interview in eliciting the interviewees' lived, pre-reflective experiences outweighed the practical advantages of written descriptions that would be less time-consuming and not require any transcription. Written descriptions would have had the additional disadvantage of resulting in loss of dialogue and the opportunity for probing.

Prior to commencing with the interview the interviewee's permission to record the interview on tape was secured:

> *"Do you mind if I tape our conversation? It helps me to remember afterwards what you said and saves me taking notes."*

With several interviewees (five of the twelve) this resulted in fears of confidentiality or anonymity being breached. The interviewees suspected that their voices would be recognized and that their having AIDS would be made public. Their fears were allayed by reassuring them that the recorded material would be destroyed as soon as an anonymous verbatim transcript had been made of it. With all of the twelve interviewees this resulted in permission to audiotape the interviews.

Subsequently the interview was opened with the mentioned wide-open, highly projective, general question:

> *"Can you tell me more about your needs as a person with AIDS?"*

Where denial occurred (and the person mentioned, for example, that they did not have AIDS but merely suffered from chronic diarrhoea), this was explored permissively with the interviewee and space was granted to express ambivalence and ventilate underlying anxiety. Throughout the interview was conducted in a non-directive, informal manner with the interviewer attempting to influence the interviewee as little as possible. Leading questions were avoided and responses consisted mainly of empathic reflection and paraphrasing.

On completing the interviews, the respondents were asked to complete, anonymously, a form aimed at receiving feedback concerning their experience of the interview. This information was used to decide whether or not to accept an interview for the research, based on openness and rapport as experienced by the interviewee. Since all the interviewees indicated that they experienced the interviews as non-threatening and spontaneous none of the protocols were rejected.

Transcription and linguistic translation of the interviews

The audio taped interviews were transcribed, or copied verbatim in writing as protocols, for the individual subjects, and subsequently explicated through four essential steps (adapted from Kruger, 1988):

Obtaining an intuitive and holistic grasp of the data

Since phenomenological research is engaged research, involving the researcher in an interpersonal situation, the researcher's mode of involvement at this stage was crucial. In the initial reading of the protocol, the researcher bracketed personal preconceptions and judgements to remain faithful to the data in the protocols to the fullest possible extent.

After achieving a holistic sense of the protocol through a first reading, it was read again in order to prepare for further stages requiring a more exacting analysis.

Spontaneous emergence of natural meaning units

Subsequently the protocols, or verbatim written records of the interviews, were broken down into naturally occurring units - each conveying a particular meaning - which emerged spontaneously from the reading. Each unit, termed a Natural Meaning Unit (or NMU), may be defined as:

> *"a statement made by the respondent that is self-definable and self-delimiting in the expression of a single, recognisable aspect of the respondent's experience of the researched phenomenon" (Kruger, 1988, p. 117).*

In other words, an NMU is observed where there is a transition from one nuance of meaning to another. Wherever possible the respondents' phraseology was adhered to in order to let the data speak for itself. This is evident in the language used in the descriptions of the generative themes in chapter four.

Rigorous reflection and transformation of the data.

Once the Natural Meaning Units had been identified and made explicit the central generative themes that characterize the respective scenes unfolding in each protocol was synthesized. This entailed grouping Natural Meaning Unit's with shared explicated meanings separately in each protocol. Subsequently inclusive descriptions of the meanings of these groups of Natural Meaning Units were generated as central generative themes. In describing these themes the researcher again adhered as far as possible to the original phraseology of the protocols to prevent interpretation of meaning.

At this stage it was noted that several of the descriptions by the respondents of the researched phenomenon were unique in being an expression of their original, personal needs experienced in their distinctly individual life worlds. Van Kaam (1975) comments that these uniquely personal descriptions of the experience of the researched phenomenon are additionally incomplete or imperfect due to forgetfulness, poor vocabulary, an inability to express themselves, etc. on the part of the respondents.

The problem presented by this is that the aim of the phenomenological inquiry is to find the underlying constants or themes in the many forms of expression of the experience of the researched phenomenon in an effort to depict its essential, shared, universally human aspects. These personal or imperfect descriptions may fail to reflect an essential or universally shared aspect of the experience.

The problem is overcome by using more than one respondent. By using twelve interviewees in this inquiry the possibility of finding underlying constants or themes that represent universal aspects of the human experience of having late stage AIDS is greatly increased. The possibility of certain aspects being omitted is minimized through this and those aspects which are most important (or central and universal) to the experience of having late stage AIDS should appear most frequently, assuming - and not unjustly so - that those aspects which are most important are least likely not to be verbalized. Practically it was found that the interviewees echoed similar concerns regarding the experience of late stage AIDS and expressed similar needs and priorities in terms of coping with the disease.

Synthesis and description

The final phase of the research methodology comprised two steps. Firstly the researcher synthesised the insights attained by taking into account all the expressed intentions derived from the Natural Meaning Units.

At this stage some discrepancies were noted. An example of this is the fact that most of the respondents did not want the AIDS Care Centre to be in their communities since they believed that this would jeopardise confidentiality by resulting in members of their communities becoming aware of their having AIDS. They expressed the fear that this would result from them being seen entering or leaving the AIDS Care Centre or when members of their families became distraught upon realizing that they have AIDS (also through seeing them at the AIDS Care Centre) and consequently inadvertently told others that they have AIDS. The majority of the respondents had not yet informed their families of their having AIDS. This was due to the presence of varying degrees of denial and their unwillingness to cope with the additional stress of their families sadness. Additionally some expressed fears for the health of relatives with high blood pressure and other chronic diseases on being exposed to this shock. Yet almost all the respondents insisted that the AIDS Care Centre should make provision for them being in private with their visiting families by providing a separate room for this purpose.

Certain themes therefore seemed to contradict each other. This is where the notion of approach in the phenomenological method comes to the fore. The researcher must:

> *"proceed with the solid conviction that what is logically inexplicable may be existentially real and valid. He must refuse the temptations of ignoring data or themes which don't fit or of prematurely generating a theory which could merely conceptually-abstractly eliminate discordance of his findings thus far"*
> *(Collaizzi, 1973, p. 161).*

Secondly the researcher communicates the phenomenological synthesis to the world of critical opinion through the formulation of a situated structure. The situated structure or general description communicates the meaning structure of the researched phenomenon in general and attempts to overcome the limitations imposed by any specific context. The use of several respondents in this research was, as mentioned, to obviate possible undetected idiosyncrasies of an individual respondent which would make it more difficult to arrive at a generally valid description of the needs of the target community of persons with late stage AIDS. This also facilitated greater fluency with the phenomenon, given the greater variability in experience thereof by several respondents. Therefore the general description of the situated structure of the experience of having full-blown AIDS is based upon several specific descriptions, each of a situated structure of essentially the same phenomenon.

Rigour of explication by the use of intersubjective judgement.

Since the hallmark of research is that there should be consensual validation of the outcome, a panel of judges may be used in conventional phenomenological research to determine whether the specific descriptions or the general description is true to the phenomenon. Usually this event in phenomenological research is addressed through giving feedback to the respondents, subsequent to the explication of their protocols, of the specific descriptions of their protocols' situated structures and asking them to judge the validity thereof.

Due to lack of time in this was not possible in this contractual research. The research had to be completed in less than one-and-a-half months since the funding for the proposed AIDS Care Centre (at that stage) was linked to an annual budget that would cease to be available after the specified period (from December 1995 to beginning February 1996).

To compensate for this lack of consensual validation in the research, the interviewer would summarize and reflect during the original audio taped interview at points of natural closure all the themes generated thus far and inquire from the respondent whether this was a valid reflection up to that point of his central concerns and needs. The fact that both these summaries and the respondents' judgements of them were audio taped made possible a consensual validation of the generative themes which were very similar to reflected summaries.

5

The generative themes

The following generative themes emerged as important shared universal dimensions of the needs experienced during the late stage of AIDS (as the researched phenomenon) from the protocols of the interviews with the respondents. As such the following represents a synthesis of recurring central concerns mentioned by the interviewees regarding their experienced needs during the interviews.

The generative themes are cited and described in order of frequency with which they appeared in the interviews and subsequent protocols. It is assumed, as mentioned in chapter four, that more important aspects of the experience of the researched phenomenon are less likely to appear less frequently. Conversely it could be hypothesised that those central concerns that appeared most frequently in the interviews represent the more important aspects of the needs experienced when having late stage AIDS.

Distraction:

The fact that one has AIDS and its destructive impact on one's life is inescapable (NMU B:IX; B:X). Therefore having AIDS is both very distressing and frustrating (NMU B:XI). Since there is no cure for AIDS, the best one can do is to prevent the spread of the disease through using condoms (NMU B:XVII; B:XVIII; B:XXIX).

Initially, on being informed that one is HIV+, one feels extremely angry. This anger is evident in one's behaviour towards others (NMU B:LXIV). One realizes soon that this is very harmful since others then become aware that one is distressed and begin to suspect that one is ill (NMU B:LXIV; B:LXV). Consequently one forces oneself to become distracted from thinking about having AIDS and becoming angry and one pretends that one's life is continuing normally, as always (NMU B:LXVI). Generally it does not seem as if others are aware of the fact that one is keeping them at a distance in this way. They seem to think that one's AIDS related illness are those illnesses in themselves and are not linked to the disease. (NMU B:LXVII). A few seem to suspect that one could have AIDS (NMU B:LXVI). When these say that they think one has AIDS, one uses humour to distract them from thinking this and keeping them at a distance (NMU B:LXXIII; B:LXXIV).

One should avoid morbid introspection about the destructiveness of AIDS (NMU A:XIV). If one remains actively occupied by a variety of activities it becomes easier to remain distracted from thinking about having AIDS (NMU A:XVI; A:X; A:XI; B:XXXII; B:XLVI; B:XLIX; C:XVII; C:XVIII). If one cannot remain distracted, one becomes distressed about having AIDS and this makes it much more difficult to cope with the disease (NMU A:XXIV; A:XXV; B:LII; B:LIII; B:LIV; B:LVIII; B:CV; B:CVI). Remaining distracted from thinking about AIDS is the only way one can enjoy the remainder of one's life to the full (NMU B:XLVIII). Therefore one should resume as normal a lifestyle as possible (NMU B:L; C:XXVII; C:XXVIII).

Occasionally, when one thinks about having AIDS, one becomes aware of its destructive and distressing impact on one's life (NMU A:XII; A:XIII; B:LI). It is important to avoid being alone when one has AIDS to avoid morbid introspection about the disease and its implications for one's life (NMU B:XXXIII). When daily activities become monotonous, it becomes very difficult to remain distracted from being preoccupied with having AIDS, since this is distressing it becomes more difficult to cope (NMU A:XXVI; A:XXVII). When the symptoms of late stage AIDS become acute, it is impossible to remain distracted from thinking about it and one becomes very sad and acutely distressed (NMU A:XXI; A:XXII). In spite of the fact that this makes one feel abandoned and forlorn, one has to make every attempt to experience one's life light heartedly in order to cope (NMU A:XXI; A:XXII; A:XVIII; A:XIX; A:XX).

When it becomes impossible to distract oneself from thinking about having AIDS, alcohol helps to elevate one's distressed mood (NMU B:XCVII; B:XCVIII; B:XCIX; C). Alternatively one can remain occupied by doing household chores to remain distracted (NMU B:CI; B:CII; B:CIII; B:CIV).

Constant preoccupation with having AIDS results in a rapid deterioration of one's physical state and precipitate a relapse of the acute symptoms of the disease (NMU B:LIX). This is particularly evident when one thinks about it before you go to sleep (NMU A:XXVIII; A:XXIX; A:XXX; A:XXXI). One can see the effect of this clearly in others who constantly experience morbid introspection about having AIDS. Their distress results in rapid weight loss. Consequently remaining distracted from thinking about AIDS ensures one's survival, constant preoccupation with the disease could precipitate one's death. (NMU A:XXXV, A:XXXVI; A:XXXVII; A:XXXVIII; B:LX;

B:LXI). Therefore one should not distress oneself with constant thoughts about AIDS when one is in an AIDS Care centre (NMU A:XLIII; A:XLIV; A:XLV). It would be useful if there were to be a game playing area at the AIDS Care centre since games are a good way to remain distracted from thinking about having AIDS (NMU B:XCV; B:XCVI).

Care:

One needs help to cope with having AIDS (NMU C:I). This help could be in the format of inpatient or outpatient care (NMU C:II). Inpatient treatment and care is preferable since it provides the experience of more consistent, enduring, uninterrupted care that seems more nurturing and reliable (NMU C:IV; C:V; C:IX). Additionally the consistency of inpatient care ensures a sustained relationship with one's caregiver that relieves the experience of isolation due to having AIDS (NMU C:X). Outpatient treatment appears inconsistent and episodic; relapses occur between periods of care and this is distressing (NMU C:VI; C:VII; C:VIII).

An important element of care is the helping relationship (NMU B:XCII). The relationship with caregivers should be characterized by compassion and empathy (NMU B:XCIII; B:XCIV). Humour is an essential aspect of one's relationship with one's caregiver since it elevates one's mood and distracts one from thinking about AIDS (NMU C:XI; C:XIV; C:XV; C:XVI). The caring relationship reestablishes a sense of belonging or a shared sense of being human that is very affirming and reassuring (NMU C:XII; C:XIII). The abovementioned are all qualities of the helping relationship as experienced with nurses at the company clinics (NMU C:XVII; C:XVIII; C:XIX).

Since one would go to the AIDS Care Centre to die, it would be good if all one's material and physical needs were addressed while you are there (NMU B:LXXXIV; B:LXXXV; B:LXXXVII; B:XC).

Awareness of physical implications of AIDS:

When friends enquire about the reasons for AIDS related loss of body weight, it is very upsetting (NMU A:XIII; A:XV). One usually responds by denying that one is ill and claiming that one has always been slender to prevent them from discovering that one has AIDS and to keep them at a distance (NMU A: XIV; A:XVI).

One is however acutely aware of the unnatural weight loss oneself and this is very distressing. It serves as a constant inescapable, physical, tangible reminder that one has AIDS (NMU A:XVIII; A:XIX; A:XX).

Similarly AIDS related illness and opportunistic infections such as kidney problems and recurring venereal disease (other than AIDS) precipitating visits to the company's health clinic serve as unwelcome reminders that one has AIDS (NMU A:XXII; A:XXIII). When this happens and one has to visit the clinic it is as if the disease returns, physically, to one's life (NMU A:LVII). Often this is so distressing that one suffers from insomnia prior to attending the clinic (NMU A:XXIV; A:XXV; A:XXVII; A:XXVIII).

One's general physical weakness and lack of strength due to late stage AIDS also serves as uncomfortable reminders of the disease. One tires rapidly, finds it difficult to lift objects, and cannot walk far (NMU A:XXXVIII; A:XXXIX; A:XL; A:XLL; A:XLV; A:XXXV; A:XXXIV; A:XXXIX; A:XLII; A:XLIII; A:XLIV).

Prior to having AIDS, one had many material aims and goals and wanted to possess many luxuries (NMU A:LXXVIII). Once one has AIDS, however, material considerations seem less important, especially since it is clear that one will die soon and never achieve those goals or possess wealth (NMU A:LXXVIII; A:LXXIX; A:LXXX; A:LXXXI; A:LXXXII). Yet one enjoys being in one's house and listening to music.

Family and community:

Often remaining distracted from morbid preoccupation with having AIDS is very difficult. One has to avoid listening to the radio when AIDS is discussed. When friends visit and talk about AIDS, one has to withdraw from the company since one finds it acutely distressing to participate in their conversation. This is excruciatingly painful (NMU B:CVII; B:CIX; B:CX; B:CXI; B:CXIII; B:CXIV; B:CXII).

One refrains from sharing with one's family that one has AIDS since their emotional reaction to this news would make it more difficult to cope. Additionally they could reject one due to their preconceived ideas about the disease (NMU C:XXV; C:XXX; C:XXXII; C:XXXI).

Similarly one does not share the fact that one has AIDS with other members of one's community (NMU C:XXXIII). Their prejudice would prevent them from understanding the true implications of having AIDS and empathising with one (NMU C:XXXIII; C:XXXIV). They could, for example, become distressed and tell others about the fact that one has AIDS since they would not understand the importance of confidentiality regarding having AIDS (NMU C:XXXV; C:XXXVI). Their lack of empathy and understanding is evident in regular jokes about AIDS, especially when they hear about it on the radio (NMU C:XXXVII; C:XXXVIII). One experiences this as very hurtful, especially since it feels as if they are making direct references to one and one feels that they should be aware how sensitive an issue it is to one (NMU C:XXXVII; C:XXXVIII; C:XXXIX; C:XL; C:XLI).

Confidentiality:

Attending company clinics is very difficult since one fears that one's regular visits would disclose to others that one has AIDS (NMU C:XLIII; C:XLIV). Since all the other employees attend the company clinics, one fears that they would see how often one is there and ask those who work there why one comes there so often (NMU C:XLV; C:XLVI; C:XLVII). Therefore the AIDS Care Centre should not be on company grounds and confidentiality should be maintained there at all costs (NMU C:XLVIII; C:XLIX).

Attitude:

Some accept having AIDS with courage whereas others are terrified by this awareness (NMU A:I; A:II). Being informed that one has AIDS leave one feeling utterly helpless (NMU A:III; A:IV). One should not, however, allow oneself to be intimidated by having AIDS (NMU A:V). One should not allow oneself to become distressed by this or blame others for the fact that one has the disease. Continually lamenting the fact that one has AIDS is futile since no-one else is responsible for the fact that one has the disease. (NMU A: VI; VIII; IX).

Material needs:

Since one is the breadwinner alternative provision in the material needs of one's direct and extended family is an important concern and need when one has late stage AIDS (NMU A:I; A:II; A:III; A:IV). Related to this are other financial concerns such as who would cover the mortgage on one's house once one has died (NMU A:V; A:VI; A:VII).

Exercise:

Exercise is an important element of coping with AIDS. It improves one's sense of well-being and health during periods when the acute symptoms of AIDS remit (NMU C:XXI; C:XXII). Therefore the AIDS Care Centre should make provision for exercise through providing facilities (NMU C:XXIII).

Environment/physical characteristics of ACC:

The AIDS Care Centre should be in a quiet environment where one could remain undisturbed, receive care and practice one's religion (NMU B:LXXXVIII; B:LXXXIX). The AIDS Care Centre should also be clean and hygienic (NMU C:LI). There should be playing areas and large grounds for walking (NMU C:LII; C:LIII).

Hope:

One does not feel hopeless about having AIDS since one still hopes that someone may someday find a cure for this disease (NMU A: XLVI; A:XLVII).

6

An overview and evaluation of the research

Discussion:

General:

Contrary to the findings of related research (Berk, Baigis-Smith and Nanda, 1995; Doka, 1993 and Flaskerud, 1992), the interviewees in the present study articulated a distinctive pattern of psychosocial health care needs with the experience of late stage AIDS. The pattern of needs that emerged does not, however, correspond with that suggested by Mason and Wood (1994) or Marazzi et al. (1994). Whereas these researchers indicate that material needs (accommodation and concern with issues such as child care and medical facilities) are the most serious problem encountered in the later stage of AIDS, the interviewees in the present study expressed a predominant desire for support and improved coping. In support of the findings by Berk, Baigis-Smith and Nanda (1995) these differences are probably an expression of the varying needs of persons with AIDS in different settings (discussed in more detail further on).

Distraction, coping and related issues:

Active versus passive coping:

An overwhelming need to remain distracted from awareness of their illness, as a means of coping, emerged as the most important or essential aspect of the experience of having late stage AIDS for the interviewees in this research. To some extent this need could be construed as reflecting a passive coping style, characterized by avoidance (see NMU B:LXVI, B:LXXIII, B:LXXIV, B:XVII).

Despite some experiences of self-blame (NMU's A: VI, A:VIII, A:IX) that has been associated as a form of personal attribution in research with passive coping styles and depression (Grummon et al., 1994), the avoidant coping style related more to experiences of lack of social support and fears of being scapegoated for having AIDS than guilt and associated perceptions of themselves as unworthy or undeserving of care (Lindegger and Wood, 1995). Rejection and stigmatization was ascribed to others' prejudice and lack of insight rather than any personal culpability (see NMU's C:XXV, C:XXX, C:XXXII, C:XXXI). Most of the interviewees acquired the disease through heterosexual extra-marital liaisons that did not seem to result in excessive feelings of guilt or self-reproach, indicating possibly the effect of culture bound norms in communities where polygamy is, or have been until recently, customary. Lack of social support, fears of rejection and expected oppositional attitudes were experienced as coercing the interviewees to maintain a facade of health and normality in the face of emotional alienation from their families and communities. This represented to them the main contribution to an avoidant approach to coping (see NMU's B:LXIV,

B:LXV, B:LXVI, B:LXIII, L:XXIV).

In support of comparable research, stereotypes and stigmatization therefore emerged as major variables complicating the experience of living and dying with AIDS (Lindegger and Wood, 1995). The respondents in this inquiry experienced expectations of the attitudes of family members and the general public to be ambivalent at best and outright oppositional at worst (see "Family and community" as generative theme in chapter five).

This is indicative of the desperate need in the Richards Bay area for educational campaigns to reduce the high levels of public intolerance regarding HIV/AIDS.

Consequently the persons with AIDS in this research experienced, in common with the finding by O'Rawe, Amenta, and Tehan (1991), notable social isolation, extending to their families of origin. In agreement with the findings of Wood and Mason (1994) and Belyeava (1993), they also expressed a predominant concern with the social implications of their illness - particularly in terms of care for their families and children - and less concern with their health. The interviewees did not experience their families as sources of emotional/social support. Rather, they experienced them as potential burdens in terms of their emotional reactions to their illness, indicating the need for a family based approach in terms of therapeutic intervention to alleviate these sources of stress and social isolation.

Additionally the interviewees refrained from disclosing their illness to family members or friends for fear of burdening them with their problems (see NMU's C:XXV, C:XXX, C:XXXII, C:XXXI). Buuren (1992) had similar findings. Accordingly persons with AIDS often erect barriers between themselves and potential caregivers due to concerns about loss of independence, fears about burdening loved ones, or out of need to avoid the high emotional costs associated with maintaining the relationship.

Conversely, it has also been shown that caregivers withdrew from the helping relationship in the later stages of the illness due to physical or emotional exhaustion and over identification with the patient (Smith and Rapkin, 1995). The latter echoes the fears and expectations that inhibited the persons with AIDS's sharing of their HIV status with their families in the present study (see "Confidentiality" as generative theme in Appendix 7, p. 22). This indicates that there will be a need for interventions at the AIDS Care Centre aimed at assisting persons with AIDS with seeking support and working through possible resistance as well as efforts at providing supportive therapy to their friends and families.

Problem-focussed versus emotion-focussed coping:

Generally, however, the need of the persons with AIDS in this study for distraction, as a means of coping, resulted from the experience of futility related to the inescapableness of death from AIDS and the scope of a short survival time within the late stage of the illness (see "Attitude" as generative theme in chapter five). This necessitated an emotion-focussed coping style (see NMU's B:XVII, B:XVII, B:XXIX)(Grummon et al., 1994). As the acute stage of a terminal illness, AIDS represents an encounter in which their options for affecting the outcome is severely limited. Thus they made efforts to manage the emotional distress accompanying having AIDS rather than problem-focussed attempts to manage the illness itself. Emotion-focussed coping was achieved through distraction, hope (see NMU's A:XLVI, A:XLVII), the use of humour (NMU's C:XI, C:XIV, C:XV), relationship (NMU B:XCII) and to a lesser extent acceptance (see NMU's B:IX and B:X) and reappraisal to avoid constant awareness of their impending death due to AIDS and the implications thereof on their families (see NMU's A:XVI, A:X, B:LII, B:LIII, B:LIV, B:LVIII). Some of these methods have direct bearing on the characteristics of appropriate helping relationships at an AIDS Care Centre, such as the qualities of interactions experienced as facilitating transcendence (see "Care" as generative theme in chapter five).

In terms of the dimensions of social support, the interviewees experienced a primary need for emotionally sustaining help (see NMU's C:IV, C:V, C:IX). This corresponds with research regarding changes in the needs of persons with HIV/AIDS for social support with the progression of the disease. Accordingly those in the earlier stages of HIV favour informational support whereas persons with ARC or AIDS preferred emotional support (Zich and Temoshok, 1987 and Hays, 1989 in Friedland et al., 1996).

Additionally this correlates with their inadequate attempts at emotion-focussed coping (see NMU's A:XXIV, A:XXVI, A:XXVII, A:XXI, A:XXII). Their primary need for distraction, resulting in avoidance, precluded a coming to terms with having AIDS and the achievement of a sense of meaning and integration. Consequently failure to remain distracted resulted, in agreement with the findings of Mulder (1992) and Friedland et al. (1996), in depression and an increased suppression of immune response due to acute psychological distress (see NMU's A:XXI, A: XXII, A:XXVI, B:LIX, A:XXVIII, A:XXIX). This indicates that psychological intervention efforts at the AIDS Care Centre should be aimed at facilitating emotional coping with emphasis on integration.

Characteristics of the study community and the experience of late stage AIDS:

Unlike the respondents in research by Mason and Wood (1994), the interviewees in this study did not express, as mentioned, material needs as a central concern. This difference could be ascribed to bias in both samples. Mason and Wood (1995) selected 15 Zulu speaking persons of whom the majority was unemployed for their unstructured research, whereas the present study consisted of twelve interviewees presently or previously employed by companies participating in the research. Several of the companies in the Richards Bay area offer extended employment to personnel with AIDS and extensive medical and financial support when this becomes impossible. Consequently immediate financial problems and unemployment would not be such pressing concerns for the present sample as that selected by Mason and Wood (1994). Yet the interviewees in the present study express some concern at their family's survival subsequent to their death from AIDS and related issues such as down payments on mortgages and unfulfilled ideals of wealth (see under "Family" as generative theme in chapter five).

Similarly a comparison of any of the protocols in the current study with a semi-structured interview with an HIV infected person by Brouard (1992), cited in full in Appendix 5 shows notable differences in attitude towards and the experience of HIV/AIDS. One could argue that the experience of HIV would naturally be different from that of late stage AIDS. Research has shown that it is associated more with distress and dysfunction rather than better psychological adaption (Thompson et al., 1996, Lindegger and Wood, 1995). Yet the interviewee in Appendix Six seems to experience more integration and active coping in this research, indicating possibly the effects of counselling interventions that improved coping.

In support of research regarding the establishment of a drop-in centre in the Pietermaritzburg area, the interviewees in this study required the AIDS Care Centre not to be at companies for reasons of confidentiality (see "Confidentiality" as generative theme in chapter 5)[13]. Yet this again

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[13] In the explication of the original twelve protocols (see Appendix 7, p. 20) this, in conjunction with a desire not to share having AIDS with their relatives, was contrasted with the interviewees' need for a separate room in the AIDS Care Centre for being private with their visiting families. This existentially valid contradiction was considered an expression of their ambivalent attitude regarding confidentiality and support.

contrasts with the need of the person with HIV interviewed by Brouard (1992) to have a place of treatment in his community with a view to reducing prejudice and intolerance and to be near his family for emotional support (see "What kind of place would you like to go to for treatment?" in Appendix 5). Once again this indicates the possible impact of social norm change, educational projects and counselling interventions aimed at helping persons with HIV/AIDS work through resistance that may be preventing them from utilizing their available resources of social support, for which there is a dire need in the Richards Bay area.

Achievement of the aims of the needs-analysis:

The aims of this inquiry was:

- To identify and describe the comprehensive needs of persons with AIDS with the aim of generating informed recommendations as to relevant and valid services to be provided at an AIDS Care Centre in the Richards Bay area.
- To assess the available services rendered through companies as well as state and welfare structures in the Richards Bay area for addressing the needs of persons with AIDS.
- To collate this information with a view to identifying specific unaddressed needs that could be provided for at an AIDS Care Centre.

General criteria for the validity of phenomenological research:

Additionally Kruger (1988, p. 155) specifies the following criteria for phenomenological research to be valid:

- The research-interview situation should entail a description of the experience or meaning structure; that is it should focus on the researched phenomenon in its lived world context.
- Explication of the protocols should be concerned with the meaning of the data from the participant perspective.
- Essential themes should be extracted in their varying manifestations.
- The dialectic between approach, method, and content should be maintained.

Limitations of the study:

While the review of the actual research indicates that this inquiry complied with the criteria for valid phenomenological research as described by Kruger (1988), there are limitations in terms of the representativeness of the sample. The entire sample for this research was drawn from persons previously or currently employed by the organisations participating in the research. This was necessitated by the high prevalence of AIDS in the Richards Bay area which would have overstrained the limited resources of the AIDS Care Centre if care were to be provided to all. Consequently the sample consisted of income-earning, adult Zulu-speaking men only. Although this sample is representative of the target population to be served by the AIDS Care Centre, it limits the generalizability of the findings of this exploratory research.

Conclusions:

With the prospect of rapidly increasing numbers of persons with HIV/AIDS in the Richards Bay area requiring palliative care, the need for further assessment of their needs in response to the changing phenomenon of late stage AIDS and to assess the effectiveness of those providing care will be vital. Since these issues are intertwined with the effects of preventative educational campaigns, social norm change projects, therapeutic intervention with persons with AIDS and other community intervention projects influencing attitudes towards AIDS, it should serve as a valuable indicator of the varying impacts of all these factors. As such this study demands follow-up research for comparative purposes and to assess the impact of these programs.

7

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Appendixes

Appendix 1: A PROPOSAL FOR AN ANALYSIS OF THE NEEDS OF PERSONS WITH LATE STAGE AIDS IN THE Richards Bay AREA WITH A VIEW TO ESTABLISHING AN AIDS CARE CENTRE

Prepared for

ATICC

by Fred Rabbets

29 November 1995

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Introduction

The aim of this paper is to provide an outline of the research methods and procedures for analysing the needs regarding and AIDS Care Centre of persons with late stage AIDS in the Richards Bay area. To this end the proposal is divided into the aims of the needs analysis, the research design and process, a proposed schedule for implementation, conclusion, and bibliography.

Aims of the needs-analysis

The aim of this needs-analysis is:

- To identify and describe the special needs of persons with terminal-phase AIDS in the Richards Bay area, as the target population, regarding an AIDS Care Centre.
- To establish what resources are already available and what services are already provided or planned through state and welfare structures in the Richards Bay area for fulfilling these needs.
- To collate this information and to identify the specific needs to be addressed through the provision of an AIDS Care Centre.
- To generate informed recommendations as to the nature and format of care an Aids Care Centre. This will reflect ways identified by the target population as to how they want their needs to be addressed within the framework of an AIDS Care Centre.

The research design and process:

As an explication of the needs experienced by persons with late stage AIDS in the Richards Bay area this research demands a qualitative and exploratory approach. This will grant the study community the space to express their needs as they experience it and, more importantly, allow them to convey their conceptualization of the issues at stake as well as their agenda for how their needs can be met. Moreover, current psychological research emphasises the importance of generating the knowledge on which community intervention is based in the specific target community (Dokecki, 1992, Newbrough, 1992, Seedat et al., 1988).

A phenomenological research design and methods will be applied to this end along the steps indicated below:

- Identification of the phenomenon (in this case the needs of persons with late stage AIDS).
- Selection of the interviewees (phenomenological research demands as selection criteria that the interviewees should have direct experience of the researched phenomenon, be prepared to share this experience with the interviewer and be able to articulate their experience - the sample will be extended to provide coverage for idiosyncratic individual differences that may exist in the experience of late stage AIDS).
- The first person description (interview and protocol - the protocol refers to a transcribed copy of an audio taped version of the interview).
- Reading the description (protocol).
- Breaking each protocol down into natural meaning units (NMU's).
- Reduction and linguistic transformation of the natural meaning units.
- Formulating the situated structure for each subject.

- Formulating the general structure (synthesis).
- Discussion: Comparing the research results with that of related research, comparing the expressed needs with services currently rendered in the Richards Bay area to identify salient unfulfilled needs, reflecting upon the entire research procedure.
- The research report: an overview, evaluation, and recommendations.

According to Polkinghorne (1989, p. 46), the general format for phenomenological research in a broad sense may be summarized as follows:

- Gather a number of naive descriptions through unstructured interviews from persons who are experiencing the phenomenon under investigation. This will entail asking a representative sample of the target group individually the research question ("What are your specific needs as a person with AIDS?") - an unfocussed, highly projective ('projective' in the sense that the question means whatever the respondents wishes to make it mean, which in turn is the significant aspects of their experienced needs the research aims to extract). This should elicit their prereflective experiences regarding their needs and problems.
- Engage in a process of analysing these descriptions so that the researcher comes to grips with the constituents or common elements that make the experience of their needs and problems what it is.
- Produce a research report that gives a clear, accurate, and articulate description of their needs and problems that are relevant to an AIDS Care Centre. The reader of the report should get the feeling that "I understand better what it is like to experience as problems and needs during the terminal-phase of AIDS.

A proposed schedule for implementation:

Due to budgetary constraints (the grant from ALUSAF to fund the establishment of the proposed AIDS Care Centre), the proposed research will, if approved, have to be completed before February 1996. This two month period (from December 1995 to January 1996) will be employed as follows in terms of the time-structuring of the research:

- One week: Planning of research.
- Four weeks: selection of interviewees, conducting of interviews.
- Two weeks: transcription of interviews, linguistic translation, synthesis and formulation of situated structure.
- One week: Collation of needs with available services and facilities in the Richards Bay area, drawing-up and presentation of report.

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Appendix 2: The Centre for Disease Control (USA) oase definition of AIDS:

Acquired immuno-deficiency syndrome (AIDS) is an aggregate of signs and symptoms and illnesses resulting from a compromised immune system. A diagnosis of AIDS requires the definitive or presumptive diagnosis of one or more 'indicator diseases' and , depending on certain criteria, may or may not require evidence of HIV infection. The following outline is used by physicians in the United States to arrive at an AIDS diagnosis.

A. A diagnosis of AIDS can be made if laboratory HIV infection has been established and a definitive diagnosis of any of the following indicator diseases has been made - regardless of the presence of other causes of immuno-deficiency.

- Adolescents and adults with CD4 and lymphocyte counts less than 200 cells/ml
- Candidiasis or oesophagus, trachea, bronchi, or lungs
- Coccidioidomycosis, disseminated
- Cryptococcosis (extrapulmonary)
- Cryptosporidiosis with diarrhoea persisting more than one month
- Cytomegalovirus disease of an organ other than the liver, spleen, or lymph nodes in a patient older than one month.
- Herpes simplex virus infection causing a mucocutaneous ulcer (eg. In eyes, nose, mouth and genito-anal areas) that persists for more than one month; or bronchitis, neumonitis or oesophagitis caused by herpes simplex virus

in a patient older than one month.

- Histoplasmosis, disseminated
- HIV encephalopathy; also called subacute encephalopathy due to HIV; also referred to as HIV dementia or AIDS dementia complex (ADC), which is clinically defined as disabling cognitive or motor dysfunction interfering with the patient's occupation or activities of daily living, or loss of behavioural developmental milestones in the absence of a concurrent illness or condition.
- HIV wasting syndrome, defined as involuntary weight loss greater than 10% of body weight plus chronic diarrhoea or chronic weakness and fever in the absence of a concurrent illness or condition; also referred to as 'Slims disease'.
- Isosporiasis with diarrhoea persisting for longer than one month.
- Kaposi's sarcoma
- Lymphoma (primary) of the brain
- Lymphoid interstitial pneumonitis (LIP) and/or pulmonary lymphoid hyperplasia affecting a child under thirteen years of age
- Mycobacterial disease including pulmonary infection, disseminated and extrapulmonary Mycobacterium tuberculosis disease
- Non-Hodgkins lymphoma
- Pneumocystis carinii pneumonia
- Progressive multi focal leukoencephalopathy
- Salmonella septicaemia, recurrent
- Toxoplasmosis of the brain in a patient older than one month

- Any combination of at least two of the following bacterial infections within a two year period affecting a patient less than thirteen years of age: septicaemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity caused by haemophilus, streptococcus or other fever-inducing bacteria.
- Recurrent pneumonia
- Invasive cervical cancer

B. A diagnosis of AIDS can be made if laboratory evidence of HIV is positive and any of the following indicator diseases is diagnosed presumptively. (A presumptive diagnosis is generally made in situations in which the patient's condition does not permit the performance of definitive testing.)

- Candidiasis of the oesophagus
- Cytomegalovirus retinitis with loss of vision
- Kaposi's sarcoma
- Lymphoid interstitial pneumonitis and/or pulmonary lymphoid hyperplasia affecting a patient less than thirteen years of age
- Mycobacterial disease, disseminated
- Pneumocystis carinii pneumonia
- Toxoplasmosis of the brain in a patient older than one month

C. A diagnosis of AIDS can be made if laboratory evidence of HIV infection is lacking or inconclusive, but a definitive diagnosis of the following indicator diseases are made, provided other known causes of immuno-deficiency are ruled out.

- Candidiasis of the oesophagus, trachea, bronchi, or lungs

- Cryptoccosis, extrapulmonary
- Cryptosporidiosis with diarrhoea persisting longer than one month
- Cytomegalovirus disease of an organ other than the liver, spleen, or lymph nodes in a patient older than one month
- Herpes simplex virus infection causing a mucocutaneous ulcer that persists longer than one month; or bronchitis, pneumonitis or oesophagitis affecting a patient older than one month
- Kaposi's sarcoma affecting a patient below sixty years of age
- Lymphoma of the brain (primary) affecting a patient less than sixty years of age
- Lymphoid interstitial pneumonitis and/or pulmonary lymphoid hyperplasia affecting a patient less than thirteen years of age
- Mycobacterium avium complex or Mycobacterium cansaii disease, disseminated
- Pneumocystis carinii pneumonia
- Progressive multi focal leukoencephalopathy
- Toxoplasmosis of the brain in a patient older than one month

D. A diagnosis of AIDS can also be made when laboratory evidence of HIV infection is negative, if all other causes of immuno-deficiency are excluded and the patient has had either a definitive diagnosis of Pneumocystis carinii pneumonia or a diagnosis of any of the indicator diseases of AIDS and a CD4 (T4) cell count less than 400 cells/ml.

Appendix 3: World Health Organisation staging system for HIV infection and disease.

Clinical stage	Clinical features
1	• Acute retroviral infection. • Asymptomatic. • Persistent generalized lymphadenopathy. And/or performance scale 1: asymptomatic, normal activity.
2	• Weight loss (<10% of body weight.) • Minor mucocutaneous manifestations (seborrhoeic dermatitis, chronic itchy skin, onychomycosis, recurrent oral ulcerations, angular cheilitis.) • Herpes zoster in the last 5 years. • Recurrent upper respiratory tract infections. And/or performance scale 2: symptomatic, normal activity.

Clinical stage	Clinical features
3	- Weight loss, > 10% of body weight. - Unexplained chronic diarrhoea > 1 month. - Unexplained prolonged fever (intermittent or constant) > 1 month. - Oral candidiasis. - Vulvo-vaginal candidiasis > 1 month or unresponsive to therapy. - Oral hairy leucoplakia. - Pulmonary TB in the last year (modify for SA) - Severe bacterial infections (modify for SA) And/or performance scale 3: bedridden < 50% of the day during the last month.

Clinical stage	Clinical features
4 AIDS Defining Conditions	• HIV wasting syndrome (defined). • PCP. • Toxoplasmosis of the brain. • Cryptosporidiosis with diarrhoea, > 1 month. • Cryptosporidiosis, extrapulmonary. • CMV (disease of an organ other than liver, spleen or lymph nodes). • Herpes simplex infection: mucocutaneous > 1 month; visceral (any duration). • Progressive multi focal leuko-encephalopathy. • Any disseminated endemic mycosis (i.e. histoplasmosis, coccidioidomycosis). • Candidiasis (oesophagus, trachea, bronchi or lungs). • A typical mycobactriosis, disseminated. • Non-typhoid salmonella septicaemia. • Extrapulmonary TB. • Lymphoma. • Kaposi's sarcoma. • HIV encephalopathy, as defined. And/or performance scale 4: bedridden >50% of day/last month.

Appendix 4: Protocols and linguistic translation

The following are linguistic translations of three of the protocols used in the research. Each Natural Meaning Unit in the protocols are assigned a roman numeral, used as reference in the central and generative themes explicated from them.

The protocols are numbered alphabetically (A, B, and C) and this letter precedes each relevant roman numeral as reference to the Natural Meaning Unit in the relevant protocol.

A: Central theme	Description
I.Attitude to having AIDS	Some accept having AIDS with courage whereas others are terrified by this awareness(NMU I; II). Being informed that one has AIDS leaves one feeling utterly helpless (NMU III; IV). One should not allow oneself to be intimidated by the fact that one has AIDS(NMU V). One should not allow oneself to become distressed by it or blame others for having the disease (NMU VI). Continually lamenting the fact that one has AIDS is futile since no-one else is responsible for one's having the disease (NMU VIII; IX).
II.Coping	I can cope with having AIDS alone by remaining distracted from thinking about it for at least one week (NMU X; XI).Accessional, when one thinks about the fact that one has AIDS, one becomes aware of its distressing and destructive impact on one's life (NMU XII; XIII). One should avoid morbid introspection about AIDS and its destructive impact on one's life (NMU XIV). If one remains occupied by a variety of activities it is easier to remain distracted from thinking about having AIDS (NMU XVI). If one cannot remain distracted by being busy or through participating in activities one becomes distressed and coping with having AIDS becomes very difficult (NMU XXIV; XXV).

A: Central theme	Description
	When daily activities become monotonous it becomes very difficult to cope with AIDS by remaining distracted (NMU XXVI; XXVII).
	When the symptoms of AIDS become acute it is impossible to remain distracted and one becomes sad and distressed (NMU XVIII; XIX; XX). In spite of this distress one has to attempt to experience life light heartedly and cope (NMU XXI; XXII). Yet one feels abandoned and forlorn occasionally.
	If one thinks about having AIDS continually one's condition deteriorates rapidly; this is particularly evident if one thinks about AIDS when going to bed (NMU XXVIII; XXIX; XXX; XXXI). One can see that others with AIDS who morbidly introspectize about the disease loose weight rapidly because they remain distressed by having AIDS instead of being distracted from thinking about it (NMU XXXV; XXXVI; XXXVII; XXXVIII).
	Therefore one should not distress oneself or others when one is in an AIDS Care Centre by remaining preoccupied with having AIDS (NMU XLIII; XLIV; XLV).
III.Hope	I do not feel hopeless about having AIDS since I still hope that someone may find a cure for this disease (NMU XLVI; XLVII).

Natural Meaning Unit	Linguistic translation
• Some people are brave,	I. Some face having AIDS with courage (attitude)
• some people are...scared.	II. Some are terrified by the experience of having AIDS (attitude)
• Once they tell you...hey you have AIDS	III. When being informed that one is HIV+(attitude)
• it's like a baby	IV. One feels helpless (attitude)
• I can say 'I don't mind',	V. I believe having AIDS should not affect me (attitude).
• I'm not always going to cry at other people saying 'they did it to me'.	VI. One should not continuously, in distress, accuse others for having AIDS(attitude)
• That is what I tell myself:	VII. This is what I say to myself regularly(attitude)
• 'always complaining is useless,	VIII. Continuously lamenting about having AIDS is futile(attitude).
• nobody sent you there'.	IX. No one else is responsible for one's having AIDS (attitude/attribution).
• Because I can take it out with myself,	X. I can cope with having AIDS alone (attitude),
• for even a week without thinking about it.	XI. by remaining distracted from thinking about it for up to a week (distraction).
• Sometimes when I think about it,	XII. When I occasionally think about having AIDS (coping)
• I think 'Hey, it's shit',	XIII. I realize how miserable it is to have AIDS(coping)

Natural Meaning Unit	Linguistic translation
• but I'm not always just thinking by myself 'what, what?'	XIV. I avoid morbid introspection about AIDS and its implications for my life(distraction).
• In terms of my needs...yaah,	XV. As far as my needs are concerned (needs):
• I need so many things to keep busy all the time,	XIII. I need a wide variety of activities to remain continually occupied (distraction).
• then there's the AIDS,	XIV. When I become aware of having AIDS (distraction)..
• when things are just like this,	XV. At times like the present when the symptoms are acute (distraction).
• it's worse...	XVI. I become distressed (distraction).
• There's no griefs,	XVII. I try not to be sad (coping).
• everything's happy,	XVIII. In spite of the distress I will cope(coping)
• everything floats.	XIX. I try to take life lightheartedly (coping).
• Maybe I just feel lonely sometimes.	XX. Occasionally I feel abandoned and forlorn (coping)
• If you've got nothing to do,	XXI. If one cannot remain distracted by being busy(distraction)
• to play or what,	XXII. Through activities, etc (distraction).
• then it's difficult,	XXIII. Coping with AIDS becomes distressful(distraction)
•	

Natural Meaning Unit	Linguistic translation
• or when there are similar days,	XXIV. When daily activity becomes monotonous(distraction)
• When you think about it,	XXV. When one thinks about having AIDS (distraction),
• it can make you worse,	XXVI. One's condition deteriorates rapidly(distraction).
• when you go to sleep,	XXVII. When one falls asleep (distraction)
• but you're always thinking about it,	XXVIII. while being preoccupied with having AIDS (distraction)
• you keep on growing worse, very fast, very fast.	XXIX. One's condition deteriorates rapidly (distraction)
• Because you know,	XXX. One can see (distraction)
• some people when they are sick,	XXXI. Some persons with AIDS(distraction)
• they become so thin so very fast,	XXXII. rapidly loose weight(distraction)
• because they are always thinking about it,	XXXIII. Due to their morbid introspection about having AIDS(distraction).
• worrying...	XXXIV. And resulting distress about having AIDS(distraction).
• So when you are there at an AIDS Care Centre,	XXXV. When one is treated in an ACC (distraction).
• something like that,	XXXVI. Or similar institution
• then it's good.	XXXVII. It would be good to...
• It's like that,	XXXVIII. One should...

Natural Meaning Unit	Linguistic translation
• you mustn't worry the other people too much,	XXXIX. not distress others (by one's preoccupation with having AIDS(distraction).
• you mustn't worry yourself...	XL. One should not concern oneself (about having AIDS) (distraction).
• then it can be good.	XLI. Then being at an ACC would be beneficial (distraction)
• I haven't lost hope,	XLII. I do not feel hopeless about having AIDS(hope)
• maybe someday people somewhere may find a way to cure this thing.	XLIII. Hopefully someone will find a cure for AIDS(hope).

B. Central theme	Description
I.Family	Since one is the breadwinner alternative provision for the material needs of one's direct and extended family is an important need when one has late stage AIDS (NMU I; II; III; IV). Related to this is other financial concerns such as who would cover the mortgage on one's house once one has died (NMU V; VI; VII).
II.Coping	The fact that one has AIDS and its destructive impact on one's life is inescapable (NMU IX; X). Therefore having AIDS is very distressing (NMU XI). Since there is no cure for AIDS all one can do is to prevent others being infected by AIDS through sexual intercourse with one (NMU XXVII; XXVIII; XXIX). This is especially important since AIDS is such a destructive terminal disease that even the strong have no resistance against it (NMU XXX; XXXI). In order to cope with having AIDS one has to remain distracted from thinking about it by remaining actively occupied (NMU XXXII; XLVI; XLIX). This is the only way one can enjoy the remainder of one's life to the full (NMU XLVIII). One should resume as normal a lifestyle as possible (NMU L). It is important to avoid being alone when one has AIDS to avoid morbid introspection about the disease (NMU XXXIII). One should only remind oneself occasionally about the presence of One becomes acutely aware of having AIDS when experiencing AIDS related weight loss (NMU XII). This is especially distressing when friends inquire the reasons for it

B. Central theme	Description
	presence of AIDS in one's life and its destructive impact (NMU LI). Generally one should distract oneself from this immediate reality since avoiding constant preoccupation with having AIDS prevents one from coping with the disease (NMU LII; LIII; LIV; LVIII; CV; CVI) since it causes distress. This is why there should be a game-playing area at an AIDS Care Centre since games are useful for remaining distracted (NMU XCV; XCVI). Constant preoccupation with having AIDS can premeditate a relapse of the acute symptoms of the disease (NMU LIX). In this way thinking about the terminal nature of AIDS can cause one to die earlier (NMU LX; LXI). When it becomes impossible to distract oneself from thinking about having AIDS, one uses alcohol to elevate one's mood (NMU XCVII; XCVIII; XCIX; C). Alternatively one can remain busy through doing household chores to stay distracted from thinking about AIDS (NMU CI; CII; CIII; CIV). Often remaining distracted is very difficult, one has to avoid listening to the radio when AIDS is discussed and when visitors discuss AIDS one has to withdraw from the company and be alone since you cannot participate in the conversation (NMU CVII; CIX; CX; CXI; CXIII; CXIV). This is excruciating (NMU CXII).

B. Central theme	Description
	Initially, on being informed that one is HIV+, one feels angry and talks angrily to others (LXIII; LXIV). This is harmful since others become aware that one is distressed and suspect that one is ill (NMU LXIV; LXV), Therefore one becomes distracted from thinking about AIDS and pretend that everything is normal (NMU LXVI) . Generally, significant others do not seem to be aware of the fact that one is keeping them at a distance in this way. (NMU LXVII). Some, but very few, of the people in one's life seem to suspect that one has AIDS since I was slender and my weight loss is not that obvious (NMU LXVIII; LXIX; LXX). Others seem to think that the opportunistic infections of AIDS one experiences are those illnesses in themselves and not linked to AIDS (NMU LXXII). When others say that they think one has AIDS, one uses humour to distract them from thinking this and to keep them at a distance (NMU LXXIII; LXXIV)

B. Central theme	Description
III. Awareness of having AIDS	When friends inquire about the reasons for AIDS related weight-loss, it is very upsetting NMU XIII; XV). One usually responds by denying illness and claiming that one has always been slender to keep them at a distance (NMU XIV; XVI). One is, however, acutely aware of the unnatural weight-loss oneself and this is very distressing since it serves as a constant reminder that one has AIDS (NMU XVIII; XIX; XX).

B. Central theme	**Description**
	Similarly AIDS related illness such as recurring venereal disease and kidney problems precipitating visits to the health clinic at the company serve as uncomfortable reminders that one has AIDS (NMU XXII; XXIII). When one visits the clinic it is as if the disease returns, physically, to one's life (NMU LVII). Often this is so distressing that one suffers from insomnia before visiting the clinic (NMU XXIV; XXV; XXVII; XXVIII). Similarly general weakness and lack of strength reminds one that one has AIDS when one tires quickly, find it impossible to lift objects, or find it difficult to walk far (NMU XXXVIII; XXXIX; XL; XLL; XLV; XXXV; XXXIV; XXXIX; XL; XLII; XLIII; XLIV). Prior to having HIV, one experienced a lot of material ambition and wanted to possess luxuries (NMU LXXVIII). Once one has AIDS, however, material considerations do not seem important, especially since it is clear that one will never achieve one's material goals in life and die soon (NMU LXXVIII; LXXIX; LXXX; LXXXI; LXXXII). Yet one enjoys being at one's house and listening to music.

B. Central theme	Description
Care	It would be nice if all one's material and physical needs were to be addressed at the AIDS Care Centre once one goes there to die (NMU LXXXIV; LXXXV; LXXXVII; XC). The AIDS Care Centre should be in a quiet environment where one could remain undisturbed, receive care and practice one's religion (NMU LXXXVIII; LXXXIX). An important element of care is the helping relationship (NMU XCII). This relationship with caregivers should be characterized by compassion and empathy (NMU XCIII; XCIV).

Natural Meaning Unit	Linguistic translation
• Actually as someone with AIDS,	I. As a person with late stage AIDS,
• I need someone to look after my children, my family, my parents,	II. a need for alternative provision of the material needs of one's family and extended family (family)
• because I'm the only to, the only one earning,	III. Since one is the breadwinner (family)
• and I've got two children, a brother and a sister.	IV. Number of direct dependants (family)
• The other thing,	V. A related issue is...(family)
• I live out near Esikaweni,	VI. my home, near Esikaweni(family)
• so I don't know who will take over when I'm dead, the down payments.	VII. Concern about the payment of the mortgage on one's house once one has died from late stage AIDS (family)
• This is the main thing, the main thing:	VIII. This is the primary issue(coping):
• I've got it, I've got it,	IX. The fact that I have AIDS is inescapable (acceptance-coping).
• so either way there's no other way.	X. It's impact on my life is inevitable(acceptance-coping).
• It's a really big trouble.	XI. It is very distressing(coping).
• I haven't always been so thin like this,	XII. It is evident in AIDS related thinning (awareness)
• but I wasn't a tough guy as well.	XIII. I have always been slender.

Natural Meaning Unit	Linguistic translation
• Later this year friends started to ask: "But why do you go down like this, but why?"	XIV. Friends inquire about the sudden loss of weight(coping - friends).
• Then I say: "But no man I wasn't a big guy".	XV. One responds by claiming weight loss is not unnatural since one was always slim (coping - friends).
• They say: "No, you are going down, can't you see?"	XVI. Friends insist weight loss is unnatural (coping)
• I say "No".	XVII. One denies it (coping).
• I keep on getting people asking me "Why?"	XVIII. The distressing experience of others continually questioning one about the symptoms of AIDS(awareness).
• Like the other day I look at myself,	XIX. One becomes aware of the physical impact of AIDS on one's body(awareness).
• I check my trousers here, it's becoming loose,	XX. Awareness of AIDS related thinning(awareness)
• hey, something is wrong.	XXI. Thinning is distressing evidence of acute AIDS (awareness)
• But the other thing is,	
• I suffer from kidneys the other day,	XXII. Experience of kidney problems related to AIDS(awareness)
• so I thought maybe my kidney trouble is coming back,	XXIII. Assumption that it may just be kidney problems in itself (awareness).

Natural Meaning Unit	Linguistic translation
• but then I hear: “no, the kidney trouble is not coming back, it’s because of the AIDS problem,	XXIV. Informed that kidney failure results from AIDS (awareness)
• and the other day I come here to the clinic. I’ve got a VD..	XXV. Mention of visit to clinic for treatment for venereal disease(awareness).
• hey, I worry so very much,	XXVI. Venereal disease as reminder of AIDS contributes to severe anxiety(awareness).
• I didn’t sleep at all, I didn’t sleep at all, I didn’t sleep at all...	XXVII. Severe insomnia, experienced as acutely distressing, due to concern about venereal disease and AIDS(awareness)
• There’s nothing you can do.	XXVIII. Experience of futility due to having AIDS(coping)
• The best thing you can do is to prevent it not to go to other people,	XXIX. All one can do is to prevent the spread of AIDS (coping)
• that’s why I make sure when I’m wearing it, I’m wearing it, not to infect other people,	XXX. This why it is important to use condoms (coping).
• because it’s a dangerous disease.	XXXI. Prevention is especially important since this is a terminal disease (coping).
• Big guy he come one time with something like this, one time, one time...	XXXII. Even the strong have no resistance against AIDS(coping).
• I need to go out sometimes	XXXIII. Need for avoidance/distraction

Natural Meaning Unit	Linguistic translation
• I don’t want to stay in a room when I’m like this.	XXXIV. One needs to avoid being alone when you have AIDS (coping).
• I’m loosing power,	XXXV. One becomes weak when you have AIDS (awareness).
• I don’t have any power anymore now,	XXXVI. One feels very weak (awareness).
• something is very heavy, I don’t touch it.	XXXVII. One cannot lift heavy objects (awareness).
• When I am all by myself I can’t lift it up.	XXXVIII. Alone one cannot lift heavy objects (awareness).
• Even walking now,	XXXIX. Less strenuous activities such as walking becomes difficult when one has AIDS (awareness).
• I can’t walk a long distance,	XL. It becomes difficult to walk far(awareness).
• I am tired very soon.	XLI. One tires quickly (awareness).
• If I am walking a long distance,	XLII. When one needs to walk far...(awareness).
• I must leave early,	XLIII. One needs to leave early.
• then I realize something is wrong.	XLIV. Physical weakness, as a symptom of AIDS, causes increased awareness of the disease(awareness).

Natural Meaning Unit	Linguistic translation
• I have to walk a lot.	XLV. Necessity for frequent walking (awareness).
• AIDS is bad,	XLVI. AIDS is destructive (awareness)
• but once you've got it,	XLVII. Once one has AIDS (awareness).
• you better forget,	XLVIII. One should remain distracted from being aware of having AIDS (coping).
• try to be happy for the last time,	XLIX. In order to enjoy the remainder of one's life to the full (coping).
• rather don't keep on thinking about it,	L. One should avoid constant rumination/preoccupation about the fact that one has AIDS (coping).
• you must just go back.	LI. One should return to living as normal a lifestyle as possible (coping).
• Just tell yourself 'it's bad' sometimes,	LII. One should only remind oneself of the destructive impact of AIDS on one's life occasionally (coping).
• don't take now as now.	LIII. One should distract oneself from the immediate reality of AIDS in one's life (coping).
• I feel like that,	LIV. I feel that this is the way to cope with AIDS (coping).
• I don't always think about it.	LV. I avoid constant preoccupation with AIDS (coping).
• I will try to forget it.	LVI. I will try to forget that I have AIDS(coping).
• It's only when I come here to the	

Natural Meaning Unit	Linguistic translation
clinic	LVII. When one attends the clinic (awareness)
• I think 'that thing is back again'.	LVIII. When this reminds one of having AIDS it is as if the disease returns, physically, to one's life (coping).
• It's not good to think about it all the time,	LIX. One should avoid continually thinking about having AIDS (coping).
• you may make a lot of sickness.	LX. Preoccupation with having AIDS contributes to illness and a relapse of symptoms (coping).
• Sometimes it may kill people to know they are going to die,	LXI. Preoccupation with the knowledge that AIDS is terminal can precipitate one's death from it (coping).
• which is not good.	LXII. It is bad to premeditate one's death in this way (coping).
• But before, for the first time,	LXIII. Initially, on being informed that one is HIV+(coping).
• I was very angry,	LXIV. One feels angry.
• but I told myself "Hey, every time I'm talking to the other people it's very harmful",	LXV. One realizes that talking angrily to others is harmful (coping).
• I say this is not good, because they can see that there is something wrong with me,	LXVI. This is harmful to one since others then become aware that one is distressed and ill (coping).
•	

Natural Meaning Unit	Linguistic translation
• and after that I just forgot.	LXVII. Then one avoids thinking about having AIDS.
• some of them see me that I've got it,	LXVIII. Some of the people in my life seem to be aware of the fact that I have AIDS (coping).
• some, few of them, just suspect,	LXIX. A few others suspect that I have AIDS (coping).
• because I was just a small guy, I wasn't a big guy...	LXX. Since I was slender, my thinning due to AIDS isn't that obvious (coping).
• and sometimes when I'm ill with TB or what what,	LXXI. When one experiences AIDS related infections(coping).
• then they just think that I've got that.	LXXII. Others seem to think that the opportunistic infections are not related to AIDS (coping).
• I make a joke of it when others say "hey, you've got AIDS",	LXXIII. One uses humour to distract others from becoming aware that one has AIDS (coping).
• just to keep them away.	LXXIV. To prevent others from becoming aware that one has AIDS (coping).
• All we can do is to pray for that maybe someday someone will get a medicine for this fucking disease,	LXXV. All one can do is to pray that someone will find a cure for AIDS (hope).
• before we die sometime.	LXXVI.Hopefully a cure for AIDS will be found before one dies (hope).
• That's what we are praying for.	

Natural Meaning Unit	Linguistic translation
• Money... one knows that those things are over,	LXXVII. Resignation to material loss.
• you wont have them anymore.	LXXVIII. Since one has AIDS one will not achieve one's material aims (awareness).
• Just like I used to buy cars, now I can see that there is no use to buy a car anymore,	LXXIX. One used to purchase vehicles, now this seems futile (awareness).
• because I will die soon.	LXXX. Since one will die soon from AIDS, material possession is not important (awareness).
• But I can enjoy fully my house, music, and everything.	LXXXI. Yet one enjoys being at one's house and listening to one's music (awareness).
• That house, that place, you know when you know you are going to die,	LXXXII. The AIDS Care Centre, where one goes before one dies from AIDS (care).
• you want to know you can get everything you want there,	LXXXIII. One wants to know that all your needs will be addressed at the AIDS Care Centre (care).
• you don't want anyone to disturb you,	LXXXIV. One wants to remain undisturbed at the ACC (care).
• and you want you're own T.V. and radio, nice bed, you get food anytime you want.	LXXXV. Physical aspects of care at the ACC.(care)

Natural Meaning Unit	Linguistic translation
• I think it must be in a still place like a church,	LXXXVI. The AIDS Care Centre should be in a quiet, peaceful environment (care).
• you know - where they can give you care and you can worship.	LXXXVII. The ACC should be a place where one can receive care and practice one's religion (care).
• And something like a swimming pool,	LXXXVIII. One would want a swimming pool(care).
• but of course guys like us can't swim anymore, one can't go to the beach,	LXXXIX. Due to AIDS related physical deterioration one would not, however, be able to use sporting facilities (care).
• Nice people must help me,	XC. Help should entail caring interpersonal relationships (care).
• people with friendship, you know,	XCI. The helping relationship should be characterized by empathy and caring(care).
• I think one needs people like that.	XCII. Compassionate, empathic helpers are an important element of care (care).
• And it has to have a place for playing games,	XCIII. The ACC should have an area for playing games (care).
• to distract me...	XCIV. Remaining busy through working facilitates distraction (coping)

Natural Meaning Unit	Linguistic translation
• When I can't distract myself,	XCV. When activity fails to distract one from thinking about AIDS(coping),
• I just go drinking,	XCVI. Alcohol use serves as a another form of distraction (coping)
• or try to do my other job outside, you know,	XCVII. Supplementary work serves as another source of distraction(coping).
• do something around the house,	XCVIII. Doing household chores helps one to remain distracted(coping).
• when I do that the thing is gone.	XCIX. When one remains distracted in this way AIDS seems to disappear, physically, from one's life(coping).
• It's better just to take your mind of it.	C. It is better to remain distracted from thinking about AIDS than to think about it continually(coping).
• It's not easy when AIDS comes to your mind,	CI. It is difficult to cope with thinking about AIDS (coping).
• that you've got this fucking thing,	CII. It is acutely distressing and frustrating to think about the fact that one has AIDS(coping).
• you listen to the radio, there they talk about it, better that you switch the radio off.	CIII. One should avoid listening to the radio when AIDS is discussed since it makes one think about it (coping).

Natural Meaning Unit	Linguistic translation
• When somebody is talking about it next to you,	CIV. When one overhears someone discussing AIDS (coping).
• you think: 'hey, here comes the story'.	CV. One becomes painfully aware of having AIDS again (coping).
• So I think my biggest need is to forget,	CVI. One's biggest need is not to think about AIDS (coping)
• not to think about something nobody can fix.	CVII. since it is futile while there is no cure and it cannot change anything(coping)

C. Central theme	Description
I.Care	One needs help to cope with having AIDS (NMU I). This help could be in the format of inpatient or outpatient care (NMU II). Inpatient treatment is preferable since it provides more consistent, enduring, uninterrupted care that seems more nurturing and reliable (NMU IV; V; IX). The consistency of inpatient care assures a sustained relationship with one's caregiver that relieves isolation experienced due to having AIDS (NMU:X). Outpatient treatment appears inconsistent and episodic; relapses occur between periods of care and this is distressing (VI; VII; VIII). Humour is an essential aspect of the helping relationship with a caregiver since it elevates one's mood and provides distraction from thinking about AIDS (NMU XI; XIV; XV; XVI). The caring relationship reestablishes a sense of belonging or shared sense of being human (NMU XII; XIII). The aforementioned are all qualities of the caring relationship experienced with nurses at the company clinics (NMU XVII; XVIII; XIX).

C. Central theme	**Description**
II.Coping	Exercise is an important element of coping, it improves one's sense of health and well-being when the acute symptoms of AIDS remit. The AIDS Care Centre should make provision for a variety of forms of exercise and sport (NMU XXI; XXII; XXIII). One refrains from sharing that one has AIDS with one's family since this would make it more difficult to cope when they react emotionally or reject one due to their preconceived ideas (NMU XXV; XXX; XXXII; XXXI). Moreover, one needs to remain distracted from thinking about having AIDS. Therefore one maintains as normal as possible a lifestyle at home and pretend that everything is as usual (NMU XXVII; XXVIII). One does not share having AIDS with others in one's community either (NMU XXXIII). Since they are rural persons their preconceived ideas about AIDS would prevent them from having empathy or to understand the true implications of having AIDS (NMU XXXIII; XXXIV). They would for example become distressed and tell others that one has AIDS, without realizing the importance of confidentiality (NMU XXXV; XXXVI). Their lack of empathy and understanding is evident in regular jokes about AIDS, especially when they hear about it on the radio (NMU XXXVII; XXXVIII). This is very hurtful, especially since it feels as if they are making direct references to one in the process and that they should be

C. Central theme	Description
	aware of how sensitive an issue it is to one (NMU XXXVII; XXXVIII; XXXIX; XL; XLI).
III. Confidentiality	Attending the company clinic is difficult since one fears that one's regular visits would disclose to others that one has AIDS (NMU XLIII; XLIV). Since all the other employees attend the company clinic, one fears that they would often see one there and ask those there why one is there so often (NMU XLV; XLVI; XLVII). Therefore the AIDS Care Centre should not be on company property and confidentiality should be maintained there at all costs (NMU XLVIII; XLIX).
IV. Physical needs regarding ACC	The ACC should be clean and hygienic (NMU LI). There should be playing areas and large grounds for walking (NMU LII; LIII).

Natural meaning units	Linguistic translation
• To live longer than this,	I. a need to *extend* one's *lifetime* beyond death from AIDS.
• we need care...yes we need care,	II. Acknowledgment of the *need for help* to cope with having AIDS (care).
• and...or, maybe hospital-like or clinic	III. expressing the belief that the care/help could be in the format of *inpatient or outpatient* treatment (care).
• but I think hospital is better	IV. Expressing a *preference for Inpatient treatment* to outpatient treatment (care)
• because you get a longer time for someone to care for you,	V. Inpatient treatment provides more *consistent, enduring care* than outpatient treatment(care).
• because the thing is	VI. The problem with outpatient treatment is (care):
• in the clinic you just go, you go home	VII. Outpatient treatment is inconsistent (care), episodic(care).
• maybe it becomes worse again	VIII. During the intervals between outpatient treatment relapses occur (care).
• then you must go back to the clinic again	IX. The relapses necessitates a return for outpatient treatment(care).

Natural meaning units	Linguistic translation
- In the hospital you just go there you get someone to care for you.	X. Inpatient treatment is uninterrupted inpatient treatment ensures a sense of a *sustained caring relationship (care)*.
- It's difficult to say what sort of care you need,	XI. It is complex to specify the nature of help/treatment required(care).
- you get someone to look after you,	XII. Emphasis on a *caring relationship* as an essential element of help (care)
- one who is always concerned,	XIII. The helping relationship should be characterized by *nurturing care (care)*
- to make you not feel always lonely,	XIV. A caring relationship *relieves isolation* resulting from having AIDS. (Care)
- always try to make some jokes,	XV. Emphasis on *humour* as aspect of caring relationship(care).
- makes you to feel that every person is alike	XVI. Caring relationship reestablishes *sense of belonging*, shared sense of being human (care).

Natural meaning units	Linguistic translation
• it makes you feel alike...yes.	XVII. As above(care)
• This someone must tell you some jokes, • something like that,	XVIII. Emphasis on *humour* as essential aspect of caring relationship(care).
• you know to always feel happy.	XIX. Humour provides *distraction* from thinking about having AIDS, providing a sense of well-being(care).
• The sisters at the (company) clinics are like that...	XX. The care by nurses at Company clinics provide humour and a sense of belonging(care).
• they are always good to me, yes.	XXI. Confirmation that nurses at clinics are very caring(care)
• They talk to me nicely always,	XXII. Affirmation of empathy, care evident in relationship with nurses at clinics(care)
• then try to make you not feel like a person who is lost.	XXIII. Reemphasis on sense of belonging, shared sense of being human as a result of caring relationship with nurses at clinics.

Natural meaning units	**Linguistic translation**
• What I want too is, when I feel a little better, I must make do a little jog, jogging, • And when you're a little better, do a little jogging, to go too...	XXIV. A need for *exercise* (particularly running or soccer) during periods when full-blown symptoms of AIDS remit(coping).
• to make you go too, to make you feel right.	XXV. *Exercise* improves one's sense of health and well-being(coping)
• I was playing football...soccer	XXVI. Mention of having played soccer before onset of acute symptoms of AIDS(coping)
• the place must make facilities for different sports, because, maybe ten people like different sport.	XXVII. Emphasis on need for variety of *sport* facilities at ACC to cater for varying interests(coping)
• At home	XXVIII. how one copes with having AIDS in the home environment(coping)
• I just be quiet	XXIX. one refrains from mentioning that one has AIDS at home(coping).
• and do as usual	XXX. Participating in the usual activities to maintain appearance of normality(coping)

Natural meaning units	Linguistic translation
• I am running away from this condition!,	XXXI. Overwhelming need to remain *distracted* from thinking about having AIDS(coping).
• not to think,	XXXII. Avoid thinking about having AIDS, to remain *distracted(coping)*
• maybe I will tell those at home later,	XXXIII. intention to share having AIDS in future with *family(coping)*
• it wont make it easier for me to tell them	XXXIV. sharing having AIDS with *family* will increase emotional burden of condition(coping)
• because these are rural people	XXXV. It is more *difficult to share* having AIDS with rural persons(coping)
• they take it very seriously	XXXVI. Rural persons react emotionally to awareness of person's having AIDS(coping)
• they won't easily understand, aai...it's hard for them to understand,	XXXVII. Rural persons have preconceived ideas about AIDS that prevents empathy with person with AIDS (coping)

Natural meaning units	Linguistic translation
• even if I could find a way to tell them,	XXXVIII. Their preconceived ideas remain irrespective of how one shares it with them (coping)
• maybe someone will come and they are crying -	XXXIX. Expectation that other, when told, may become distressed (confidentiality)
• they are going to tell the others,	XL. Fear that distress may cause person to be compelled to tell others despite confidentiality (confidentiality).
• they don't know it's confidential.	XLI. Rural persons do not understand the necessity for one's having AIDS to be kept confidential (confidentiality)
• They always talk like the AIDS, joke like it,	XLII. Rural persons often joke about AIDS (coping/confidentiality)
• they always joke about it	XLIII. People in the rural area joke about AIDS -
• when they hear it on the radio,	XLIV. especially at times of hearing about it on the radio (coping).
• when they know that it would hurt me,	XLV. It seems as if they should be aware of the fact that joking about it would hurt one as a person with AIDS(coping).

Natural meaning units	Linguistic translation
• because I think they are talking about me,	XLVI. It is especially hurtful since it seems as if they are referring to one.
• every time.	XLVII. It feels this way each time they do this (coping).
• It's not easy at the clinic,	XLVIII. Visiting the clinic is difficult (confidentiality).
• because maybe everybody knows why are you there,	XLIX. One fears that visits to the clinic would make others aware that one has AIDS (confidentiality).
• you won't feel happy	L. It is uncomfortable to attend the clinic (confidentiality).
• because everybody goes in there, the workers,	LI. Since everyone attends the clinic (Confidentiality)
• and they always see you there,	LII. and one is often seen there (confidentiality)
• maybe they will ask anyone there: why is he always here?	LIII. one fears that it will result in a breach of confidentiality when they enquire why one is there so often(confidentiality).
• I think it's better when this place is not in company,	LIV. The AIDS Care Centre should not be in company grounds (confidentiality)
•	

Natural meaning units	Linguistic translation
• when it's somewhere else	LVI. The ACC should not be on company property(confidentiality).
• and when it's strictly confidential	LVII. At the ACC strict confidentiality should be maintained (confidentiality)
• and maybe this place will be clean, yes,	LVIII. The ACC should be neat, hygienic (needs)
• and there must be playgrounds	LIX. The ACC should have playing areas (needs)
• it must be a bigger place to walk about,	LX. There should be large areas for walking (needs)
• that's all.	LXI. End of interview.

Appendix 5:

Available services and facilities rendered through state and welfare structures in the Richards Bay area for persons with late stage AIDS.

Introduction

This appendix documents the services and facilities available to persons with full-blown AIDS in the Richards Bay area. The services and facilities are categorised as physical, psychological, and spiritual with subdivisions of primary, secondary, and tertiary care where appropriate. All information were provided by caregivers in the relevant organisations.

Definitions of key terms

The following provides operational definitions of modes of treatment and facilities used as operational categories to structure the analysis of services available to persons with full-blown AIDS in the Richards Bay area:

Primary medical care:

This refers to first-order medical intervention - usually uncomplicated procedures required for the maintenance of basic health. Practically, in the case of the PWA's, this could for example be receiving medication for diarrhoea associated with AIDS from the clinics.

Secondary medical care:

Secondary medical intervention refers to more complex procedures, usually requiring hospitalization with a view to reestablishing normal health. An example would be when persons with late stage AIDS are treated in hospitals as inpatients for severe dehydration associated with AIDS-related diarrhoea.

Tertiary medical care:

Also known as terminal care, this refers to medical intervention aimed at relieving the symptoms of a terminal disease without the prospect of restoring normal health. During late stage AIDS this would entail treatment for severe infections to ease the dying process.

Counselling:

The World Health Organisation (WHO) Global Programme on AIDS (GPA) has proposed that HIV related counselling seeks to encourage self-determination, enhance self-confidence, improve family and community relationships and, through them, support the quality of life of those most affected by HIV (Carballo and Miller, 1989 in Lindegger and Woods, 1994). Balmer (1991, in Lindegger and Wood, 1994) suggests that the WHO/GPA guidelines separate counselling objectives into two broad categories:

- to prevent HIV infection,
- and to provide psychosocial support for those already infected.

The responsibility for the former has largely been assumed by the paramedical profession, whereas that of the latter has been largely assumed by non-governmental organisations and groups of people with AIDS. Balmer (1991, in Lindegger and Wood, 1994) argues that there is a need for psychosocial counselling which is independent and separate from the medical setting, best situated within the community served.

Home-based care:

The provision of most of the above services in the home environment by trained nurses visiting persons with full-blown AIDS on a routine basis.

The following is a summary of the services and facilities available to persons with late stage AIDS through organizations in the Richards Bay area.

Organisation	Contact person	Medical care	Material/financial support	Psychological care	Social care	Spi l ca
ATICC	Ms. A. Potgieter; ph.: 0351-21131	• HIV-testing	• Legal and ethical issues workshop	• Pre-and post-test counselling • Ongoing counselling • Couples counselling • Rape counselling • Training of HIV/AIDS counsellors • 'Train the trainer' workshops - training of trainers	• AIDS awareness campaigns • ATICC acts as resource and referral - its links with other organisations in this field is outlined below • 'Workplace AIDS project' - increasing AIDS awareness and understanding at the workplace	None

ALUSAF	*Sr. M. Bosch, Ph.: 999244*	• *HIV-testing* • *Primary, secondary, and tertiary medical care (treatment of ARC and related infections).* • *ALUSAF clinic provides some terminal/tertiary care when there are no alternative facilities - this is not one of the clinic's regular services and will not become so in the future.*	• *Ill-health retirement* • *Free medical care (before and after ill-health retirement*	• *Pre- and post-test counselling* • *Ongoing counselling*	*None*

Richards Bay Minerals	*Sr. S. Daniel; Ph.: 903111*	- *HIV-testing* - *Primary and secondary medical intervention (treatment of ARC and secondary infection)*	- *Ill-health retirement* - *Free medical care (before and after retirement)* - *Extended employment: RBM keeps persons with late stage AIDS employed as long as possible and provides sick-leave* - *Short-term credit: to provide for funeral and other arrangements money is forwarded by RBM to the family against the persons with late stage AIDS group-life*	- *Pre- and post-test counselling: primary health care trainers, nursing staff, and a training officer (trained by ATICC)provides counselling, training, and information to employees on ways of coping with AIDS* - *Ongoing counselling* - *Most of the counselling is done on an individual basis - apparently the persons with late stage AIDS prefer not to engage in group counselling due to among other considerations fear of breached confidentiality*	*None*	

Portnet	*Sr. A. Naidoo; Ph.: 0351-9053440*	• *HIV-testing* • *Primary and secondary medical intervention (treatment of ARC and related infection)*	• *Extended employment (keep persons with late stage AIDS employed as long as possible)* • *Ill-health retirement* • *Free medical care (on ad hoc basis before and after retirement)*	• *Pre- and post-test counselling* • *Follow-up counselling (nurses and staff trained to provide this)* • *Psychotherapy: The services of registered psychotherapists are available* • *Counselling is mostly on an individual rather than group basis*	• *Social work: the services of a registered, full-time social worker is available to the persons with late stage AIDS* • *Liaison with other organisations: Portnet liaisons with other organisations to provide access for the persons with late stage AIDS to a wide range of services*	*None*

Churches and religious organisations	*various religious denominations - contact researcher for contact persons*	*None*	*Churches provide welfare and material support*	*Churches provide pastoral counselling*	*Depending on the religious denomination churches provide acceptance and understanding*	*Past l coun ing*

Traditional healers		• *Most of the persons with late stage AIDS visit sangomas at least occasionally during the course of the syndrome for treatment (many sangomas claim to cure it)* • *Additionally sangomas provide a form of 'inpatient treatment' - the patient resides with the sangoma for the duration of the treatment*	*Officially none*	*Most persons with late stage AIDS receive at least occasional treatment from Nyangas (spiritual healers) and faith healers - this area requires further investigation*	*Officially none*	*Nyan s*

Richards Bay Collieries terminal	*Sr. S. Van Vuuren*	- *HIV-testing* - *Primary and secondary medical intervention*	- *Ill-health retirement (currently this issue is complicated by the subcontracting of most work to outside companies)* - *extended employment* - *Free medical care*	- *Pre- and post-test counselling* - *Ongoing counselling*	*None*	*None*
Mondi	*Sr. S. Van der Westhuizen, Ph.: 0351-902111*	- *HIV-testing* - *Primary and secondary medical intervention*	- *Ill-health retirement* - *Free Medical care*	- *During late stage AIDS, the families of persons with AIDS provide most of their care - Mondi provides little in the form of direct intervention.*	*None*	*None*

Ngwelezana hospital	Dr. P. Hasleau, Ph.: 0351-942311	• HIV-testing • Primary, secondary, and tertiary medical care (ranging from outpatient treatment to inpatient treatment for acute symptoms). • Once persons with late stage AIDS receive home-based care, they are integrated into the usual medical services - the services of the clinic and hospital are available to them and they are advised as to how to use it.	• None	• Pre- and post-test counselling • Ongoing counselling • Training and support for counsellors • Support group for healthy, unemployed, HIV-positive persons - this group provides both emotional/psychological and material support - one of the aims of the group is to be income generating - when they meet they participate in home-industry type activities. At the moment Ngwelezana is in the process of employing	• Home-based care: Once the PWA is diagnosed as HIV-positive, he/she receives with the post-test counselling the offer of the facility of being serviced at home. • If they accept, they are visited once a month and both they and their families receive counselling, support, and primary health-care as well as instructions on how to maintain it. The focus of the home-based program is on equipping the family with basic nursing skills. • Additionally help is provided for the family to come to	

Ngwelezana (continued)		*only the destitute and those experiencing extreme denial use this facility*			*to die at home. Those who are admitted to Ngwelezana as inpatients are apparently either destitute or in severe denial.* • *Home-based care focuses on persons with late stage AIDS with acute, full-blown symptoms. Apparently it is impractical to provide it to those who are still working since they are seldom at home and have access to the hospital's usual services.* • *Some persons with late stage AIDS refuse home-based care and prefer inpatient treatment at the hospital. At the moment 83 patients*	*None*

The Bay Hospital	Sr. Du Toit	• HIV-testing (routine testing for AIDS is not done - there has to be a valid reason for doing the test, on average Bay hospital treats 4 persons with late stage AIDS per month • Primary and secondary medical care: Bay hospital does not provide terminal/tertiary care for persons with late stage AIDS	None	• Pre- and post-test counselling: Five nurses (trained by ATICC) supervised by a head educator (Sr. Taylor) provide counselling and liaisons with employers of persons with late stage AIDS. • Ongoing counselling • Support groups: Although persons with late stage AIDS are encouraged to bring their families in, this does not happen very often	None	None

Empangeni hospital	*Sr. S. Oldworth, Ph.: 0351-21111*	- *HIV-testing* - *Primary and secondary medical care: Empangeni hospital deals mostly with persons with late stage AIDS in the acute phase since patients who are HIV-positive receive treatment with ATICC and the municipal clinics* - *The hospital does not provide long-term terminal care - since beginning 1996 the hospital has treated 40*	*None*	- *Pre- and post-test counselling: Nurses (trained by ATICC provide this service)* - *The hospital does not provide any support groups. When the family is present (seldom) they also receive counselling*	*None*	*None*

unicipal linics:	*Ph.: 0351-21131*	- *Primary medical intervention: municipal clinics focus on the relief of the secondary symptoms of AIDS as primary care providers.* - *If the presence of AIDS is suspected the patient is referred to ATICC for testing*	- *Children with AIDS: The clinic service large numbers of babies with AIDS who are left in the care of grandparents once the primary caregivers cannot care for them - the clinic provides milk free of charge in these situations.*	- *Counselling: The district nurse does home visits and provides some emotional support - this service is, however, primarily aimed at the management of the secondary infections and physical symptoms of AIDS and does not represent a home-based care program*	*None*	*None*

Christian Welfare Council	*Ms. E. Veldsman; Ph.: 0351-9238949*	*None*	- *The CWC is planning to launch self-help schemes in the communities and mobilize communities to provide physical and material care for the persons with late stage AIDS*	*None*	*The Task Team for Community Care and Treatment of the CWC*	
Hospice	*Ms. Gates, Ph.: 24910*	- *None: Hospice does not provide any care for persons with late stage AIDS - it is against the local branch's policy*	*None*	*None*	*None*	*None*

Zululand Mental Health	*Mr. M. Clack, Ph.: 25996*	- *None*	- *Potentially sheltered employment: ZMH have facilities in six adult workshops in Kwazulu to provide sheltered employment for unemployed persons with late stage AIDS - if they are too weak to work on these mostly self-sustained farms, another member of the family can be employed tp provide income for the family.*	- *None - ZMH is prepared to provide counselling to persons with late stage AIDS once their employees are trained by ATICC.*	- *None*	- *N e*

SHAPE	Sr. N. Khamsa , Ph.: 0351-941722	● None	● Transport: SHAPE assists Ngwelezana's home-based programme through the provision of transport.	● Training: SHAPE liases with Ngwelezana hospital to provide training for community Health Workers who focus mainly on the prevention of AIDS as voluntary counsellors	● None	● N e

Appendix 6: A semi-structured interview with a person with HIV (Brouard, 1992).

le weakness on the s and legs. I get aches in the centre of kull and occasional rashes. Also persistent len glands. I'm observ- ll these things happen- me rather than ng hysterical or cky.

Primary health care needs of people with HIV

t kind of place would like to go to for ment?

a busy environment. e should be an easy of people. Somewhere nice scenery. After my nosis I'm aware of how t nature is. could be a clinic where of other things are ening. If it's specifically IV clinic, there would feeling of seclusion, being officially removed society. I wouldn't like

should not be near to e I live because my munity still doesn't rstand the HIV/AIDS . As an HIV-positive on, I conduct informal views with people e I discuss HIV in a thetical way with them. e are a lot a negative responses and I've picked up a lot of negative feedback over the years. This has given me strength because I want to fight this prejudice. So, a clinic which I would go to should not be far away but also not in the precise area where I live. If push comes to shove I might get ill and I wouldn't want to be far away from my family.

Do your family know of your HIV status?

I did mention it to my parents but they kind of shut it out. I think they're in denial about it. That's how they were able to handle it. My girlfriend also knows and she believes it's a bug which has been planted by the devil - she's very religious! It's not a problem to her. She says going for a test is a waste of time, that it almost puts HIV into your mind. Her belief is to take it one day at a time.

How do you feel about safer sex?

Well I know that condoms are available at clinics but they need to be distributed better. Males have a fear of going into a clinic and being given condoms by a woman. They feel shy because it makes them look promiscuous. There's a lot of difficulty in men going to clinics for condoms. When they have a STD, then they think about condoms, otherwise not.

Another problem is that condoms are usually in the family-planning section of a clinic. Normally women attend and it's tough for men to go into that setting with 50 - 70 seated women. I believe more men would come forward if men gave out condoms.

What do you think about the government's approach to AIDS?

It's not doing enough seeing that it's a global problem. Sex is a controversial issue and ministers who come from communities with certain values fear that their constituency might not vote for them in elections. The government has power to deal with the problem, even a future government. We need a drastic AIDS policy which should provide a smooth flow of education. This should start with schools, the most important target area. Children need to be educated before they reach Standard six - if we target the adult population only, there will be problems. The graph of infection is rising at a very fast rate and the government needs to act. Politicians need to think about the people who are out there. Who's going to vote for them if people are dying from AIDS?

Have you experienced any discrimination?

No, because I've kept my HIV very private. I've been living my life like anyone else. I don't want fingers pointed at me - I might get bogged down and withdraw from people.

What about in the workplace?

Well, there's a lot of negativity in workplaces. They ask you, especially government services, to have the HIV blood test because training is an investment. There are still some private companies which limit policies, like insurance companies. There hasn't been much done by companies in promoting AIDS awareness - their approach hasn't changed for the better. Often company AIDS programmes are part of a policy but not carried out in full. They don't necessarily change employees themselves. You find companies talking about empowering employees - black empowerment - we need to empower through education on this issue. It affects all of us in one way or another.

How do you live life with HIV?

I need to let all my ideas flow out, live my life to the fullest, enjoy it, appreciate it and create the best out of it.

Addressing AIDS

Continued from p.2

would be provided together with all other PHC services.

The 'beloved' district PHC centre thus becomes a 'one-stop shop' (AIDS-friendly) offering HIV care, tests, counselling, family *planning, condoms*, psycho-social support, referral, child care, home care, immunisation, etc.

Support services such as the AIDS *training*, information and counselling centres (ATICCs), STD reference clinics, TB reference centres and social welfare services would serve to support the local district PHC services (*train staff, referral*, research, centres of expertise, etc.).

Collaboration with community organisations, NGOs, AIDS *service* organisations, hospices, etc. could best be achieved via the district PHC system.

The NACOSA AIDS strategy goes further than primary health care needs alone. It addresses the need for other sectors to fulfill their obligations. These include the educational institutions, the *mass electronic and print* media, the correctional services, commerce and industry, religious institutions, the military, sport *and community organisa*tions, political organisations, civic bodies and legal and human rights organisations. An *intersectoral effort is vital* in preventing the spread of HIV and in minimising the impact of the disease on individuals and on the *community* in general.

These sectors will play crucial roles in minimising the spread of HIV and reducing the impact of the disease *on* individuals and communities. The primary health care services will ultimately be responsible for providing the lion's share of the health and psychosocial care and support.

Strategies to combat AIDS must include aggres*sive calls and demands to* develop and strengthen our PHC infrastructure. The present fragmented, disjointed and unco-ordinated *PHC sector will not with*stand the projected needs of the HIV/AIDS epidemic. The hospital services are largely inappropriate and too expensive to provide for the primary medical and psychosocial needs of those with HIV/AIDS, and will anyway have their hands full dealing with the secondary and tertiary care load.

Conclusion

In the meanwhile, while the health services reorganise and restructure, the present system will need to cope as best as possible. Hospitals *will continue to provide* primary HIV care via their polyclinics and specialised HIV clinics, family-planning services will need to include *prevention and care for* STDs, ante- and postnatal clinics will need to prioritise AIDS prevention and education, and STD and TB services *will need to in*crease their capacity and coverage. Counselling and *psychosocial support will* struggle to find a comfortable home in any of the above services and ATTICs will run the risk of being *overloaded and unable to* meet the demand.

In the absence of a rapidly restructured, comprehensive district PHC *service, there is a distinct* risk of a vertical development of HIV/AIDS services *promoting* inefficiency, fragmentation and costly care and ultimately an inability to meet the overall HIV/AIDS needs.

The establishment of a comprehensive district-based *PHC model is* strategically the highest health care priority for the *new* South Africa.

INDIVIDUAL FOCUS

An interview with an HIV-infected person
conducted by Pierre Brouard of the Johannesburg Community AIDS Centre

Vusi (not his real name) is a man in his early 30s. He lives in Soweto *and was diagnosed HIV-positive in* September 1991. He had lost some weight and had acute tonsilitis. He consulted a clinic on the West *Rand and an* HIV test was performed without his knowledge or consent. Shortly after his diagnosis, Vusi left his job because it was strenuous and the working hours were long. He agreed to be interviewed on condition that his identity was not revealed. The interview is presented *in* Vusi's *own words - the* opinions expressed are his own.

What did you know about HIV or AIDS when you were diagnosed?

Although I wasn't pre- or post-test counselled, I was not totally blank about AIDS at the time. But the AIDS issue was taken lightly. I was afraid to go for a second test to confirm the result and I can't remember if a *Western Blot test was done - I don't dwell on these* things.

***Have you ever consulted a doctor since your* diagnosis?**

No. I know I *need* to but I just let it pass. I feel I shouldn't rely on medicines - I try and let my body do its own recovery. If I get weak, I exercise at home, like lifting weights for a month. My body puts on muscle and I get strong. I respond to weakness by building strength. I'm not *opposed to seeing doctors but time* is often a problem. But I also think I avoid going to see them because it might make me worry more. Maybe *I'm in denial.*

What kind of approach should doctors have when dealing with people with HIV or AIDS?

They should be *able to* deal with any *kind of person.* I would like to be treated naturally, like anyone else. I don't want to be put on a pedestal - I need to be just *like anybody else. I feel if I make my* HIV status known to doctors, I would be treated differently, with kid gloves, like I'm fragile and could break. I don't want that. I've observed as an HIV-positive person how those who come forward are given kid-glove treatment.

Do you have any health problems at the moment?

I get foreskin pains sometimes and I've lost some weight - *this* fluctuates and picks up at times. I have sore throats and eyes. I suffer from tiredness and

Appendix 7: The generative themes explicated from the original twelve interviews conducted for the research:

The generative themes

! The following generative themes emerged as important shared, universal dimensions of the needs experienced during the terminal-phase of AIDS, as the researched phenomenon, from the protocols of the interviews with the respondents. As such the following represents a synthesis of recurring central concerns mentioned by the interviewees regarding their needs during the interviews.

! The themes are cited and described in the order of frequency with which they appeared in the interviews. It is assumed that more important aspects of the experience of the researched phenomenon are less likely to appear less frequently. Conversely it could be hypothesised that those central concerns that appeared most frequently in the interviews represent the more important aspects of the experience of needs related to having full-blown AIDS.

!. It is essential to note that each NMU and central theme exists in the context of the other interrelated meanings of the protocols - there is an inseperable relatedness in their lived semnse. Therefore the following synthesis is presented as a coherent expression of the interrelated central themes. It articulates the needs of the PWA's in the interrelated format in which it appeared in the protocols (Kruger, 1988).

Distraction

! Since there is no cure for AIDS, the most one can do is to live for the moment; to make the most of the limited time one has left to live. To do this one has to remain distracted from thinking about having AIDS in order to be able to be happy and enjoy the moment.

! Moreover, thinking about having AIDS results in distress. The distress is accompanied by depression and related symptoms such as insomnia, weight-loss, and morbid introspection. This precipitates a relapse of the more serious symptoms of AIDS. In this way thinking about having AIDS can actually deteriorates one's health and precipitate one's death. Therefore continuously thinking about having AIDS is, in fact, bad for one's health.

inability to share it with others makes one more aware of the terrible nature of the disease, and not being able to share it makes one more preoccupied with it.

! Monotony makes it more difficult to remain distracted. When one is faced with monotonous days at work, for example, one starts thinking about having AIDS again.

! Being alone also makes it more difficult to forget. When one is alone, one always switches on the radio to provide distraction, whereas one didn't use to do that before discovering that one has AIDS.

! The comprehensive care centre could help one to remain distracted from thinking about having AIDS in the following ways: Through the provision of T.V.'s, video-recorders, and radios in the rooms one could watch movies or listen to music. This is a good way to remain distracted because one becomes engrossed in especially the movies and forgets about one's own life. Music on the radio is especially helpful when one is alone, because it elevates one's mood and mind. Reading books and papers would also be a useful way to remain distracted in a comprehensive care centre. Doing things like reading the newspaper also makes it easier to pretend everything is normal.

! Another effective way to remain distracted is through activities. The ACC should provide activities - such as gardening, arts and crafts, working with computers, doing sports or going for walks - that will engross one and through that distract one from thinking about having AIDS. At home, for example, a very effective way to remain distracted from thinking about having AIDS is to work on the house or in the garden.

! A very important source of distraction is light conversation and humour. Therefor the ACC should have two people in each room, so that they can keep each other company when they're awake since it is difficult to be alone with knowing that one has AIDS. There should be two people per room since more than two would result in others talking and a third or fourth sleeping person being kept awake by this.

! It would also be important for the ACC to have an outside recreation area for distraction. This would be outdoors, with an awning, T.V. and some tables where one could play games with the other people.

! When it has become very distressful to be aware of having AIDS, it has helped to drink or smoke dagga, when there are no other alternatives, to help one to forget. This isn't always good since it can exacerbate other medical problems such as diabetes.

Confidentiality

! It is important not to let others in the community know that one has AIDS. This is due to the fact that they will avoid one for fear of being infected when they realise that one has AIDS. As rural people they believe that it is very easy to be infected with AIDS. Moreover, the people in the community would blame one for bringing this syndrome into the community.

! It is very difficult to share having AIDS with others. Perhaps one could be shown easier ways at the ACC in which one could tell one's family about having AIDS. If one were to tell them about having AIDS it would make matters worse for one. They would view one's life the way one views it oneself - you would be seen as someone who is lost, and you're life would be seen as futile. One would also have to deal with their sadness and distress, which would be difficult. Moreover, if persons in one's family has illness such as hypertension one has to consider the impact of the shock on them. Apart from this one has to consider the impact of the emotional shock. It is also very difficult to tell one's wife since she would see it as a sign of infidelity.

! In this regard talking to one's family and the proposed ACC presents a problem. If one were to tell one's family that one has AIDS, they could get distressed and rush of and tell others in a moment of sadness. If one's family were to visit one in an ACC they would inevitably realise that one has AIDS and could go back to the community and tell others that one has AIDS.

! A similar problem is experienced at the clinics at the companies. When one goes there often due to having AIDS, one becomes scared that other workers may notice and ask the nurses why you come there regularly. Through the nurses telling them they may realise that you have AIDS and tell others about it.

! A related problem is that other persons with AIDS may come to the ACC and see one there. Once they return to the communities, they may deny having AIDS and inform others that one has it.

! Therefore the proposed ACC should not be on company grounds or in the community since it would make one's having AIDS public, which would be very negative.

! Another solution to make it even more unlikely that others will assume one has AIDS from being there is not to call this ACC an ACC, but rather something like a training centre. If they provide training in arts and crafts or gardening there, it would seem even more authentic and convince others that one is only there for further training.

! Furthermore the doctors and nurses who work at the ACC should wear civilian clothes so that others don't realise that they are medical professionals working with persons with terminal-phase AIDS. They should also be known as 'trainers' or something other than doctors.

! The nurses and doctors who work at the ACC should also maintain the strictest possible levels of confidentiality and not disclose to anyone that one has AIDS.

! It is very important that the ACC should have security fencing around it and a point of access control at the entrance. If people were to come and visit one, the access control at the gate should contact one first and ask one if you know this person who wants to see one. Potential visitors, therefore, has to be screened first before they can see you.

Relationship/companionship

! When the symptoms of AIDS becomes worse, what really helps is acceptance and caring, empathic dialogue that affirms one's personhood. This sympathetic, interested care should be sustained - provided constantly - since this reassures one that, although the symptoms are bad, nothing will go wrong because there will be someone to care for one. This is why it would be better if the ACC were created in the format of a hospital rather than a clinic, since this would provide more security and predictability of care. Consequently it is important to have a caring, nurturing, empathic relationship one has with care-givers. At the company clinic the nurses provide this by treating one like someone who is not lost. They treat one as a person who is alive and not as someone with AIDS who is condemned to die. Therefore it is essential that the care-givers who work at the ACC should be kind and patient. They should also be emotionally generous and not get distressed by one's having AIDS or by one's secondary symptoms of AIDS. They should have understanding and not become irritated when one makes mistakes due to the experience of loss of memory due to AIDS-related-dementia.

! The care-givers that works with one - like nurses - are of primary importance in providing a supportive relationship to help one deal with having AIDS. This is due to the fact that one cannot share having AIDS with anyone else, which implies that they are the only people who can be with one in this experience. This is especially relevant when one considers that it is impossible to share having AIDS even with one's best friends or family.

! It is very important that the nurses and other care-givers at the ACC should maintain the strictest possible level of confidentiality. This would make it possible to trust them which would make it easier to share one's experiences with them.

Spiritual needs

- Since there is at yet no cure for AIDS, one of the only things one can do is to pray. Some Christians believe that prayer could result in being healed. One is also always praying that someone would discover a cure for AIDS.
- Consequently the ACC should have a place where one could worship God, or a church. It would also be helpfull if someone could come and preach to one periodically in the ACC.

Hope

- It would be better if the doctors who do research on AIDS could give one a sense of hope, instead of insisting that all is hopeless when one has the syndrome. Then one would have something to hold on to.

Environment, location and physical characteristics of building

- The following characteristics of the building and location of the ACC would provide in one's needs as a person with AIDS. Additionally one longs for luxury when one is about to die, for all the things one will not have because one will not live longer.
- The ACC should be on large grounds with rolling lawns and trees and flowers. It should be in a quiet area and the grounds should be clean and well-kept. One should be able to go for walks on the grounds. The grass should especially be well-kept (it should be nice to lie on) and the gardens would, additionally, provide the opportunity to do some gardening.
- The ACC should not be on company property, as mentioned, because it would jeopardise confidentiality. Similarly, it should not be in the community, since it would be obvious to the people in the community that one has AIDS when one goes there. It should therefore preferably be somewhere in the countryside.
- The ACC should be in an area where the climate is cool. It would be usefull if the ACC could be located near the beach, but not to close to the beach. The building should be air-conditioned.
- The building should have large, spacious rooms. The roof should be tiled. It should be a new, clean building. There should be posters of soccer-players and pop-stars on the inside-walls.
- There should be big bedrooms, providing for two people per room (as mentioned). The bedroom should have a T.V., radio, and there should be provision for seeing videos. The bedrooms should be cream-white or ivory on the inside and white ceilnings with ceiling-panneling or ceiling board. It would be preferable to have small-panelled louvre windows in the bedrooms. The windiws should , however, be big. There should be blinds, not curtains, in front of the windows. The blinds should also be of the louvre-type. The