AN EXPLORATORY STUDY OF THE PSYCHOSOCIAL NEEDS OF HOMOSEXUAL AIDS PATIENTS

by

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Declaration

All information in this paper has been originally compiled and composed by the author and the format and all references have been acknowledged according to the Publication Manual of the American Psychological Association (2nd Edition). The study conducted is an original study with no falsification of information or results.

Licia Blyth Karp

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Licia Blyth Karp   University of Cape Town   April 1989

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The acquired immune deficiency syndrome (AIDS) is primarily a sexually transmitted disease. The majority of those infected in the First World are homosexual and bisexual men, and intravenous drug users.

The study combined a literature review and a case example to explore psychosocial needs of homosexual AIDS patients with a view to presenting recommendations for mental health practitioners to help alleviate the psychosocial trauma of these patients and their significant others.

The literature review focussed on the psychosocial experiences of homosexual AIDS patients; their losses, reactions of their significant others; their emotional reactions to medical treatment, and, psychosocial treatment issues and approaches. The case example was a twenty-nine-year old hospitalized homosexual male. Information was received from the patient's befriender, his lover and from the patient himself. The reactions and experiences of this patient were concomitant with many of those discussed in the literature review, namely:

AIDS: Psychosocial Needs

The patient suffered major losses: employment, income, house and household possessions as well as social status, with the primary psychosocial effect of loss of independence and control. The patient also experienced some isolation and rejection from some friends, family and hospital staff, and geographical isolation for a period of time from his lover and family. He displayed anger and denial - aspects of his personality which were evident prior to his diagnosis but exacerbated by his illness.

INTRODUCTION

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Terminal illnesses generally cause emotional trauma. In the past, leprosy was greeted with horror and revulsion, and victims of the disease were totally rejected by society. Over the years scientific research led to the development of cures and a more enlightened attitude in society. Victims of cancer, for example, are often seen as tragic heroes - the innocent victims of a disease that ravages the body. The acquired immune deficiency syndrom (AIDS) seems to have caused a general regression to the attitudes and feelings that were once expressed towards lepers. Those who suffer from AIDS are frequently not seen as tragic heroes. They are often seen as dangerous and immoral, and are scorned and repulsed. The term 'Gay Plague' embodies these feelings, so that AIDS sufferers are socially ostracized and often left to suffer in desperate isolation.

In this section some medical and statistical information is provided as an essential background to a better understanding of the psychosocial implications of AIDS.

AIDS was first described by the Centre for Disease Control in America in 1981, as an illness usually associated with a defect in cell-mediated immunity, such as Kaposi's Sarcoma (KS), Pneumocystis Carinii Pneumonia (PCP), or some other serious intercurrent infectious disease, but where there is no known explanation for the immunological deficiency, e.g. immuno-suppressive therapy, or congenital immunodeficiency (Deuchar,1984).

The cause of the disease is now considered to be the Human Immunodeficiency Virus (HIV), presenting with rapidly progressive physiologic and neurologic manifestations leading to a high fatality rate (Helquist,1987).

Transmission is primarily through specific sexual behaviours. In 1984, the NHMRS Working Party reported that transmission through this mode was highest among homosexual or bisexual men associated with multiple sexual partners. Some two years later, Peter W.A. Mansell contrasted the incidence of AIDS in America where the male-to-female ratio was 13:1, to the incidence in Zaire and Ruanda Burundi where the male-to-female ratio approached 1.1.

In the same year, John Seale gave a convincing argument as to the reasons for the high incidence in Third World countries, including Africa. He reported that rapid spread of the virus occurred through repeatedly reused unsterilized hypodermics and by sexual practices that damage the rectal mucosa of people who frequently change partners. He postulated that once this occurred in a critical mass of people, then the virus may be transmitted by less efficient means including, amongst others, biologically normal sexual intercourse, and chance contact of sores or abrasions with contaminated blood, saliva or sputum. Whatever the reasons for the high incidence, the message that the virus spreads rapidly, is clear.

The specific sexual behaviours conducive to transmission are considered to be:

- Those practices that could generate sexual injury, albeit minor, including anal intercourse without the use of a condom and sterile lubricant.
- The injestion of semen, blood, faecal matter and urine.

- The exchange of any body fluid with sexual partners in individuals who are high at risk because of their history of sexual activity (Isaacs and Miller,1985).

Other modes of transmission are intravenous drug usage where contaminated needles are shared, through blood transfusion when contaminated blood is received, and from an infected woman who may spread the disease to her child during pregnancy, birth, or shortly after birth (NHMRC Working Party,1984).

Although the focus of this study is on homosexual full-blown AIDS sufferers, it is important to outline the course of HIV infection. With this knowledge, Mental Health practitioners can provide the appropriate treatment focus required during the various stages of infection.

Miller, Green and McCreaner (1986) divided those requiring counselling into five groups:

1. The "worried well" persons. They emphasize that those requesting screening need to be counselled prior to testing to allow them to make informed decisions; if the person was tested positive and

their status became known, they could lose their jobs, and the knowledge of their status could cause relationships to become strained. This is also the appropriate time to educate the patients about risk reduction - whether they decide to be tested or not.

2. Those who are tested positive but who are asymptomatic. These patients would require counselling to educate them about preventing the spread of their infection, and about the course of the illness, to help them manage their anxieties and cope with the perpetual insecurity of whether and when they will develop the full-blown AIDS syndrome.
3. Those who are seropositive and symptomatic. Similar educative counselling is required, plus anxiety management and management of depression, which is common due to the effects of the symptoms on their ability to work and socialize.
4. Patients with AIDS and AIDS Related Complex (ARC). Here the authors point out the need for coordinated services amongst the disciplines and assisting the individual to make long-term adjustments.
5. Lovers, families and friends of the patient. The discussion by the authors was very limited here,

> although they made a pertinent point about the lovers' psychological morbidity as a result of 'sharing' the diagnosis in a sense, and fears regarding their own antibody status.

As previously stated, the two most common diseases found in AIDS patients are Pneumocystis Carinii pneumonia (PCP) and Kaposi's Sarcoma (KS). PCP is a lung infection which is normally destroyed by healthy immune systems and KS is a tumour of the walls of the blood vessels which usually appears as pink to purple spots or lesions on the skin, but may also occur internally (Helquist,1987). PCP represents approximately sixty per cent of the initial diagnosis in AIDS patients. After the diagnosis of KS, survival time for the patient is usually less than two years.* Most AIDS patients experience rapid deterioration resulting in death within twenty-four to twenty-six months, and those with the best prognosis die within five years (Faulstich, 1987). The disease has now reached pandemic proportions. Nielsen (1987) reported World Health Organization statistics

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*Verified with John Pegge, Director of GASA Counselling Service, Cape Town, in February 1989.

which showed that five to ten million people are already infected with the AIDS virus and, if things continue as they are, there could be as many as fifty to a hundred million people in the world infected with the AIDS virus by 1991. Twenty to thirty per cent of those infected develop the full-blown disease within five years. In the United States, twenty thousand people have died from AIDS and it is suspected that one and a half million people may already have been infected.

Latest statistics were reported by John Pegge of GASA, Cape Town; By January 1989 there were eighty-four thousand, five hundred and three cases of full-blown AIDS in the United States of America. The estimate of those infected was reported to be between one, and one point eight million. The World Health Organization has been notified of one hundred and thirty-nine thousand, eight hundred and eighty-six confirmed cases of AIDS, and the estimate for those infected stood at three hundred and seventy-seven thousand.*

*Verified with John Pegge, Director of GASA Counselling Service, Cape Town, in February 1989.

I. RATIONALE

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With a terminal illness such as cancer, friends, family and society generally rally round the dying patient. Those who are HIV infected, however, are often stigmatized because the disease is transmitted primarily through certain sexual behaviours, and sensationalist media coverage further ignites the generally negative attitudes society holds towards homosexuality (Goulden, Todd, Hay and Dykes,1984). Given this factor, plus the nature of the course of the disease, those who are infected experience unique psychosocial effects from the time of diagnosis until their eventual death.

These psychosocial implications are complex, affecting every aspect of the patient's life. A literature review and case example are provided to gain insight into the issues faced by those infected, with the emphasis on full-blown homosexual AIDS sufferers, and, to consider how their needs may be addressed by mental health professionals.

Compared to the rest of the world, the incidence in South Africa remains relatively low. In February 1988, the total number of persons with AIDS up to December 1987, was seventy-six South Africans and twenty-two non South Africans. The total number of AIDS cases to that date in Cape Town was thirteen, of which eleven had died. The estimated number of those infected at that date (in South Africa) was one thousand five hundred people.* By January 1989, John Pegge reported that there were one hundred and seventy confirmed cases of AIDS in South Africa, and the estimated incidence was considered to be 24 per million of the white population in South Africa.

These figures have major implications for future service delivery in South Africa. As the majority of people with AIDS are homosexual and bisexual men, and because the case example available for this study fell in the former category, the literature review and case example focus on the psychosocial effects of full-blown AIDS as experienced by homosexual men and their significant others.

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*Verified with Dr. F.H.N. Spracklen, Head of Department in the Department of Medicine, Somerset Hospital, and Honorary Senior Lecturer at the University of Cape Town, on 23.02.88.

The areas explored are as follows:

- Exploring the personal reactions of the AIDS patient prior to diagnosis, during the process of diagnosis and after diagnosis. This includes information on the thoughts, feelings and behaviour of the patient.
- Exploring the experience of the patient during the above process related to:
    - lovers, close friends and family,
    - lifestyle and broader social network,
    - employment and financial effects,
    - medical treatment,
    - psychosocial treatment.

In February 1988 it was estimated that the number of HIV infected people in South Africa was one thousand five hundred. Ten months later, the South African Institute for Medical Research reported that the number of people tested as positive carriers of the virus had, excluding mine workers, risen to two thousand ("AIDS Positive Carriers", 1988).

This alarming figure, plus the far-reaching psychosocial effects of the disease has two major implications for South

Africa; Firstly, there will be a greatly increased demand for psychosocial services from mental health practitioners which will require that they are au fait with the special needs of those infected and their significant others. Secondly, it will require a review of social work/mental health policy to enable the provision of coordinated and effective services to the greatly increasing HIV infected population.

II. LITERATURE REVIEW

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During the early eighties there was a plethora of literature on medical aspects of the illness and only brief reference was made to psychosocial needs. This was an appropriate response to a new and life-threatening disease, where the focus of attention was primarily to seek treatment and cure. Early discussions on psychosocial needs were brief. For example, Holtz, Dobro, Palinkas, Kapila and Oleske (1983) reported the patients' loss of social support and finances, difficulty finding accommodation due to their diagnosis, and rejection by their families and medical personnel. They also referred to patients reacting by losing interest in their condition and in human contact - hiding beneath their bedsheets.

These themes were repeated and expanded upon in later literature with some emotive, and often sensitive accounts of the AIDS experience in such lay magazines as Cosmopolitan (September 1988), Self (January 1988) and the British Sunday Times Magazine (June 21, 1987).

It cannot be overemphasized that the impact of AIDS is far-reaching. This author concurs with Furstenberg and Olsen (1984) who stated:

> The situation surrounding AIDS serves to bring into sharp relief that fact that every health condition, good health, illness and disability, is at once a physical, psychological, social, economic and political phenomenon.

They point out that a theme concomitant with politics and illness is that of power and power relationships. It is not however, within the scope of this study to discuss these ramifications. Suffice it to say that every person faced with AIDS, the patient, family member, physician, or any significant other, will in some way be part of the broader issues and themes, affecting their sense of helplessness, frustration and confusion, or confidence, hope and acceptance.

It seems that not only ignorance of AIDS but also moral judgements about those infected and at risk, have led to the fear, rejection and, at times punitive behaviour on the part of the public. Deuchar (1984) reported that after three AIDS patients died at Auburn Prison, upstate New York, a hundred inmates went on a hunger strike, demanding that all homosexuals and intravenous drug users be banned from the kitchen. The prison guards asked for protective masks and called for isolation of all prisoners with AIDS.

This dramatic event highlights the prejudice that often affects the homosexual population. It is important here to refer to issues related to homosexuality, as these issues entertwine continually with issues related to AIDS, often eliciting extreme reactions from both those infected and their significant others.

Moses and Hawkins (1982) refer to Morin who points out that the words homosexual and lesbian are purely descriptive terms for choice of sexual partner, revealing nothing about individual patterns of behaviour.

Moses and Hawkins then conclude:

> ...gayness is not a clinical entity and is neither indicative of nor a causal factor in psychological disturbance or social malfunctioning. Individuals who are homosexual or lesbian have every chance of leading lives as productive, fulfilling, and mentally healthy as their nongay counterparts.

Furstenberg and Olsen (1984) seem to concur with the previous authors but also mention some negative and sub-cultural issues faced by homosexual men. They state that:

> ...as members of a minority population unacceptable to the majority, they have had certain common experiences and a number of shared ways of dealing with them.

These specific sub-cultural elements then indicate that the diagnosis of AIDS will have different significance for the homosexual patients as opposed to, for example, intravenous drug users and children with AIDS.

Preventive education is another aspect that is part of the illness. It is often a felt and expressed need on the part of the HIV infected person, but is sometimes disregarded by those who are denying their diagnosis.

Isaacs and Miller (1985) emphasize the pivotal role played by the medical practitioner in containing the spread of AIDS through education - specifically on sexual practices that are considered to decrease the exchange of body fluids and thereby decrease the chance of contracting HIV infection. Although they concentrated on the role of the medical practitioner, if preventive education is to make a significant impact, it needs to be provided both formally and informally through a variety of groups and organizations.

Goulden, Todd, Hay and Dykes (1984) discussed the reactions of gay men when it was suggested that they needed to change their sexual behaviour. They reacted with denial or intense anger, as the suggestions were perceived as direct threats and assaults upon core elements of their sexual identity. Goulden et al also felt that depression, with the associated apathy, self-destructive impulses and personal neglect, might play a significant role in making some people more susceptible to AIDS. They suggested that depressed people increase sexual encounters in a vain attempt to cope with emotional isolation and depression itself. It must be pointed out that the authors do not clarify the stage of the depression when the patients are most at risk. In the depths of depression the patient remains passive and lethargic. The patient becomes more active once the depression begins to lift, which enables activation of self-destructive impulses. This is an important point, as it means that timeous intervention by mental health practitioners could help to contain the self-destructive behaviour and help to prevent the spread of the disease.

Flavin, Franklin and Frances (1986) also felt that the active search to contract a communicable disease is a means of attempting self harm. In two out of three case studies they found that patients discussed their conscious wishes to spread AIDS through sexual activity without precaution, warning or regard for others. These patients were all dependent on alcohol and actively attempted to contract the disease whilst intoxicated. This emphasizes that preventive education needs to be aimed at the widest range of the population as possible with particular attention given to those who abuse substances.

In 1985, Miller and Green advocated that those men who were suffering from AIDS refrain from sexual contact:

> ...perhaps with the exception of and established monogamous partner.

This seems somewhat over-reactive when compared to suggestions by Isaacs and Miller in the same year. They referred to gay health publications that advocated sexual practices that minimize the risk of infection; hugging, caressing, mutual masturbation and dry kissing.

Personal Reaction of the AIDS Patient

The common theme throughout the relevant literature was that of the emotional and behavioural effects of loss, those losses incurred by the fact of having contracted a terminal illness and exacerbated by particular issues faced by homosexual and bisexual men.

Referring to reactions of terminally ill patients, Kübler-Ross (1973) reported a five stage reaction; denial and isolation, anger, bargaining, depression and acceptance. Miller and Green (1985) and Goldmeier (1987) felt that AIDS patients pass through some of these stages, but not necessarily all. It is noted that they do not provide suggestions as to the reason for this, or the significance, and this is an area for possible future research. Deuchar (1984) also referred to these stages, but added that the shock reaction in AIDS patients manifested in sleep disorders, derealization and depersonalization.

Pertinent to these emotional responses to the fact of being terminally ill, are the emotional responses to the nature of the course of the illness. That is, because AIDS usually results in recurring medical crises (as the individual can repeatedly contract opportunistic infections), emotional crises are rekindled with the waxing and waning of each medical crisis.

In January 1987, Isaacs also referred to the crisis element contained in the HIV infection range, emphasizing that those with AIDS Related Complex and the "worried well" form a larger proportion of the wider AIDS scare. He made a crucial point that with regard to this, crisis psychotherapy needs to be available to persons on a twenty-four hour basis.

The traumatic combination of having to come to terms with a terminal illness, its consequent disfigurement and debilitation and having to cope with family and friends' realization of the patients sexuality, was discussed by many authors.

Deuchar (1984) reported that ignorant and fearful family and friends outrightly reject the patient at worst, and at best avoid contact with the patient.

Guilt and homophobic symptoms were considered rare amongst patients who had felt comfortable about their sexuality, but expressions of regret might be found in these patients about the importance they had once placed on large numbers of sexual partners. Also, feelings of guilt may be compounded in bisexual patients who had passed the disease to their partners, often leading to regression, with both partners denying the illness.

Fear of giving AIDS to others was detailed by Forstein (1984) who felt that the diagnosis of AIDS often initiates an intensive need for physical contact and emotional intimacy. With this need, the patient's sense of being alone is reinforced by the withdrawal of the patient's support group.

The denial stage was also emphasized, particularly in those patients who pretend the diagnosis is not real by acting-out with self-destructive behaviour, including drug or alcohol use, indiscriminate sexual exploits or excessive drug taking. An important correlation was found between the ability of the individual's peer group and family to confront such self-destructive behaviour and the way in which the person accepts the diagnosis and feels supported.

An important issue causing great anxiety for the AIDS patient is the decision whether to tell others the diagnosis. Miller and Green (1984) reported that the anxiety is increased when the families are not aware that the men are homosexual, resulting in mixed responses.

Psychological themes consonant with those previously discussed were illustrated by Dilley, Ochitill, Perl and Volberding (1985). They reported that patients who had had multiple sexual partners expressed considerable guilt over their behaviour,blaming themselves for the illness and experiencing their illness as retribution.

It seemed that Dilley et al implied that only those with multiple sexual partners felt guilty. Feelings of guilt are often part of the dying process alone and these feelings can be exacerbated by a number of factors such as the patient's lifestyle, degree of comfort about his sexuality and the manner in which he (and others) dealt with the 'coming out' process. Not only feelings of guilt are elicited and exacerbated, but feelings of anger, confusion, anxiety and even intense ambivalence can be aroused, especially in one who was already struggling with the 'coming out' process. Moses and Hawkins (1982) dealt with this subject in a sensitive and direct manner:

> Coming out of the closet, that is, identifying or labeling oneself as gay, is one of the most difficult and potentially traumatic experiences a gay person undertakes. For many gays, it is a long process from the first awareness of being different to self-labeling, and from there to letting others know of one's sexual orientation.

They describe the processes experienced by adolescents and adults in 'coming out' to oneself, to other gays, to heterosexuals and to parents. Considering that this process can be a long-term, traumatic process for the gay person and his significant others, the emotional turmoil of the patient can be explosive and devastating when the issues of 'coming out' are interposed with issues related to having AIDS.

Uncertainty about the etiology, course and treatment of the illness, resulting in feelings of anxiety and anger amongst patients, was found to be one of the most pervasive themes.

In a detailed description of the bereavement process of the AIDS patient, Goldmeier (1987) explained common denial reactions as the patient who carries on life as before or who withdraws into bed, in effect denying the existence of the world. Denial was considered to be a tacit acceptance of the truth.

Enormous anger and hostility expressed by patients at various times, against society, old or contemporary sexual partners, their families and their health care workers, was explained by Deuchar (1984). Patients were described as being angry because of their increased isolation (even if it was to some degree self-imposed) because of changes in their lifestyle created by the illness, the lack of response to this disease by the government and medical community, and why they were stricken when so many others with similar life-styles and risk factors have escaped unscathed.

Goldmeier (1987) also referred to anger expressed in two ways; irrational anger expressed outwardly, focused on lovers, friends, family, health care workers and society in general, and internalized anger which might result in fearful nightmares and thoughts of death and dying.

Kübler-Ross (1973) referred to the bargaining stage as the phase in which the patient makes a promise, usually with God, such as those who promise "a life dedicated to God" in exchange for extra time. Forstein (1984) referred to AIDS patients in this stage often using their education and knowledge about their illness to acquire as much control and hope as possible.

With regard to sadness and depression, Goldmeier (1987) reported that patients may lose everything, including health, job, social standing, friends, lovers, family, dignity and independence. Less ill patients may sustain one or two of these losses but whatever the extent of the loss, it cannot be accepted unless it has been grieved for, through sadness and regret.

Furstenburg and Olsen (1984) also discussed the theme of loss of control and seemed to draw together succinctly the issues mentioned by other authors. They stated that the patient's loss of control of his body, his relationships and his future can be aggravated by a sense of powerlessness through a lack of information - especially when they are subjected to painful and frightening tests and treatments with little or no explanation. This is worsened when the patient feels totally dependant on the medical practitioner to provide his hoped for cure and alleviation of pain and discomfort, making it all the more difficult for him to assert his needs, queries and rights.

Forstein (1984) explained the final stage of acceptance as the patient's attempt to integrate the limitations imposed by the illness, leading to a sense of peace and resolution for some, with preparation for dying taking precedence over the will to live. This includes planning realistically for death, withdrawing appropriately from those around and helping others to withdraw.

These experiences might be compounded by Central Nervous System (CNS) dysfunction. Faulstich (1987) reported that approximately thirty to forty per cent of AIDS patients present signs and symptoms of CNS dysfunction as the disease progresses. These symptoms include: psychomotor retardation, incontinence, confusion, impaired memory, language and integrative abilities and may gradually result in seizures, mutism and coma. In this writer's experience, this can be traumatic for both the patient and the family. In lucid moments the patient can be painfully aware of his condition and the sense of helplessness, dependence and loss are highlighted. The family are often shocked at the changes in the patient's functioning and need much support and guidelines on practical care, especially if they are caring for the patient in the home.

Lovers, Close Friends and Family

Helquist (1987) discusses the emotional responses of partners of AIDS patients as similar to family responses but with unique concerns. Due to the sexually transmissible nature of AIDS, the partner has likely been exposed and possibly infected with the virus through sexual contact. Feelings of guilt or self-recrimination may occur if one partner feels blame for infecting the other. The couple must therefore deal with the impact of the AIDS diagnosis on the relationship, as well as the uncertainty of the partner's future health.

Goulden, Todd, Hay and Dykes (1984) reported that in many homosexual relationships, the person closest to the patient is not necessarily the sexual partner or lover. Whether it be the lover or a close gay friend who is closely bonded to the patient, the imminent death of the patient can be very threatening to the survivors, resulting in denial. When denial is no longer possible, survivors avoid the patient, causing further trauma to both patient and survivors.

Deuchar (1984) explained that rejection by lovers and families is due to their being faced with impossible dilemmas; they are forced to wrestle with their love for the patient and the confusion and humiliation of being closely associated with him.

Dilley, Ochitill, Perl and Volberding (1985) reported that friends failed to support or visit the patient during hospitalization. Patients often responded by being convinced that their friends feared that they might "catch something". Sometimes there had been longstanding problems with others' acceptance of the patient's sexual orientation and often patients' geographical isolation from their families was in part due to these problems. Notifying family and friends of their illness would mean disclosing their sexual orientation or rekindling old conflicts and having to deal with the anticipated negative reaction. This led to some patients failing to inform their friends and families.

Moses and Hawkins (1982) referred to negative parental reactions to their child's 'coming out' to them. They inferred that parents experienced anger, guilt, resentment, and pain, without the ultimate relief of increased closeness between parent and child and that these reactions caused the individual additional pain and resentment towards the parent and towards self. These emotions then, are often transposed on those related to AIDS, affecting both the patient and significant others.

Goulden et al (1984) also emphasized the possibly devastating impact on the family, stating that family members have to deal with their own feelings of guilt, anger and possible rejection of the patient's homosexuality and lifestyle, as well as trying to deal with their feelings about the patient's approaching death.

Employment and Financial Effects

The literature briefly refers to the financial impact on AIDS patients. Deuchar (1984) mentions that unless patients are admitted to a municipal hospital, the expense of treatment can be financially crippling.

It must be remembered that the majority of those who suffer from AIDS are young, previously healthy people in the prime of life (Forstein, 1984). This means that many AIDS patients have not had a life span to benefit from financial investments, income from life-long employment, pension and insurance schemes, etc. Therefore, illness eventually results in unemployment and lack of income. Any investments, or other financial schemes would then be quickly eroded by the substantial medical costs and the costs of providing the basic necessities of food, clothing and shelter. Many times the family must incur the medical costs, resulting in additional anger from the family towards the AIDS patient.

Medical Treatment

Polan, Hellerstein and Amchin (1985) reported that psychiatric hospital staff perceived AIDS as an overwhelming threat, resulting in strong negative reactions towards AIDS patients and disruption of the usual functioning of the therapeutic milieu. They felt that staff anxieties reflected: knowledge gaps about AIDS and its possible danger to others outside the groups at risk; the absence of definitive treatment, and other unconscious determinants.

In 1986, Amchin and Polan again reported on staff reactions. They felt that ongoing education and experience were major contributors to staff adaptation. Education and experience should enable staff to anticipate and address fears evoked by AIDS patients. They also recommended that unit leadership should assess the needs of both patient and staff and be alert to underlying fears of death or loss of control as well as anger and identification with the AIDS patient.

Psychosocial Treatment

Most of the literature refers to the need for counselling to focus on working through the feelings of the AIDS patient. Deuchar (1984) refers specifically to the need to deal with each of the stages suggested by Kübler-Ross, whilst providing constant support and showing optimism to the patients. Denial, with the attendant problems of treatment compliance and response to instructions, such as abstinence from sex, may prove difficult to dislodge. It was suggested that the question "What do you understand about your illness"? can enable sudden transgression into major anger or sadness episodes.

Forstein (1984) and Isaacs and Miller (1985) emphasized the need for care-givers to provide practical guides to enable AIDS patients and their partners to be sexual without the exchange of body fluids which could transmit the virus.

Goldmeier (1987) also referred to the need for education about safe sex, but added that for some homosexual men, the 'fast lane' gay lifestyle is so much a part of their personality that any change is impossible.

A number of authors (Deuchar (1984); Forstein (1984); Miller and Green (1985), and Goldmeier (1987) referred to the need for providing practical support and thereby helping the patient take more control of his life, by helping with such problems as finding housing, helping with daily chores, and, especially, in the final stage of acceptance, helping the patient with legal matters such as the drawing up of wills, granting power of attorney to the lover or significant other, and decisions such as whether to withhold treatment.

With regard to the type of help needed by patients, a number of authors referred to support groups of different kinds. Goulden, Todd, Hay and Dykes (1984) suggested that AIDS patients join support groups to acquire information, share concerns and feelings, learn habits of emotional freedom, expressiveness and assertiveness, how to set limits in stressful situations, enhancing communication skills and improving the quality of relationships. Joining social and political groups such as fundraising for AIDS programmes or eliminating stigmas, was also suggested as a means of helping patients to channel their anger.

Deuchar (1984) stated that there were over twenty AIDS related organizations in the greater New York area that provided valuable services such as financial, practical and emotional support. Forstein (1984) also suggested couples therapy.

Psychotherapeutic approaches of different types, such as cognitive, psychodynamic, or others, were considered as being helpful (Goldmeier, 1987). Cognitive therapy was considered particularly helpful for patients with no insight and who are stuck at an earlier stage in the bereavement process. Similarly, Perry and Markowitz (1986) felt that medically hospitalized patients with AIDS responded to standard psychotherapeutic approaches.

Deuchar (1984) felt that AIDS patients should be offered psychiatric consultation or counselling. However, it was stated that referral to any psychiatrist is not justified as many mental health professionals who have not had experience in conducting therapy with homosexual men often insufficiently grasp homosexual issues such as sexuality, and anxieties and problems in coming to terms with one's sexuality in a society where homophobia is so prevalent.

As opposed by this rather limited mention by Deuchar, Perry and Markowitz (1986) dealt comprehensively with countertransference issues of caregivers and it is felt that this deserves elaboration. Countertransference refers to the unconscious feelings of the caregiver (usually associated with a patient or significant other) which are transferred or projected onto the patient. With regard to hospitalized AIDS patients, they found the most common countertransference reaction was the fear of contagion, exaggerated and fuelled by unconscious forces such as the need to avoid (and not to be infected by) the illicit impulses that AIDS patients present. The caregiver displaces unconscious concerns onto the fear of contagion and then develops a reaction formation.

Another reaction they described was the tendency to stereotype the patient on the basis of his being a member of a high risk group. Another countertransference reaction was described as the failure to find the appropriate empathic distance, with caregivers over-identifying with the patient or emotionally detaching themselves.

With regard to out-patients with AIDS, they explained that the most common countertransference reaction was the fear of contagion. In this case, concerns about what can be considered to be the therapist's physical space can be a displacement of fears about the invasion of the therapist's internal world, unconscious fears that are heightened as the relationship with the patient becomes more intimate. Another countertransference reaction can be the irrational need to assume the stance of an omnipotent expert on AIDS, partly because of the therapist's own feeling of helplessness and partly as a response to the idealization delegated by the regressed patient in his search for certainty and authority. They also felt that another countertransference reaction was the premature referral to self-help groups, with some patients possibly too overwhelmed or too concerned with confidentiality to accept such a referral. Also, some patients may be too distressed by their homosexuality to participate in a group process with those who are more open and comfortable with being Gay. The premature referral may induce feelings of rejection, the same feelings that brought the patient to psychotherapy.

The most comprehensive publication found to date is a book edited by Michael Helquist (1987). This publication was written as a guide for mental health professionals who see patients with AIDS and related conditions. Apart from the detailed coverage of all psychosocial needs of AIDS, the importance of professional sensitivity to social, political and cultural issues is stressed. Guidelines for case management are presented through case examples, with succinct listing of key concerns and a description of counselling plans. They emphasize that it is essential that mental health professionals become skilled helpers to ameliorate the distress of AIDS sufferers.

III. METHOD

III. METHOD

The incidence of the disease in Cape Town and the requirements of this study precluded such research designs as single subject design and survey. As the disease is still relatively new in South Africa, a case study method was deemed most appropriate, since it would be an exploratory study which could lay the foundations for possible future research.

A medical practitioner involved with AIDS patients in Cape Town was contacted to obtain permission to interview patients. It was felt that a number of case studies would enable some comparison. However, it became clear that sampling was restricted by the patient's circumstances. Of the three AIDS patients in Cape Town, one was in the last stages of the disease and the researcher felt it would be unethical to use this patient as a subject. The second patient had been discharged from hospital to spend some time at home, and it was felt that using this patient as a subject would be an intrusion into the patient's (and probably the family's) privacy. The third patient, a twenty-nine-year old homosexual man, had been hospitalized with thrush and was due for discharge. This patient was chosen for the study.

The medical practitioner concerned (who was well known to the patient) approached him and explained the aim of the study and the need for an interview. The patient expressed his willingness to be involved in the study and established a time and date for the interview. The interview was conducted in the patient's private hospital room and the duration of the interview was three-quarters of an hour, due to the patient's physical weakness. Another session was not considered due the patient's condition and unwillingness to engage in further discussion.

The unstructured interview was chosen as the most appropriate research tool to use in this study and the use of a tape recorder was considered to allow more effective communication between the interviewer (the researcher) and the interviewee. Although the knowledge that the interview is being taped might cause the patient some anxiety, it was felt that writing down information would block effective communication, and that having to rely on memory would lead to gaps and discrepancies. Information from professionals involved in the case was considered as another useful tool to increase reliability. However, as the patient reported no contact with mental health professionals, only minimal information was obtained from the nursing sister on the ward at the time. Further information was obtained from the patient's lover and from the GASA Counselling Service where the patient had made contact.

The main advantage of the case study method relates to the fact that the problem is a sensitive one, and relatively new to South Africa. This approach might lead to the acquisition of useful data for more structured enquiries in future.

The unstructured interview allows probing into the subject's deepest feelings and experiences, which may elicit emotions, beliefs and attitudes which were previously unexpressed. It also encourages the subject to give free expression without the formal restrictions of a questionnaire or structured interview. The interviewer also has unlimited freedom to ask wide-ranging questions, to clarify, probe and explore issues with the subject. However, in this case, it was assumed that deep probing would require a subject who, firstly, was reasonably comfortable with his sexuality;

secondly, had a healthy, trusting attitude towards professionals, and thirdly, and most importantly, was able to recognize and express his feelings. It would seem, however, that the patient interviewed for this study had some difficulty in all these areas, as will be illustrated in the ensuing chapters.

The limitations of this study were those of reliability and generalization. Generalizing from the subjective experiences of one individual is extremely difficult. Therefore, efforts were made to draw inferences that could possibly apply to other cases.

Issues of reliability, concerned with interviewer and the interviewee biases, were considered extremely important and can be outlined in some detail.

Issues of Reliability

The interviewer could influence the subject in many ways. For example, the interviewer's non-verbal communication could increase the subject's anxiety by being too agitated, by appearing cold and formidable through manner or dress, by intruding on the subject's personal space or by being too distant. The questions posed by the interviewer might exaggerate or undermine the importance of the question thereby confusing the subject, or might imply certain expectations.

Negative attitudes and feelings on the part of the interviewer might be unintentionally expressed by the words, tone and expression used in the questioning. Questions that would have influenced the subject in this way were considered as follows:

"When you told your family you were diagnosed as suffering from AIDS, did they reject you?"

"Surely you must feel guilty about possibly having given AIDS to your lover?"

"When you found that you had AIDS, did you regret your promiscuity?"

"Could you tell me very briefly about the reaction of hospital staff members to you?"

With regard to interviewee biases, Grinell (1985) explained that there could be errors and biases as the respondents may:

- deliberately lie because they do not know the answer,
- make mistakes without realizing it (often because they are not able to admit socially undesirable feelings, attitudes, or traits, even to themselves),
- give inaccurate answers by accident, simply because they misunderstand or misinterpret the question, or forget facts despite their best efforts. They may even blend truth with fiction to cover memory gaps.

To avoid influencing the subject, it was felt that the most appropriate method would be to ask brief questions aimed at eliciting cognitive, emotional and behavioural information. As the interview was unstructured, only examples of questions used in the interview are provided, for the purpose of brevity. They are as follows:

"Could you tell me generally about your life before you were diagnosed as having AIDS?"

"What did you think and feel when you were told of the diagnosis?"

"What did you do then?"

"How did your lover .... friends .... family react?"

"How did you feel about this?"

"How have you managed financially?"

"How did you feel about your medical treatment?"

"Have you received any counselling?"

"How did you feel about that?"

In an attempt to limit the problem of bias, an outline was created to use as a guideline for the interview and to ensure that as many aspects as possible could be covered.

The outline is as follows:

A 'warming up'/ social phase, including introductions and 'small talk', thanking the patient in advance, and reassuring the patient that if he felt certain issues were too personal to discuss, there would be no pressure from the interviewer.

Clarifying confidentiality with the patient, emphasizing anonymity, obtaining permission for the use of the tape recorder and obtaining written informed consent to protect both the interviewer and patient.

Obtaining identifying particulars in general, such as occupation, age and general lifestyle to obtain an idea of the patient's status, cultural issues and premorbid personality.

Acquiring information about the patient's thoughts, feelings and behaviour prior to diagnosis, during the diagnostic process, and after diagnosis.

Obtaining information about the patient's experiences during the above process related to:

- lovers, close friends and family,
- lifestyle and social network,
- employment and financial effects,
- medical treatment,
- psychosocial treatment.

Finally, a termination phase, thanking the patient again and withdrawing.

IV. CASE EXAMPLE

IV. CASE EXAMPLE

The subject was a twenty-nine-year old homosexual man, who had been hospitalized for thrush for one week and was due for discharge. The interview lasted for three-quarters of an hour and took place in the patient's private hospital room. During the initial phase of the interview, the patient was requested to sign a written informed consent form, but he said that he felt this was unnecessary.

To maintain clarity, the discussion of results has been separated under the following headings: observations, premorbid functioning, personal reactions, lovers, close friends and family, employment and financial effects, lifestyle and broader social network, medical treatment, psychosocial treatment, and information from staff.

Observations

The patient appeared to be underweight and was obviously physically weak. He remained, for the full length of the interview, lying on his back or side, with the sheets covering him up to his neck and sometimes half covering his face. He frequently wiped the perspiration off his brow with his hand, and half way through the interview he asked the interviewer to hand him a glass of water.

The flow of the interview was frequently disrupted by the patient's loss of concentration and occasional announcements through the hospital loudspeakers.

The patient's responses were occasionally delayed and generally very restricted, and on a few occasions his speech was incoherent. Attempts by the interviewer to encourage the patient to elaborate were mostly unsuccessful.

The patient reported that his mood was angry, and this was also noted in his facial expression, clipped speech and occasional harsh hand movements. The interview ended when the patient admitted to feeling too tired to continue.

Premorbid Functioning

The patient was born in Johannesburg and completed his schooling there. He then studied accountancy at the

University of Stellenbosch and after a short term of employment in Cape Town, he returned to Johannesburg. He reported that he worked at a bank for a number of years as a planning manager and then a general manager, and later worked at a motor garage until his illness.

The patient initially lived by himself, and later with his lover, in a house which he owned. He explained that he had been very healthy most of his life and that his life-style was considerably influenced by overwork. He reported no specific sporting, cultural or recreational interests: "No, I worked too hard". He stated that his social life consisted of seeing a few close friends whenever he had the time.

Personal Reactions

The patient's initial symptoms of the illness were coughing and fever. He reported that he had full knowledge of AIDS as he had worked on the AIDS Action Committee in Johannesburg in 1985. He, therefore, immediately recognized the symptoms and spoke to a friend who was a medical practitioner. This friend soon confirmed the diagnosis. The patient initially stated that this occurred in July 1987 and later stated that he contracted AIDS in August 1987.

He was then hospitalized with PCP in Johannesburg with a subsequent short hospitalization for thrush. He stated that he came to Cape Town recently: "Because I wanted to be near the sea". Prior to this hospitalization he had stayed in an hotel but now refused to return there, as: "I hate hotels and they are too expensive".

The patient frequently stated that he accepted the fact that he had AIDS. His first statement was as follows:

> I overworked at the motor garage and that caused great fatigue and I also smoked a lot so I came down with AIDS in August last year. Well, I didn't have any open shock myself, you know, I didn't have any open shock myself, I just accepted it.

He later reported that: "Stress is one of the big causes of AIDS. You can't get AIDS unless you've got severe fatigue."

On two occasions when the interviewer probed for the patient's personal reactions, he responded by referring to other AIDS patients. In the first instance, he explained that he accepted his condition because of his knowledge of AIDS and that another patient who had both thrush and PCP remained unaware of his diagnosis. On the second occasion, while discussing his anger and concerns for his future, he referred to an AIDS patient who had been suffering for seven years, and in a rather fearful manner, he stated: "He's thin, thin, thin. Very, very weak".

The patient denied any feelings related to his condition from the time just prior to diagnosis, until two months ago. He said that at that time he noticed that he was feeling angry and the feeling had continued unabated. Probing by the interviewer failed to elicit any further information, apart from as follows:

> Well, I feel very angry all the time, but that's understandable. I feel antagonistic and I have terrible thoughts. Blood and gore and horrible machinery that chops people up into bits. I sort of feel, what's the future? I don't want to be around dying for seven years.

He felt that his anger was possibly related to his loss of health, as he said: "I don't like being sick, I'm sick and tired of being sick. I hate being sick, I never used to be sick."

Lovers, Close Friends and Family

The patient reported that his lover had lived with him periodically for four years: "We had tiffs, we divorced sometimes".

He felt that this relationship was one of the closest he had ever experienced. He explained that he had experienced no difficulty telling his lover about the diagnosis as, "My lover is very understanding, kind and understanding". From the time of the diagnosis they abstained from sexual contact and the patient said that it had not affected their relationship due to his lover's understanding attitude. He reported that his mother and his lover had a good relationship, and they had both visited him in hospital in Johannesburg. Since his recent move to Cape Town, he and his lover maintained occasional telephonic contact.

When referring to the reaction of close friends, the patient said that he had told them without difficulty and that they had been supportive, visiting him often while he was at home in Johannesburg.

The patient's family live in Johannesburg. He is the oldest of five children and he reported a close relationship with his mother, but referred to his other relationships as follows: "I never had such a marvellous relationship with my brothers and sisters or my father".

The patient had told his diagnosis to his mother and had accepted that she would tell the rest of the family when she felt the timing was appropriate. During this discussion, the patient only referred to the reactions of three family members; his mother and two brothers. He repeatedly stated that his mother was very "upset" but was "coping". He also mentioned that she was planning to travel to Cape Town to visit him the following week.

He spoke about his younger brother who is a medical practitioner, saying that this brother thought that his son would be infected with AIDS through contact with the patient. The patient expressed himself as follows: "I thought he was a fool because he should know how it's contracted. He should relax a little bit".

Concern was expressed for his younger brother, aged twenty-two, as the patient felt that this brother was having the most difficulty in coming to terms with the patient's diagnosis: "He was very upset and doesn't know how to cope. He's intelligent and sensitive and I think he'll come to accept it."

Lifestyle and Broader Social Network

The patient provided minimal information related to these issues. He expressed some surprise that a few acquaintances in Johannesburg had been openly supportive. He reported that in Cape Town he had a few friends looking for accommodation for him. He said that the hospital had recently contacted GASA (a counselling service to persons experiencing any Gay-related difficulty and providing services to HIV infected persons) to obtain assistance in finding accommodation. He said that fifteen Gay men who had AIDS-related complex (ARC) had been contacted to request that they accommodate him: "They freaked, they didn't want anything to do with it ...... I was horrified."

Employment and Financial Effects

With regard to employment, the patient said that he had told his employer as soon as he knew the diagnosis:

> He was very upset, because he needed me to help with the duties, and he feels guilty because I had been overdoing things. The patient had refused to tell his fellow workers because: 'It's got nothing to do with them......and they are clods anyway'.

He had attempted to return to work in October or November but had found that he was too weak to continue.

The patient stated that he had no medical aid or insurance, and no income since his illness. He reported that he had coped with this by selling his house and possessions in Johannesburg, and by not paying his hospital bills. In response to the question as to whether there had been any difficulties with regard to the non-payment of bills, he answered: "Well, they haven't sent the police to arrest me yet!".

Medical Treatment

Negative reactions from the Johannesburg hospital staff were reported by the patient: "They only came into the room covered in plastic all over, with masks and gloves, but after the third day it was all sorted out. I think it's stupid."

He felt that the hospital staff in Cape Town were well trained except for a few initial problems which had been resolved after the patient had spoken to the doctor concerned.

The patient also expressed his feelings about the medication he had received and the need for alternative treatment: "I shouldn't have had any (medical treatment). I feel the medical treatment I had in the Jo'burg hospital did more harm than good because they put me under general anaesthetic and stuffed me with antibiotics and I think it would have been better if I stayed at home and just had homeopathic treatment."

Psychosocial Treatment

The patient stated that he did not receive any form of counselling apart from a social worker who had visited him while he was in hospital in Johannesburg. He reported that he was not aware of who had arranged these visits, and when asked to elaborate on these sessions, he said, "She just sat there with a horrified look on her face. It seemed that people were praying my life away. It was quite sweet (sic) but it didn't help me."

He also stated that if AIDS patients had support from their families, "they are half way there". He felt that he had adequate support from his family and friends.

At the end of the interview the patient referred to his needs as follows:

> I need a little flatlet, a tiny one...... and, er, also preferably in time that this AIDS will go away.

Information from Staff

As the patient reported that he had received no counselling, information could not be obtained from other professionals. However, the sister in the ward agreed to meet with the interviewer.

The ward sister reported that the patient had been somewhat short-tempered with the ward staff. He had not been over-demanding or openly aggressive but occasionally cursed, or snapped at staff when his requests were not immediately dealt with. She felt that as he had been recently hospitalized and he had slept most of the time, the staff did not know him well and she could therefore provide no further information about his behaviour.

Information from the Befriender

Early in nineteen eighty eight, the patient contacted GASA with a request for a befriender to visit him. The befriender began working with the subject of this study on the third of February nineteen eighty eight, maintaining at least daily contact until the patient returned to Johannesburg some weeks prior to his death in May. The information that follows has been summarized from verbal and written material received from the befriender.

The befriender mainly provided the patient with practical assistance; providing transport, helping him find accommodation, buy a car and other purchases. Another important role he played was that of liaising with others such as potential landladies, hotel managers, some of the patient's family members, and acting as part of the general support team provided by GASA.

The general theme recognized by the befriender was that the patient was angry and demanding. Some of his comments are as follows:

> He does have a very aggressive streak when he realizes his weaknesses and demands much attention from the hotel staff.
>
> I have found that setting time limits with him helps me to cope better as he is a very demanding person and being with him can be very tiring.

The befriender reported that they had much difficulty finding appropriate accommodation for the patient. He stated three possible reasons for this: Firstly, the patient could not afford high rental, and needed accommodation with easy access because of his weakness. Secondly, he was open about his diagnosis and on one occasion, a potential landlady turned him down once she had been told that he was suffering from AIDS. Thirdly, the befriender felt that the patient was "uninhibited and too relaxed", for example, on another occasion the patient asked another potential landlady if he could sunbathe in the nude, resulting in him being turned down again.

The befriender also saw the patient's reaction towards GASA members as angry and disappointed - especially with the fact that they personally could not accommodate him. The befriender felt that their reasons for this were quite realistic; that the patient was well known to the members who were aware that the patient's manner would be too stressful and that he would require too much nursing care.

Although the befriender eventually helped the patient to buy a motor car, the patient rarely used it as it was being road-worthied and when not in the garage, the patient found that he was much too weak to use it for any length of time.

Some issues need to be highlighted here. The befriender expressed some confusion about the patient's reason for coming to Cape Town. He said that the patient had discussed his belief in homeopathy, including a need to explore spiritual issues, and that the being near the sea was conducive to this. The befriender interpreted from the patient's behaviour that he had also come to Cape Town to avoid the stress of his relationship with both his mother and his lover. The patient at one stage described his mother as "hysterical" and also said that he had difficulty communicating with his lover. The befriender felt that the patient was also testing his support system in Cape Town, and due to his high expectations, was sorely disappointed.

The patient's difficulty in coming to terms with his illness was also emphasized by the befriender. He reported that the patient did not believe that AIDS was a virus, he was adamantly opposed to medical treatment and was convinced that he would survive the illness. At one stage the patient told his befriender: "I've got spots in my eyes and I might go blind before I am eighty."

The befriender met the patient's mother on a number of occasions when she visited her son in Cape Town. He maintained that the patient was not pleased that she had come to see him and had referred to her as "neurotic". The befriender agreed that the mother was emotional, interpreting her emotional pain as related to her recent divorce from the patient's father, and that she seemed to accept her son's homosexuality but was having great difficulty coming to terms with his illness.

Also noted by the befriender was the patient's poor concentration and memory, with the patient frequently misplacing keys, wallet etc.

The patient's condition continued to deteriorate to the point where the befriender wrote, towards the end of February:

> He seems to have lolled into a state where he has no interests at all. He is not particularly interested in what is going on around him.

The hospice was contacted to request accommodation for the patient, but they refused. According to the befriender, the hospice was inexperienced in dealing with AIDS patients and probably felt that they were not suitable for him.

The befriender then reported that the patient

> ...had not faced death, even
> when he went to Johannesburg
> a while later.

Contact was maintained by the befriender with the patient and significant others until the patient's death.

The befriender reported that he had gained awareness and improved his skills through his experience with the patient. He now acts as the befrienders' coordinator for GASA.

Information from the Lover

The following information was received telephonically from the patient's lover.

The lover reported that both he and the patient were "fiery" about the gay movement. He had heard about the patient as one of the founding members of the 6010 gay group in Cape Town. He then met the patient through the Johannesburg gay movement in 1983, and they soon started an intense relationship. The lover spoke with pride about the patient's work with the movement. He said that the patient had been involved in creating all the following groups and services for the gay community:

- 'Gay Between' - the first gay magazine in South Africa.
- The Gay Community Centre.
- The Johannesburg gay switch board.
- The gay library.
- Benefit - an alliance of gay organizations.
- The AIDS Action Group.
- The Gay Employment Workshop.
- The GASA Rand newsletter.
- He was also a founding member of GASA on the Rand, having joined the committee in 1983, acting as treasurer in 1984 and chairperson in 1985.

He also worked with helping others start a gay group in Soweto, and created the AIDS Support and Education Fund.

The lover reported that he was vey much in love with the patient and that:

> Most people were attracted to him because of his lack of inhibition, very dynamic and extrovert, especially when he was healthy.

He said that the patient was always demanding and difficult and that his illness just worsened this aspect of his personality.

With regard to their relationship, he said that the patient was not interested in a committed relationship with him, and that this caused much contention between them, resulting in a decision to break their relationship on a number of occasions. He learnt of the patient's HIV positive status in 1984, and they both decided to continue as they were regardless of the diagnosis. In 1985 they broke up again for a longer period, although they continued with "an intense, but uncommitted relationship".

He related his reaction to the patient's diagnosis as:

> Shocked. Also because there were implications for myself. That's why I wouldn't encourage testing, because one has to become celibate - and the gay community is very sexual.

The lover felt quite strongly that the patient must have been HIV positive a number of years prior to the time he was tested, but managed to continue symptom free because of his extreme good health. One year after he was tested, the patient developed lymphodenopathy, which developed into thrush and PCP.

Relating to the patient's move to Cape Town, the lover said that the patient had become involved in conflict with the gay movement, who seemingly saw the patient's manner as too "status hungry and dramatic". He said the patient was very depressed as a result of this and became very spiritual - attending the spiritual church, practising yoga, etc. He said that the patient felt that he would improve his Karma if he went to Cape Town. The lover felt that it was good for him to try this. He had also been nursing the patient;

> ...and it was really tiring. Also all the friends continually visiting, and it was terrible having to always talk about it and face it all the time. Frankly, I was a little relieved when he left.

The lover said that the patient's father was cruel to him, not accepting him at all. However, he said that the mother was a great help when the patient returned to Johannesburg, as she visited frequently and helped nurse the patient.

The lover said that the patient continued to be demanding, but as he weakened, so his anger lessened. The visitors also decreased and the lover felt this loss keenly, as he would have appreciated some extra assistance.

After the patient's death, the lover moved away from the city;

> He was one of the few people to be so public about his homosexuality and AIDS. The Gay community lost a star. I moved to my sister - a time of mourning. They have been very caring and I am getting ready to return to life again.

V. DISCUSSION

This case study indicated that the patient was undergoing considerable emotional trauma related to his illness. He had been suffering from the full-blown AIDS syndrome for approximately seven months and appeared to be stuck in the phases of denial and anger. Interpretations were complicated by possible interviewer and interviewee biases. These points are discussed under the separate headings which follow.

Premorbid Functioning

The information that the patient provided about his premorbid functioning indicated that he would have been viewed as a high achieving young executive, with a successful career and bright future. His reported "overwork" could be interpreted as a result of his achievement needs and/or other personality factors such as difficulty in coming to terms with his sexual orientation, resulting in avoidance of social contact.

Whatever the reason for his overwork, he was healthy and active, and seemed to enjoy a relatively high status in Johannesburg society. Once he contacted AIDS however, he suffered multiple losses; his employment, his income, financial and social status, his possessions, and his presumably bright future.

Observations

The patient's appearance and behaviour showed that he was experiencing the early effects of debilitation; he required long periods of rest, assistance when walking and most likely required assistance with any physically demanding activity (although the latter was not clarified with the patient).

His poor concentration during the interview was in all likelihood due to his weak condition, which would also account for inconsistencies in his recollection of the dates of events. Although it was not verified with the medical practitioner, these symptoms could also have been early signs of AIDS Dementia. This raises questions about the patient's general functioning, especially when he is discharged. Coping with the daily tasks of living requires energy and concentration which the patient lacks. Without an adequate support system to help him with this, it is questionable whether the patient would be able to cope in the community for any length of time.

The patient also showed 'sheet sign', a condition described by Holtz, Dobro, Palinkas, Kapila and Oleske (1983). They observed that hospitalized AIDS patients hide beneath their bedsheets, withdrawing from contact with the world. The information received from the ward sister seemed to verify this as she reported that he had slept a great deal.

It was felt that the patient's delayed and restricted responses and his lack of elaboration could have been due to various factors: Firstly, physical factors: Talking for any length of time undoubtedly requires energy and concentration which the patient lacked. Secondly, the patient's mood was angry, which presumably caused resentment toward the interviewer's probing questions and resulted in a passive-aggressive reaction. Thirdly, it seems that the patient's primary defence was intellectualizing, which meant that he generally was not prone to recognizing and expressing his feelings, resulting in difficulty in communicating with the interviewer at this level.

Lifestyle, Lover, Close Friends and Family

The patient's lifestyle prior to his illness seemed restricted due to his reported overwork, both in employment and his work with the Gay Movement. His illness caused great changes in his lifestyle. It is felt that his decision to move to Cape Town may have had much to do with the impact of the illness. Although he reported his reason as "to be near the sea", it is suggested that his reasons were more involved than that. If it is assumed that the patient had difficulty coping with his losses, which were inextricably associated with Johannesburg, it could be interpreted that one reason for his moving to Cape Town might have been to 'escape' these losses and return to the Cape where he spent his student years.

However, this meant that he was geographically isolated from his family, lover and friends. Dilley, Ochitill, Perl and Volberding (1985), referred to patients who were already geographically isolated from their families, partly due to conflicts surrounding the patient's sexual orientation. Patients often feared to tell their families about their diagnosis out of fear of a renewal of such conflict.

In this case, although the patient had already told his family about his diagnosis, he reported poor relationships with his siblings and his father. It could be interpreted then, that the patient had moved to Cape Town partly as a means of geographically isolating himself from his family to minimize a resurgence of conflict over his sexual orientation. Also, since he experienced his mother as emotionally overwhelming, moving away from her would allow a reduction of this stress.

This need for isolation from his family is also supported by the patient's report of the reaction of his brother who feared contagion of his son (and possibly himself), and seemed to react in a rejecting manner. Although the patient stated at one stage that his family was supportive towards him, his other comments indicated that his family members (apart from his mother) rejected him, or at best, avoided him. This meant that while the patient was attempting to deal with his own reactions to his illness, his sense of isolation was exacerbated by his family's reaction.

It seemed that the patient's lover was able to act as a buffer against the rejections the patient received. Once again though, the patient suffered another loss; he and his lover abstained from sexual contact and periodically terminated their relationship which means that they were deprived of a means of fulfilling both their needs for sexual expression and for affection, at a time when the patient needed it most.

The patient and his lover had a somewhat unstable relationship which had lasted for four years. He also asserted that his lover was very supportive, and yet they maintained only occasional telephonic contact. This raises questions about possible changes that occurred in their relationship since the patient was diagnosed as suffering from AIDS.

Goulden, Todd, Hay and Dykes (1984) referred to the fact that lovers and Gay friends of AIDS patients are usually close in age, status and lifestyle, are often at the peak of their careers, intelligent, attractive and in the prime of life. The imminent death of the patient can, therefore, be very threatening to the survivors, resulting in denial of the patient's illness and in avoidance of the patient.

The minimal contact between the patient and his lover whilst he was in Cape Town, seems to indicate that they were both experiencing difficulties, with the unfortunate consequence that it increased the patient's sense of aloneness. This seems to have been largely resolved when the patient returned to Johannesburg to be nursed by his lover prior to his death.

Employment and Financial Effects

The manner in which the patient discussed his employment indicated that he had a good relationship with his employer, who encouraged the patient to continue working until he could no longer cope. However, the patient's relationship with his fellow workers seemed poor, possibly because of prejudice against the patient because of his sexual orientation. It seems more likely though, that the patient's antagonistic comment about his fellow workers, "they're clods anyway", reflected his anger and hostility towards society due to the isolation he experienced after having contracted AIDS (Deuchar 1984).

The patient suffered loss of employment and the consequent loss of income. His lack of any further financial backing such as medical aid and insurance, meant that he faced a financial crisis. By selling his possessions (house and household goods - another loss), he implied that he had enough money to continue coping financially for a limited period. He had been hospitalized three times since his diagnosis and it is assumed that the costs of hospitalization and medical treatment had been high.

He had coped with this by not paying his hospital bills. It is important to consider his statement in response to this when he referred to the police. This statement implies a number of things. Firstly, that the patient had experienced some anxiety about this as he was aware that there might be legal consequences. Secondly, the patient's primary concern, understandably, was his daily coping with his health. Therefore, the issue of non-payment of bills was avoided or postponed and his anxiety surrounding the issue was suppressed. Thirdly, it implied that he had not discussed these issues with a professional who might investigate realistic options with him. The consequences of this could be traumatic, as the patient is likely to experience renewed health crises with concomitant financial crises in future.

Medical Treatment

The results showed that the patient's experience with hospital staff was similar to those discussed in the literature review. Deuchar (1984) reported that many hospitalized patients expressed feeling 'dirty', as if they should be wearing bells around their necks. The use of gowns, masks, etc. by hospital staff increased the patient's sense of rejection and isolation. The patient in this study expressed his anger related to this through his scornful statement: "I think it's stupid".

It was felt that the patient's expressed need for alternative (homeopathic) treatment indicated his ambivalence. Perry and Markowitz (1986) referred to hospitalized AIDS patients who remain unreasonably hopeful despite the presence of a fatal illness. The denial can become so extreme that it interferes with the patient's receiving palliative medical care or it jeopardizes others because the patient refuses to practice risk-reducing behaviour.

The patient in this study was not denying to the extreme, in that he was receiving some palliative medical care. However, his need for alternative treatment indicated his ambivalence, as it implied both hope and despair: Despair in the sense of his anger and loss of faith in the ability of the medical profession to cure him, and hope (albeit irrational) in the sense that maybe alternative treatment might hold some 'miracle' cure not yet realized.

Psychosocial Treatment

The interview indicated that the patient received little psychosocial treatment. His one, brief experience (with the social worker in Johannesburg) was not therapeutic, as he perceived the social worker as 'horrified' and by implication, distanced from the patient at best, and at worst, rejecting of the patient.

The patient's denial was evident in his assertion that he had adequate support from his family and friends, thereby implying that he did not need psychosocial treatment. As previously discussed, there were indications that he did not have adequate support from his family and friends.

A major problem here was that the interviewer did not explore the reasons for the patient's lack of psychosocial intervention. Perhaps he had been offered professional consultation and had refused. It seems however, that the patient was in great need of psychosocial services, but due to his anger and denial, and his beliefs, he was unable to accept the need for psychosocial services.

Personal Reactions of the Patient

Although the patient was by no means articulate in expressing his thoughts and feelings, his brief responses were expressed in an emotionally-charged manner. It seemed that he was unaware of the intensity of emotions he was experiencing and unconsciously expressing.

In order to understand the patient's reactions, it is important to think carefully about the process he had been through. The patient denied any shock, or for that matter, any feelings when his diagnosis was confirmed. Yet, his shock, denial, confusion and anger was evident in the way he expressed himself. Firstly, his continued repetition of his "acceptance" of the diagnosis indicated just the reverse.

Secondly, his knowledge about the disease became confused, as he repeatedly stated that AIDS is caused through stress and fatigue. This meant that he was denying the full implications of the disease. These responses could have been due to the patient's reluctance to give a socially undesirable response, and/or due to his possible discomfort with his sexual orientation. However, the results suggest that the patient was struggling with coming to terms with the fact that he had contracted a fatal disease.

Although the patient had been involved with the AIDS Action Committee in 1985, his "full knowledge" of the illness was interpreted as 'intellectual knowledge', i.e., he had gained factual knowledge without considering the possibility that he might become infected. Assuming then, that his primary defence was intellectualizing, the knowledge of his diagnosis probably intensified his fears and anxieties, resulting in increased efforts to keep control by maintaining a conscious, intellectual approach. However, as his condition worsened over the months, so his fears and anxieties increased, resulting in initial fleeting transitions into the anger phase, and, by the time of the interview, both anger and denial were evident. This implies that his primary defence was slipping, allowing some movement towards eventual acceptance to take place. It appeared that the patient had just begun the early phase of anger; he had recognized a feeling of antagonism, a feeling which he was unable to focus, and was unable to recognize the source or meaning that the feeling had for him.

His anger was translated into expressions of extreme and graphic violence: "Blood and gore and death and horrible machinery that chops people up into bits". Once again, this statement indicated an unfocused anger, directed neither inwardly, towards himself, nor outwardly towards society/the medical profession.

He recognized that he resented the loss of his health: "I'm sick and tired of being sick", and, that he had doubts about the future: "I sort of feel what's in the future....". His references to the circumstances of other hospitalized patients were linked with these feelings and were interpreted as the patient beginning to identify with the feelings and circumstances of other patients, and, in a sense, both denying, and tacitly accepting the implications of the disease for himself. It could also be viewed that as the patient had difficulty in identifying and expressing his feelings, referring to the feelings of others was an indirect (and therefore safer) way of expressing his feelings - especially his fears of death.

These issues suggest that the patient had experienced tremendous difficulty working through the phases faced by terminal patients, as outlined by Kübler-Ross (1973). This raises questions about the patient's long-term adjustment to his condition: Is this patient able to negotiate the phases of loss without professional help? If not, what are consequences for him and perhaps his family members and friends.

Goldmeier (1987) suggested that patients who are unable to negotiate these stages themselves, may become chronically anxious and depressed and need psychotherapeutic intervention and possibly psychiatric help. The patient's final comment in response to what he saw as his needs, shows that psychotherapeutic intervention was indicated as he expressed a realistic need for accommodation with a very unrealistic expectation (or hope) that his disease would vanish. It must be emphasized that many AIDS patients, such as the subject of this study, suffer recurring bouts of opportunistic infections. This has major implications for psychosocial management: Firstly, the counsellor needs to treat the patient with full awareness of the impact of psychosocial factors (such as denial and anger) and physical/ medical factors of the illness which combine and interrelate in their effect on the patient Secondly, the counsellor needs to continually monitor the patient's mental and physical state to help the patient prepare for the recurring medical crises and the various psychological phases of the illness.

In sum, this case study indicated that the patient experienced major psychosocial trauma as a result of having contracted AIDS. He was a successful healthy businessman in the prime of life, and his illness reduced him to a dependent existence with major losses. Due to the nature of the disease, the patient experienced some rejection and isolation from others. Because of this factor, plus his loss of independence in every area of his life, and certain personality factors, the patient showed difficulty in coming to terms with his fatal illness, resulting in a somewhat fixed reaction of denial and anger.

This had implications for the patient's reaction during the interview, which illustrates the major limitation of the study. It was felt that as the patient had not come to terms with his illness, and greatly resented his loss of independence, he attempted to respond to the interviewer in a way which denied and minimized the intensity and scope of the psychosocial impact of his illness. This, therefore, led to the need for much interpretation and drawing inferences, which were influenced by the researcher's knowledge of the subject.

Other limitations were the lack of further collateral information, for example, from family members, employers and significant others, and a lack of other cases which would have allowed comparisons.

The major question that arises out of this study is: Do all AIDS patients need psychosocial treatment? It is felt that the answer is a definite 'Yes'. The psychosocial impact of the disease is devastating. Whether psychosocial intervention is minimal due to the patient's adequate coping mechanisms, or whether it is intensive (for the opposite reason), is not the issue. It is considered the responsibility of mental health practitioners to provide services to help AIDS patients negotiate the physically and emotionally painful adaptation to their condition.

It must be stated that GASA has developed comprehensive services for persons who are HIV AB+ or who have an HIV related illness or AIDS (see Appendix D). These services include support groups, individual counselling and practical assistance. However, patients receive these services on the basis of referral. This means that patients such as the subject of this study, might remain isolated, as there is a limited reaching out system. GASA seems to be working on a reaching out system, as they have compiled a letter offering their services to HIV AB+ patients which could be handed to the patients by their doctors or health care workers. This means that at least in the future, most AIDS patients will not be left to suffer in isolation - they will be made aware that there are people who care and who are willing to help.

There is one crucial point here. As Perry and Markowitz (1986) point out, referral to Gay-related organizations might cause further problems for patients who are not comfortable with their sexual orientation. It is likely that there will be a great increase in AIDS patients some of whom might not be homosexual or bisexual men. This raises an important question about the services offered in South Africa. This researcher is not aware of any other agency or organization that has made it clear that they offer counselling services to AIDS patients, potential AIDS patients, or their significant others. It is important that AIDS patients (as will anyone needing help) are offered a range of services to enable them to choose the source of help with which they feel most comfortable.

In conclusion both the literature review and the case example highlighted the unique and traumatic psychosocial experiences of homosexual AIDS patients and their significant others.

When the virus is contracted, profound changes will, at some stage, take place in the patient's life and relationships. People who once were significant to the patient may lessen contact, whilst other individuals who previously played a minor role in the patient's life, such as landlords or employers, can have great effect on the patient's future. Simultaneously, the patient becomes increasingly dependent on a network of medical and related personnel who inevitably become extremely significant in their lives.

In South Africa much can be learnt from experience gained elsewhere to foster the planning and provision of comprehensive and effective psychosocial services to all who are affected by AIDS.

The aims of these services are firstly, to prevent the spread of the disease, and secondly, to alleviate its effects. Therefore, at the foundation of the provision of services is the effective continued education of all.

This study has explored psychosocial issues related to homosexual AIDS patients and it is felt that serious attention needs to be given to the following recommendations:

1. Services offered by mental health practitioners need to be publicized in some form to ensure that these services are made easily accessible and attractive to AIDS patients.

2. Serious consideration needs to be given to the provision of a comprehensive service to the significant others who are affected by the AIDS patient's condition.

3. As AIDS patients suffer recurrent medical crises with concomitant psychosocial effects, the mental health and medical professions need to coordinate and cooperate in order to provide the most comprehensive care possible.

4. Mental health practitioners also need to cooperate with the medical system to ensure that medical staff are educated, and comfortable with treating AIDS patients.

5. Mental health practitioners need to be aware of the countertransference issues in dealing with AIDS patients, to prevent patients from dropping out of treatment and so ensure appropriate referrals.

6. It is crucial for mental health practitioners to be fully aware of the complexity of the psychosocial issues that involve every aspect of the AIDS patient's life, in order to provide comprehensive and effective services.

VI. APPENDICES

APPENDIX A : LETTER TO A DOCTOR REQUESTING ASSISTANCE WITH THE STUDY

Dear Doctor

"An Exploratory Study of the Psychosocial Needs of Homosexual Aids Patients" is the research study I am conducting in part fulfilment for my Masters degree in Clinical Social Work at the University of Cape Town.

My literature review shows that there has been increased investigation into the psychosocial aspects of the illness in the rest of the world in recent years. I feel that it is important to explore these issues with AIDS patients in Cape Town to prepare guidelines for the management of present and future AIDS patients.

I have chosen a case study approach and will, therefore, need to conduct an in-depth interview with preferably three AIDS patients. I fully appreciate the delicacy of the situation and I will endeavour to be as sensitive as possible to the needs of all concerned.

Your cooperation will be greatly appreciated.

Yours faithfully

Licia Blyth Karp
Student - Masters in Clinical Social Work

<u>APPENDIX B</u> : LETTER TO THE AIDS PATIENT REQUESTING HIS PARTICIPATION IN THE STUDY

Dear Patient

"An Exploratory Study of the Psychosocial Needs of Homosexual Aids Patients" is the research study I am conducting in part fulfilment for my Masters Degree in Clinical Social Work at the University of Cape Town.

In order to help present and future AIDS sufferers in Cape Town, I would like to interview you to explore emotional and social issues that you have experienced to gain insight and prepare guidelines for providing emotional support to fellow sufferers.

All information will remain anonymous. Please liaise with your doctor, or contact me at tel. No. 617729 if you would like to discuss this further.

Your cooperation will be greatly appreciated.

Yours faithfully

Licia Blyth Karp
Student - Master in Clinical Social Work

APPENDIX C : CONSENT FORM

CONSENT FORM

I, ..., have agreed to discuss my health and issues related to my health with Licia Blyth Karp with the full understanding that all information will remain anonymous.

SIGNED:

DATE:

PLACE:

APPENDIX D : GASA CIRCULAR

1988. 2. 15.

6010
GASA

Counselling Service
Raadgewende Diens

Tel: 21-5420 Telecall
8.00 a.m. to 6.00 p.m. Page 45452
6.00 p.m. to 8.00 a.m. Page 45907
Weekends Page 45907
Appointments:
Tuesdays 5.00 p.m. to 9.00 p.m. Tel: 23-6826

P.O. BOX 6010,
ROGGEBAAI,
8012.

CIRCULAR TO:

Medical Practitioners
Medical Superintendents of Provincial Hospitals in the Cape Town Area.
The Director, W.P.Blood Transfusion Service.
The Medical Officer of Health, Cape Town.
The Medical Officer of Health, Divisional Council of the Cape.
Dr F.H.N. Spracklen, Dept. of Medicine, Somerset Hospital.
The Director, Cape Mental Health Society,
The Regional Director, Dept. of National Health and Population Development.

5th February, 1988.

Dear Sir / Madam,

COMMUNITY SUPPORT SERVICES FOR PERSONS WHO ARE HIV AB+, HAVE AN HIV RELATED ILLNESS OR AIDS.

This Counselling Service has been in operation since 1982 providing psycho-social care to persons experiencing any Gay related difficulty. The influx of HIV infected persons seeking our assistance increased dramatically in 1986 and continued unabated throughout 1987. This has necessitated a re-organisation of our services.

This circular and the attached memorandum outlines the services we provide and how referalls should be made. Our services to HIV AB+ persons are not restricted to homosexuals.

COUNSELLING CLINIC EVERY TUESDAY 5-00 p.m. TO 9-00 pm

Venue: GASA-6010 Community Centre, Mercantile Centre,
Corner of Bree and Victoria Streets, Cape Town.
Entrance is in Victoria Street.

Appointments: Persons who present at any Clinic session will be seen during that session. Alternatively appointments can be booked in advance with the professional counsellor of your choice:

Gordon Isaacs	(W) 650-3485	(H) 45-4993
Mike de Villiers	After Hours Only	(H) 44-9622
John Pegge	(W) 45-1859	(H) 47-3614

The nature of the services provided for HIV infected persons at the clinic are detailed in the attached memorandum.

THE HIV POSITIVE SUPPORT TEAM.

Where appropriate and at the discretion of the counsellor, HIV AB+ persons are referred to a member of our HIV AB+ Support Team, which consists of persons who are themselves positive, for shared experience positive support. This is usually very beneficial and helpful during the days and first weeks following diagnosis of HIV AB+ status.

THE HIV POSITIVE SUPPORT GROUP.

This is a social group and not a therapy group where persons who are HIV AB+ get together on a regular basis. Referral is via the counsellor or a member of the HIV Positive Support Team.

THE AIDS SERVICE GROUP.

Members of this group befriend and assist persons with AIDS or AIDS related illness with services such as transport, shopping, banking, household chores, drives and outings. Referrals to this group are made by the counsellor.

THE AIDS ACTION GROUP.

This group monitors AIDS research, liaises with health care providers in the interests of our clients and undertakes the Safer Sex Campaign. The latter campaign is undertaken by means of public addresses, the showing of relevant videos and the publication of Safer Sex pamphlets which are distributed every month at all known Gay commercial venues in the city. Invitations to address interested groups or requests to borrow videos should be addressed to myself.

THE 24-HOUR TELEPHONE COUNSELLING SERVICE.
TELEPHONE 21-5420 (Telecall)

This service is provided by 25 lay counsellors who have undergone a fourteen week training course and who work under the supervision of our professional counsellors. This team is very skilled at dealing with all gay related difficulties and those which cannot or should not be dealt with telephonically are referred to the Clinic.

THE PROTECTION OF CONFIDENTIALITY.

The success of any work with HIV AB+ persons is dependent on their knowing that their right to confidentiality will be completely and utterly respected at all times. Particular care is taken of client records and clients are free to use pseudonyms if they so wish.

Most HIV AB+ persons have low self esteem and manifest "self imposed social withdrawal" which reveals itself in a reluctance to be referred or a stated distrust of a "Gay" organisation. It is necessary to deal with these issues by being directive, by accompanying the client to his first appointment with us or by telling clients that you will ask us to follow up those who do not show.

Yours sincerely,

Signature Removed

JOHN V. PEGGE
DIRECTOR

AIDS.

MEMORANDUM ON THE NATURE OF SERVICES PROVIDED BY THE GASA-6010 COUNSELLING SERVICE TO HIV AB+ PERSONS AND PERSONS ASSESSED AS HIGH RISK FOR EXPOSURE TO HIV.

OUR CLIENT POPULATION IS DRAWN FROM:

Sexually active homosexual men.
Sexually active bisexual men
Chronically promiscuous men / women, eg. prostitutes.
Sexual partners of the above.
Children born to HIV AB+ women. (None yet seen)
I.V. Drug users.

REFERRALS ARE MADE TO US BY:

Doctors
Hospitals.
Blood Transfusion Service.
Welfare Organisations
Clients themselves.

REFERRALS ARE MADE TO:

THE GASA-6010 COUNSELLING CLINIC
held every Tuesday throughout the year, including public holidays at
THE CASA-6010 COMMUNITY CENTRE
MERCANTILE CENTRE
CORNER BREE AND VICTORIA STREETS,
ENTRANCE IN VICTORIA STREET,
CAPE TOWN.

TIMES: TUESDAYS 5-00 p.m. TO 9-00 p.m.

APPOINTMENTS ARE MADE WITH THE COUNSELLOR OF YOUR CHOICE:

GORDON ISAACS	(W) 650-3485	(H) 45-4993
MIKE DE VILLIERS	After Hours Only	(H) 44-9622
JOHN PEGGE	(W) 45-1859	(H) 47-3614

If you experience difficulty in contacting any of the above leave a message with the counsellor on duty via our 24-hour Counselling Service, Telephone 21-5420 (Telecall) or with

The Counselling Clinic Secretary, Doug Whyte (H) 25-1844.

EMERGENCY CLIENTS CAN BE SEEN OUTSIDE CLINIC HOURS.

Our experience has taught us that clients going through the following situations should be regarded as emergencies and should be seen as soon as possible and should not wait for the following Tuesday.

The period immediately following being informed of HIV AB+ Status.
The period immediately following diagnosis of HIV related illness.
The period immediately following discovery that a previous sexual partner is HIV AB+ or has AIDS.

PRE-TEST COUNSELLING.

Usual Time Required: Two 45 minute appointments, one week apart.

Issues covered during first appointment:

Client fully informed regarding significance and possible consequences of test, particularly difficulties that can be encountered in trying to obtain or change employment, medical aid and life cover either group or individual.

Client given written information regarding HIV infection and Testing.

Client informed that Test has little or no benefit if he/she is healthy and:

1. Practising Safer Sex.
2. Eating a balanced diet.
3. Getting regular exercise.
4. Not abusing alcohol or drugs.
5. Getting sufficient rest.
6. Avoiding unnecessary stress.

Homosexual clients are evaluated carefully in terms of where they are in their "Coming Out Process" and what support systems they have. Have "Gay" significant others been reconciled with family of origin and non-gay significant others?

The RISKS and BENEFITS of Testing are then carefully evaluated according to the following criteria

BENEFITS

1. To assist a medical diagnosis in persons who exhibit suspicious symptoms.
2. To challenge and reduce anxiety in persons assessed low risk but having high anxiety.
3. To motivate persons who practice high risk behaviour and who feel a positive test result may help reduce these behaviours.
4. To protect recipients of donated blood, semen, tissue and organs.
5. To assist high risk persons in decisions related to having children.

RISKS

1. Severe psychological reactions - anxiety, nightmares, sleep disturbance, depression and suicidal behaviour.
2. Disrupted interpersonal relations including potential for rage reactions and violence.
3. Social ostracism and self-imposed social withdrawal.
4. Relationship problems.
5. Stigmatization and discrimination if HIV AB+ status is made public.
6. Difficulty with employment and insurance

Benefits and Risks of Testing continued on Page 3.

BENEFITS (Continued)

6. To assist high risk women in decisions related to breast feeding and innoculations produced from live virus.

7. To assist decisions related to participation in experimental treatment programmes.

8. To assist couples entering monogamous relationship in decisions related to permissable sexual practices. Must test HIV AB Neg now and 6 months later before relaxing safer sexual practices.

RISKS (Continued)

7. Pre-occupation with bodily symptoms.

8. False security and denial of risk if test result is negative - continues high risk behaviours.

IF BENEFITS OUTWEIGH RISKS GIVE CLIENT ONE WEEK TO CONSIDER RECOMMENDATION TO HAVE TEST. (Exception is for medical diagnosis)

IF RISKS OUTWEIGH BENEFITS GIVE CLIENT ONE WEEK TO CONSIDER RECOMMENDATION NOT TO HAVE TEST.

Issues covered during second appointment.

Revision of issues dealt with during the first appointment and a re-evaluation of the recommendation to have or not to have the Test.

Counsel Safer Sex Practices and warn against donating Blood, Semen, Tissues and Organs.

Warn that Negative Test result does not imply immunity and could be false if infection occurred within the past 3 or possibly 6 months.

Help with sexual orientation problems.

Provide assistance in achieving positive adjustment to homosexual orientation.

Where appropriate make the referral for HIV AB Testing and make provision for a follow-up appointment should test result be Positive.

COUNSELLING AT POSITIVE TEST RESULT STAGE.

Usual Time Required: Two 45 minute appointments approximately 3 days apart.

Issues covered during first appointment.

Result of Test given.
Permit time for and encourage ventilation.

Counsel on:
1. Significance and meaning of test result.
2. Safer sex practices.
3. Infection control.
4. Health boosting.

COUNSELLING AT POSITIVE TEST RESULT STAGE (Continued)

Issues covered during first appointment (Continued).

Re-inforce issue of confidentiality and the need for protection from stigmatization and discrimination. Inform lover only.

Provide a "Lifeline"; telephone numbers where counsellor can be contacted at any time.

Make follow-up appointment for approximately three days hence.

Issues covered during second appointment.

Repeat counselling done during first appointment (with partner).

Questions answered.

Who and how to tell (Confidentiality / Development of Support System)

Problem solving.

Psychiatric / Psychological screening.

Discuss future strategy:
1. Medical.
2. Psychiatric.
3. Social Support Systems.

Make follow-up appointment if client is to join the ongoing HIV AB+ Counselling Programme.

ONGOING COUNSELLING PROGRAMME FOR PERSONS WHO ARE HIV AB+.

Usual Time Required: One 45-minute appointment per week for the first three to eight weeks, dependent on individual circumstances and thereafter one 45-minute appointment every two months

Issues covered during first appointment.

If the client does not join the programme directly after receiving the counselling described above at "Positive Test Result Stage", the issues described therein are reviewed with the client and a full assessment made of his present knowledge and situation.

The client and the counsellor, either jointly or separately, complete the questionaire "HIV AB+ MONITOR" repeated on pages 5 and 6. Joint agreement is obtained on the rating scores assigned to each item and the client is encouraged to believe that proper attention to areas requiring improvement can secure the maintenance of good health.

GASA-6010 COUNSELLING SERVICE. **HIV AB+ MONITOR.**

Completed either separately by client and counsellor, or jointly, preferably every 2 months after learning HIV AB+ status.

NAME OR CODE:______________________ DATE:__________

AGE:______ DATE OF SEROCONVERSION (If Known):__________

DATE OF HIV AB+ TEST RESULT:______________________

The Lower the Rating Score the Better.

	EXCELLENT No attention Required	AVERAGE Can be Improved	POOR ImprovementEssential

PHYSICAL CARE.

Exercise	1-----2-----3-----4-----5-----6-----7
Sleep	1-----2-----3-----4-----5-----6-----7
Sex Life	1-----2-----3-----4-----5-----6-----7
Adjustment to Safer Sex Prac.	1-----2-----3-----4-----5-----6-----7
Alcohol use	1-----2-----3-----4-----5-----6-----7
Smoking	1-----2-----3-----4-----5-----6-----7
Diet	1-----2-----3-----4-----5-----6-----7
Recreational Drug Use	1-----2-----3-----4-----5-----6-----7
Prescribed Drug Use	1-----2-----3-----4-----5-----6-----7

PSYCHO-SOCIAL STRESS FACTORS.

Integration of Gay Identity.	1-----2-----3-----4-----5-----6-----7
Support Systems: Parents/Family	1-----2-----3-----4-----5-----6-----7
Support Systems: Friends	1-----2-----3-----4-----5-----6-----7
Support Systems: Work Colleagues	1-----2-----3-----4-----5-----6-----7
Anger: Expressed----Suppressed	1-----2-----3-----4-----5-----6-----7
Anxiety	1-----2-----3-----4-----5-----6-----7
Depression	1-----2-----3-----4-----5-----6-----7
Coping Mechanisms	1-----2-----3-----4-----5-----6-----7
How do you feel about yourself	1-----2-----3-----4-----5-----6-----7

HEALTH.

Your present weight:________kgs = _______kg LOSS /GAIN since:________

Are you taking any dietary supplements or vitamin tablets? If "Yes" give details:

Do you have or have you had any of the following?

		Date of Onset.
Swelling of lymph glands?		
Skin conditions?		
Tiredness?		
Fungal Infections?		
Raised Temperature?		
Night Sweats?		
Shortness of Breath?		
Diarrhoea?		
Cough?		
Memory loss?		
Slower Mental Reactions?		

RELATIONSHIP STATUS. Are you presently in a relationship:

If "yes" rate the quality:

Have you terminated a relationship in the past 3 years?

Do you have a lover or close friend who is HIV AB+ or has AIDS:

NOTES:

Issues covered during first appointment. (Continued)

After the questionaire have been completed the items requiring the client's attention are prioritised and a strategy decided upon.

Check for depression / anxiety and refer for medication if necessary.

If there are any medical symptoms refer for medical assessment and treatment.

Assess the need / benefit of linking client with the HIV AB+ Support Team or the HIV AB+ Support Group and refer if necessary.

If appropriate raise and discuss the issue of estate planning and making a Will.

Plan ongoing contact.

Issues covered during second and subsequent weekly appointments.

Review progress in dealing with items requiring attention, motivate, encourage and revise where necessary.

Assess medical / psychiatric status and progress on medication.

Check for depression / anxiety and refer for medication if necessary.

Weekly appointments are terminated when a positive adjustment to HIV AB+ status has been secured and the client's social functioning is satisfactory. Then seen at two monthly intervals.

Issues covered during appointments at two monthly intervals.

Client and counsellor, either separately or jointly, again complete the questionaire "HIV AB+ MONITOR", printed on pages 5 and 6. They jointly agree on rating scores and then compare with the results obtained on previously completed questionaires. This determines progress and the items requiring further attention.

Assess medical / psychiatric status and progress on medication.

Check for depression / anxiety and refer for medication if necessary.

Book next appointment.

Throughout counselling contact, from Pre-Test to Ongoing Counselling, clients are made aware that if they are sexually active, condoms and KY Lubricating Jelly are obtainable from the GASA-6010 Community Centre. We regard it as irresponsible for sexually active Gay men at risk to be given condoms without KY Lubricating Jelly or other water based lubricant. Used without such lubricant condoms split or disintegrate.

COUNSELLING AT THE STAGE OF DIAGNOSIS OF HIV RELATED ILLNESS.

Usual Time Required: 3 to 6 weekly appointments of 45 minutes each.

Issues covered: Psycho-social impact of diagnosis takes time, anticipate the process of;

1. Denial.
2. Depression.
3. Anger.
4. Bargaining.
5. Acceptance

Psychological reactions can be severe and must be referred for medication where necessary.

Support sytems must be reviewed and strengthened where necessary.

If not already attended to, estate must be planned and Will made, if delayed to a later stage, the mental status of the client could be contested should symptoms of AIDS dementia arise.

Problems of low self esteem and living with ambiguity can frequently be alleviated by engaging the client in altruistic activity.

Attention given to depression, anxiety, loss of libido and social alienation.

Impairment of social function varies from mild to severe and may require client to assign his power of attorney to someone.

The need for the client to be assigned a befriender from the AIDS Service Group should be assessed. If needed the introduction of the befriender to the client should be carefully planned and executed in an unobtrusive manner. Many clients are very sensitive about accepting the need for this kind of help.

Plan ongoing contact according to needs.

COUNSELLING AT AIDS DIAGNOSIS STAGE.

Usual Time Required: 3 to 6 weekly appointments of 45 minutes each. The need varies from patient to patient and is determined by the patient's circumstances and the amount of previous contact with the counsellor.

Issues Covered: These are identical to those dealt with in the previous stage of counselling at the time of diagnosis of HIV related illness.

The process of denial, depression, anger , bargaining and acceptance should again be anticipated and worked through with the client.

COUNSELLING FULLBLOWN AIDS PATIENTS.

Usual Time Required: This is determined by the individual circumstances of each patient. Those without adequate support systems need to be seen on a weekly basis. They can seldom come to the clinic and are therefore seen at home or in hospital.

Issues covered.

Mid-stage AIDS:	Loss of hope, emotional exhaustion. Grief-work, anticipating and mourning loss. Extent of treatment, pain control. Unfinished business, life review.
Terminal Stage AIDS	Pain Control. Family and Friends. Death and Dying. Honouring client's wishes.

MAKING OUR SERVICES KNOWN TO PATIENTS.

Attached to this memorandum is a copy of a letter which is designed to be given to HIV AB+ patients by their doctors or attending health care professionals. It would be appreciated if you give a copy to each of your HIV AB+ patients.

The letter can either be duplicated or you can order a supply of them from us :

The Secretary,
GASA-6010 Counselling Clinic,
P.O. Box 6010,
ROGGEBAAI.
8012.

5th February, 1988.

JOHN V. PEGGE

Signature Removed

DIRECTOR - GASA-6010
COUNSELLING SERVICE.

6010
GASA

Counselling Service
Raadgewende Diens

Tel: 21-5420 Telecall
8.00 a.m. to 6.00 p.m. Page 45452
6.00 p.m. to 8.00 a.m. Page 45907
Weekends Page 45907
Appointments:
Tuesdays 5.00 p.m. to 9.00 p.m. Tel: 23-6826

P.O. BOX 6010,
ROGGEBAAI,
8012.

Dear Friend,

It is not easy to be confronted with the fact that you have been exposed to the HIV virus and therefore stand a chance of one day developing AIDS or related illness. This letter is our way of introducing ourselves to you in a manner which does not invade your privacy. It was either handed to you or posted to you by the medical professional attending to you without our being aware of your identity. We offer a number of services which could lessen the loneliness of your experience and which may be of assistance to you. You are therefore most welcome to contact us but before you do so, I am sure your would like to know a little about us and what we offer.

This Counselling Service is a separate project of GASA-6010, Cape Town's Gay service organisation. Separate because not all who seek our assistance are gay, because of the need for absolute confidentiality and because GASA-6010 members are amongst those whom we assist. We are a voluntary organisation staffed by both professional and lay volunteers. Services are provided free of charge but you will be invited to contribute towards the costs.

Before mentioning the specific services we offer it is important for you to realise that you have a great deal to offer. By contacting us you will not only be at the receiving end but you will be exploring ways and means of assisting others who share your situation. We would welcome your contribution.

COUNSELLING CLINIC IS HELD EVERY TUESDAY FROM 5.00 PM TO 9.00 PM

AT THE GASA-6010 COMMUNITY CENTRE, MERCANTILE CENTRE,
CORNER VICTORIA AND BREE STREETS, CAPE TOWN.
Entrance is in Victoria Street.

This is where we like to first meet you and discuss the various ways in which you can maintain your health and thereby considerably reduce the chance of one day developing AIDS or related illness. Make an appointment with me or with either of the two senior professional Social Workers who staff the clinic with me.

JOHN PEGGE	(W) 45-1859	(H) 47-3614
GORDON ISAACS	(W) 650-3485	(H) 45-4993
MIKE DE VILLIERS	A/H Only	(H) 44-9622

The Counselling Service promotes access to:

The Parents of Gays Support Team
The HIV Positive Support Team

The Gay Parents Support Team
The HIV Positive Support Group
The AIDS Action Group

The Wives of Gay Men Support Team
The AIDS Service Group

All manner of enquiries and problems are dealt with at our Counselling Clinic so there is no chance that by using this facility you would be identified as a person facing the threat of AIDS. If you would feel more comfortable doing so, you are welcome to use a pseudonym.

THE HIV POSITIVE SUPPORT TEAM.

This team consists of people who are themselves HIV Antibody Positive, who have positively adjusted to the situation and who are happy to provide shared experience support to their fellows. Should you wish to meet a member of this team, ask the person you see at our Counselling Clinic to introduce you.

THE HIV POSITIVE SUPPORT GROUP.

This is not a therapy group but a group of persons who are HIV Antibody Positive and who meet together socially every once in a while. They enjoy each other's company and at least for the duration of their meetings don't have to be secretive about being positive if they don't want to be. If you wish to join ask the person you see at our Counselling Clinic to introduce you.

THE AIDS SERVICE GROUP.

The members of this group befriend and assist persons with AIDS or related illness, with services such as transport, shopping, hospital visiting, household chores, drives and outings. One of the most difficult aspects of dealing with illness is accepting the fact that you need this sort of help. Many patients live on their own and it is vital that their independence and dignity be maintained: this group aims to achieve this. Therefore if you need this sort of help don't have any hangups about asking.

THE AIDS ACTION GROUP.

The members of this group disseminate information about AIDS and its prevention plus liaison with health authorities and the media in the interests of the best possible care for patients. The medical professionals who head this group make a point of monitoring research and findings regarding AIDS and keep us informed.

THE 24-HOUR TELEPHONE COUNSELLING SERVICE.

This service operates by means of a radio pager and is therefore available 24 hours a day for those seeking information or experiencing a problem. Telephone 21-5420 (Telecall) and leave your telephone number for the counsellor on duty to return your call.

Take care and use your exposure to the HIV virus as a positive growth experience. I look forward to hearing from you when you feel ready or have the need.

With best wishes.

Signature Removed

JOHN V. PEGGE.
DIRECTOR.

VII. BIBLIOGRAPHY

BIBLIOGRAPHY

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