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**CLIENTS' PERCEPTIONS OF  
SIGNIFICANT PSYCHOLOGICAL ISSUES  
ACROSS THE HIV/AIDS CONTINUUM**

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June, 1995**

**A thesis submitted to the Faculty of Graduate Studies and Research in partial  
fulfillment of the requirements for the degree of Master of Arts.**

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## Abstract

The objective of the proposed research study was to answer the following research questions; Do clients in their respectful stages of diagnosis place more emphasis on certain psychological issues than others? And if so, can we identify the specific psychological issues that were considered to be most significant and unique across the stages of the HIV/AIDS continuum? To test these research questions, 37 homosexual men falling in three specific stages of the infection were surveyed. These three stages included; (1) HIV+ asymptomatic, (2) HIV+ chronic symptomatic, and (3) AIDS diagnosis. The HIV/AIDS Client Concern (HACC) questionnaire was developed to assess the significance clients placed on certain psychological issues and, was administered to all the subjects. The statistical analyses revealed that clients' level of diagnosis influenced how much emphasis they placed on what they considered to be significant psychological issues. More specifically, clients in the asymptomatic group reported a higher concern with issues surrounding confidentiality of their HIV/AIDS status than the AIDS diagnosis group. The chronic symptomatic group, on the other hand, was significantly more concerned with issues regarding feelings of guilt/shame, shock, depression, fear, loneliness, and anxiety of infecting other people through casual contact than the other groups. In addition, the AIDS diagnosis group was most concerned with issues surrounding the planning of their future care in comparison with the asymptomatic group. A more detailed analysis of each questions' content and its significance as well as, the implications such results have for both researchers and practitioners alike will be discussed.

Le but de cette recherche était de trouver une réponse aux questions suivantes:

Les clients, dans chacun de leurs stages respectifs, placent-ils plus d'importance sur certaines questions d'ordre psychologique que d'autres? Si oui, pouvons-nous identifier celles qui seront plus significatives et uniques dans l'évolution du virus du SIDA. Pour répondre à ces questions, nous avons demandé à 37 homosexuels mâles, dont les conditions de santé répondaient aux trois stages prédéterminés du virus, de se prêter au questionnaire "HIV/AIDS Client Concern (HACC)". Ce questionnaire, développé pour évaluer l'importance que les clients placent sur certaines questions d'ordre psychologique, s'adressait aux trois stages du virus du SIDA dont: 1) HIV+ sans symptômes, 2) HIV+ avec symptômes chroniques, et 3) diagnostiqué SIDA. Les sujets dans la catégorie HIV+ sans symptômes ont démontré un intérêt plus élevé concernant la confidentialité de leur statut de HIV/AIDS que ceux diagnostiqués séropositifs. Le groupe avec symptômes chroniques, eux, ont été plus concerné que les autres groupes par les questions portant sur le sentiment de gêne, de culpabilité, de dépression, d'anxiété, de solitude, de choc et aussi par la peur d'infecter d'autres personnes par des contacts casuels . Aussi, le groupe diagnostiqué séropositif était plus concerné par les soins qu'ils devront dans un avenir rapproché en comparaison avec le groupe sans symptômes. Une analyse plus détaillée du contenu de chacune des réponses, aussi bien que les implications que de tels résultats pourront avoir autant pour les chercheurs que pour les praticiens, seront discutés.

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## Chapter 1

### Literature Review

#### Introduction

Worldwide, the rate of HIV infection continues to spread exponentially among men, women, teens, and children. In addition to being viewed as the primary medical health problem of the 1990's, HIV/AIDS has also been referred as a psychological emergency. Individuals not only have to deal with the conceptual and medical changes that are stressful enough, they must also cope with the array of complex, psychosocial issues that accompany HIV infection. These issues exacerbate their level of psychological distress and ultimately create an urgent need for counselling services (Herek, 1990; Hoffman, 1991). The common perception in the literature is that psychological issues related to HIV infection are more complex and overwhelming than in any other disease (Scappaticcio, 1989). This is due to the fact that HIV/AIDS is associated with numerous psychological effects that stem from different sources and occur at different stages of the illness. This may ultimately lead to many different psychological problems and complications (Anderson, Landry, & Kerby, 1991; Batchelor, 1984; Chuang, Devins, Hunsley, & Gill, 1989).

HIV/AIDS has been described as one of the most pressing medical, and social problems of this century, which inevitably induces numerous psychological concerns throughout the course of the illness (Bor, Miller, Scher, & Salt, 1991). Since HIV was first recognised as a problem in the early 1980's, extensive research has supported the idea that

a diagnosis of AIDS does not only induce various medical issues, it also incorporates numerous psychosocial and psychological concerns that an individual faces (Dilley, Batki, & Shelp, 1985; Dworkin, & Pincu, 1993). In addition, HIV illness is associated with a highly negative social stigma. This may lead HIV infected clients to experience a wider spectrum of psychosocial issues, such as fear of social isolation, than individuals facing other chronic illnesses (Govoni, 1988; Lancot & De Monting, 1989). As such, recent evidence suggests physicians are now recognizing the psychological stress faced by clients in dealing with the medical and psychosocial issues inherent in their illness. Consequently, they increasingly recommend that HIV infected clients seek out psychological counselling (Antoni, 1991; Winiarski, 1991).

Recent evidence suggests that over the course of the HIV infection different psychological issues will emerge (Anderson, Landry, & Kerby, 1991). These psychological issues significantly affect the social, emotional, and overall well being of people living with HIV/AIDS.

As such, the objective of the proposed research study is to identify the various psychological and psychosocial issues that exist across the HIV/AIDS continuum. More specifically, the aim of this study is to answer the following research questions; 1) Do HIV clients who are asymptomatic, symptomatic or who have received a diagnosis of AIDS have different psychological concerns and place more emphasis on certain psychological issues than on others? and 2) Can we identify specific psychological issues that are important and unique in each of the three aforementioned groups?

In other words do HIV asymptomatic clients experience psychological stressors at a significantly higher degree than HIV symptomatic and AIDS clients?, and are these stressors significantly related to their stage of affliction?

#### Brief History & Nature of the Illness

During the late 1970's, symptoms of HIV or Human Immunodeficiency Virus and AIDS (Acquired Immune Deficiency Syndrome), were first recognized in North America. In 1981, after physicians began noticing that numerous young gay patients in several large cities presented themselves to hospitals with unusual opportunistic illnesses and evidence of immune system suppression, the medical profession recognized AIDS as a disease. (Centres for Disease Control, 1981a, 1981b). Since then, it quickly became obvious that AIDS was a sexually transmitted disease (STD) that could also be spread through blood and some blood products (i.e. contaminated needles or syringes). It also became clear that both gay and heterosexual activity could transmit the virus, as well, prenatal events leading to pediatric AIDS cases.

As of January 1992, the World Health Organization (WHO) estimated that 9 to 11 million individuals were infected with the human immunodeficiency virus (HIV) (WHO, 1992). More recently, in the United States, AIDS has become the leading cause of death in men aged 25-34 years -exceeding heart disease, cancer, suicide, and homicide- (New York Times, 1995). Such statistics clearly indicate the widespread and impacting nature of this disease. As a result, it now becomes even more apparent that additional

research is required to help find ways to alleviate the heavy psychological burden that HIV/AIDS inflicts upon infected individuals.

The human immunodeficiency virus (HIV) is believed to be the cause of a chronic, progressive, immune deficiency disease, the most severe phase of which is Acquired Immune Deficiency Syndrome (AIDS). Currently survival time after infection with the HIV virus has been lengthened considerably. It has been reported that the incubation period from infection to the development of AIDS is approximately 10 to 15 years (Gilmore, 1990; Hockings, 1989). The symptoms and signs of HIV disease occur in a sequence of predictable stages ranging from HIV positive but asymptomatic to HIV symptomatic illness to AIDS. The final stages eventually end in the development of a severe deficiency of immune functioning, that threatens both the quality of life and survival. Quite early in the history of this epidemic it was concluded that the modes of transmission include sexual contact involving an exchange of body fluids, drug use with contaminated blood needles, and administration of contaminated blood products (Frierson, 1987).

In terms of the conceptualization of the HIV/AIDS illness, information related to the medications and treatments recommended, as well as, the social and political climate surrounding the illness change almost daily (Dworkin et al., 1993). Currently, HIV-infected individuals are experiencing lengthier periods of healthy living between the time of infection and the development of AIDS symptoms, and individuals who have full blown AIDS are now living for a substantially longer period of time than those who became sick

in the early years of the epidemic (Anderson et al., 1991; Douce, 1993). As a result what was once considered a death sentence has now become a chronic illness. Despite such developments however no consensus has yet been reached in regards to the aspects of the epidemiology of this illness. In other words, even though medical science has provided a clear picture of the methods of transmission of the virus, neither a cure for AIDS nor a vaccine or anti-viral treatment is currently available (House & Walker, 1993).

Thus, it appears clear that HIV/AIDS is a chronic illness which affects greater numbers of individuals every day. Experiences of physical deterioration and societal rejection increases one's susceptibility to psychological distress. Currently with the lengthening of the life for infected patients, the need for psychological services becomes even more evident.

#### Evolving Perspectives of HIV/AIDS Research

During the early 1980s, the first cases of AIDS were reported by the Centers for Disease Control (1981). The sudden appearance of this illness led to considerable confusion in the medical profession as to possible aetiology. As a result, initial research in the area of HIV/AIDS was primarily directed towards the medical aspects of the disease as well as towards the psychopharmacological modes of treatment (Coates, Morin, McKusick, 1987). Subsequently, House and Walker (1993) report that a great deal has been learned particularly with respect to viral transmission and risk behaviours. For example, it has now been established that the HIV virus can only be transmitted during any activity where semen, blood, or vaginal fluid enters a partners body (Fietz, 1991)

Less emphasis, however, has been placed on the potential psychological impact of this growing health crisis. The early literature in HIV infection pertaining to the various psychological issues that exist mainly included anecdotal reports based on clinical observations and experience (Anderson et al., 1991; Dilley et al., 1991). For example, Batchelor (1984), Catalan (1988), Holland & Tross (1985), Morin & Batchelor (1984), Penzien (1986), and Servellen (1989) reported that scientific literature on HIV/AIDS in the early years consisted of personal and professional experiences and opinions, rather than theoretically derived scientific findings. Such investigations have produced substantial amounts of qualitative data and as a result have increased our conceptual understanding of various social, political, medical, and psychological issues related to research on HIV infection (Ankrah, 1989; Kaplan, 1989). However, not enough attention has been devoted towards conducting more experimental, research-based studies (Anderson et al., 1991; Lamping & Sewitch, 1990). Such studies can establish explicit methodologies for assessing therapeutic models which address some of the most important issues that are likely to surface in counselling with gay men. This can ultimately prepare the therapist in dealing with their clients' distinct psychological concerns in a more helping context.

Soon after this period of predominant clinical literature, the psychological research on HIV infection began to adopt a more research-oriented approach. For example, Ankrah (1989), Gilmore (1989), Kaplan (1989), Livingston (1988), and Nelkin (1987) significantly contributed relevant findings that addressed the conceptual and methodological issues related to behavioral research on HIV/AIDS. In other words, these researchers were



among the first to systematically evaluate distinct conceptual models used to describe the various psychological and psychosocial needs and relevant mental health issues for specific groups of persons infected with the HIV virus. According to Hoffman, 1991 and Lamping et al., (1990), literature reviews concentrating on the different psychological issues faced by persons with the HIV/AIDS virus, and research attempting to formulate practical models of clinical interventions have just began to surface in any significant degree in the literature. Consequently, even though there appears to be a steadily increasing accumulation of research dealing with the psychological factors that exist in the literature on HIV/AIDS infection and mental health, there still remains an urgent need to combine clinical interventions with more research based methodologies (Anderson et al., 1991; Lamping et al., 1990).

More specifically, systematic approaches for dealing with the progression of pervasive emotional reactions surrounding one's HIV/AIDS status have not yet been fully understood. In addition, there have been very few studies that have examined the role of counselling and its effectiveness in coping with the HIV disease (Anderson et al., 1991; Blaney, Millon, Morgan, Eisendorfer, & Szapocznik, 1990; Atkinson, Grant, Kennedy, Richman, Spector, & McCutchan, 1988).

#### Brief Outline of Differing Issues/Stages of the HIV/AIDS Virus

HIV/AIDS is a devastating illness with profound medical, psychological, and psychosocial consequences. Mental health care professionals in every service delivery setting are increasingly encountering HIV infected clients at various stages of the illness, as

well as, seronegative clients or clients of unknown status whose behaviour places them at high risk for exposure to the HIV illness.

Working with clients who are anywhere on the HIV/AIDS continuum from asymptomatic to having HIV-related symptoms to having AIDS is both rewarding and demanding work. Determining which psychological issues are specific to this population will provide mental health care practitioners with valuable information on planning effective treatment strategies (Dilley, 1990).

In order to provide sufficient psychological care, counsellors need to understand and appreciate the different psychological issues and adaptive demands clients may be experiencing along the continuum of the HIV/AIDS illness. Several researchers have asserted that this continuum can be divided into different groups, according to clients' medical progression of the physical conditions associated with this illness. These groups may range from HIV positive but asymptomatic to HIV symptomatic illness to AIDS. Thus, in order to fully comprehend the differences between these groups it is important to have an awareness of the common medical progression of the illness. In addition, clinicians should be aware of distinct psychological concerns associated with the progression of these physical symptoms. For example, it has been suggested that individuals in the initial stage of HIV infection (asymptomatic) face uncertainties about the future (e.g., ultimate progression of the HIV illness, not being able to realize life goals), fears of pain and suffering, social isolation, and rejection (Morin, Charles, and Maylon, 1984). Similarly, Kurdek and Siesky (1990) asserted that asymptomatic clients reported experiencing

increased level of anxiety, less optimism, greater distress, and frequent use of coping mechanisms involving avoidance and distancing since receiving sero-positive test results.

On the other hand, individuals with HIV related symptoms (symptomatic) have been reported to be especially concerned with their current symptoms (e.g., fear about loss of mental abilities, getting sick or sicker, concern about not being able to take care of themselves, side effects of HIV medication), all of which serve as a constant reminder of their condition and future prognosis (Lamping, 1990). In addition, Catalan (1988), Sheridan & Sheridan (1988), and Tross & Hirsch (1988) reported that clients in this group experienced significantly greater distress than did those with AIDS. Consequently, findings from these studies indicated that this may be due to increased uncertainties about the potential course of the illness.

Finally, patients who have progressed to the point of developing AIDS, experience different psychological stressors. These include coping with a life-threatening illness, uncertainty about the implications of an AIDS diagnosis, social withdrawal, and guilt over their previous life style (Dilley, 1990). Thus, mental health care providers should always recognize the evolving psychological concerns and issues that clients face across the full spectrum of the HIV/AIDS virus, rather than only focusing on issues that are associated with one particular stage of the syndrome (Chuang, Devins, Hunsley, & Gill (1989). Furthermore, recognizing the progression of clients' psychological and physical reactions at each stage of the illness can facilitate counsellors with planning effective treatment strategies.

### A Stage Model Approach to HIV/AIDS Counselling

As with other serious and life-threatening illnesses, a variety of stage models have been incorporated to help describe the distinct psychological issues and concerns that individuals with HIV/AIDS face throughout the course of the illness (Gutierrez & Perlstein, 1992). Over time, stage models have been designed to help specify and distinguish the different psychological issues relevant to each sub-population group of individuals infected with HIV/AIDS virus. For example, Nichols (1985) describes such a framework wherein, he conceptualizes the different stages of a patient's emotional responses to the virus. He proposed a situational distress model that describes the psychological and psychosocial stages of the virus. These stages include; 1) initial crisis, 2) transitional state, 3) deficiency state (acceptance), and 4) preparation for death stage.

The initial crisis stage includes altering periods of denial and intense anxiety (e.g., shock, fear, sadness, and bargaining). The transitional state is characterized by feelings of anger, guilt, self-pity, distress, and confusion. Social rejection and withdrawal, suicidal ideation, acting out in the form of sexual behaviour or substance abuse are a few of the common reactions experienced in this stage. The deficiency state includes the formation of a new, more stable and reliable identity that is based on acceptance of the disease. There is a more conscious effort to live each day fully, and to reevaluate ones' values. The final stage involves preparing for death by completing unfinished business and discussing death. When patients are comfortable talking about death, they are then, encouraged to share their feelings about the specific arrangements that should be handled after their death.

Similar psychological and psychosocial stage models have been recently developed by Lamping et al., (1990), and Hoffman (1991).

Subsequently, stage models such as the one just described, can be used to acknowledge that each stage of the illness consists of clusters of distinct psychological issues. As such, individuals in each stage face different psychological issues and thus, require particular clinical interventions. The nature and content of these interventions however, should differ according to an individual's needs, that are governed by the particular stage in which they belong .

#### Overview of the Different Stages of HIV/AIDS Infection

The remaining part of this chapter will concentrate on the specific psychological issues that are prominent for patients across the different stages of HIV/AIDS infection. These stages have been divided into three broad groups of individuals who may present themselves for counselling. These three stages of affliction have been derived from Olivier and Thomas' (1993) classification, and they include; (1) HIV+ asymptomatic, (2) HIV+ with chronic symptoms, and (3) AIDS diagnosis.

The first group, HIV positive and asymptomatic, categorizes infected individuals who have developed antibodies to the virus but have not yet manifested any symptoms (infections). The second group, HIV positive with chronic symptoms, classifies infected persons who present signs, symptoms and blood anomalies that are not serious enough to warrant an AIDS diagnosis. Finally, the third group, are persons diagnosed as having the syndrome with symptoms characterized by opportunistic infections, rare cancers,

pneumonia, mental disturbances and other manifestations that are indicative of the AIDS syndrome. What follows is a detailed presentation of the distinct psychological issues that research findings have outlined for each of the different HIV/AIDS sub-population groups.

#### HIV+/Asymptomatic

HIV seropositivity is associated with a variety of predictable, short and long term psychological symptoms (Sheridan & Sheridan, 1988). Empirical studies of HIV seropositive persons who are asymptomatic, suggest a range of adverse psychological reactions. These include, high levels of distress and depression following notification of HIV seropositivity status (Cleary, Singer, Rogers, Avorn, VanDavanter, Soumerai, Perry, & Pindyck, 1988).

Persons who test positive for HIV infection commonly experience a major psychosocial crisis followed by a series of reactions that emerge after notification. For example, Lo, Steinbrook, Cooke, Coates, Walters, and Hulley (1989), and Buckingham (1987) asserted that these reactions include emotional distress, loss of confidentiality, fear of transmission, stigma, and discrimination. Furthermore, other studies suggest that the most common psychological reactions experienced after receiving a HIV positive test result, usually include feelings of shock, anger, depression, anxiety, frustration, hypochondria, and fear and uncertainty about the future (Grant & Anns, 1988; Morin, Charles, & Maylon, 1984; Pohl, Deniston, & Toft, 1990; Coates, Morin, & McKusick, 1987; Miller, 1988). These reactions may take the form of anxiety and depression about the inevitability of developing the AIDS syndrome, morbid obsessions about the disease,

guilt about one's sexual orientation, and social, domestic, and occupational disruption (Miller & Green, 1985).

Denial. Similarly, denial of one's new serostatus may also be present. This can be a very important concern since previous evidence suggests that denial is the strongest predictor of failure to take the necessary risk-reduction steps (Joseph, Montgomery, Kessler, Ostrow, Emmons, & Phair, 1987). The denial may be so strong that the patient will adopt an attitude of indifference, possibly leading to promiscuous sexual activity, substance abuse or even ignoring important medical treatment and emotional support. This has been explained as a form of self-protection because it reduces the overwhelming emotional distress. (Douglas, Harder, & Polk, 1987). Denial may be overcome by participating in a support group, individual counselling, or attendance at non threatening and structured social activities (Nichols, 1983).

Shock. Shock is another very common initial reaction which is usually expressed in two forms. One form of shock is regression into an immobile state whereby the client is unable to articulate his feelings, while the second form of shock is a very casual acceptance characterised by comments such as, "I thought I would be...No, I have no questions, thank you." (Grant and Anns, 1988).

Anger. The feared progression from HIV infection to AIDS can produce feelings of anger in certain clients. Social discrimination and stigmatization encountered by HIV+ persons, the lack of effective treatments, and the absence of any reassurance that medical

solutions will emerge in the near future may also contribute to such feelings of anger (Kelly, & Lawrence, 1988).

Depression. Levels of depression have been found to be significantly higher among those who have tested HIV+ than those who are seronegative or unaware of their antibody status (Coates, Morin, & McKusick, 1987; Cochran, 1987). Sadness, hopelessness, frustration, withdrawal, isolation, passivity, and guilt are a few of the symptoms of depression usually experienced (Kelly, & Lawrence, 1988). Research suggests that the client's feelings of guilt and the desire to blame oneself for the illness need to be explored and dealt with at this stage (Dilley, 1990; Nichols, 1985). Similarly, Dilley (1990) asserted that connections between sexual orientation and the illness should be confronted by pointing out the existence of the disease in other groups.

Anxiety. Predictably, anxiety is one of the most common reactions to HIV seropositivity (Coates, Morin, & McKusick, 1987). It has been reported that more than 50% of HIV+ homosexual men experience significant anxiety, insomnia, and memory problems after learning they were exposed to the HIV virus (Joseph et al., 1987; Pollak, Gharakhanian, Rozenbaum, Viallefont, & Aine, 1987). The general concerns revolve around the fear of developing AIDS, the stress of coping with the uncertainty of one's future health, the loss of control leading to dependency, as well as, possible loss of social or relationship supports (Kelly & Lawrence, 1988). Those who have not previously disclosed their sexual orientation face the added burden of "coming out" to their family and friends (Nichols, 1983). It has been suggested that one of the critical counselling



issues for this particular group is reducing anxiety and its attendant physical stresses (Morin, Charles, & Malyon, 1984). Coates, Temoshok, and Mandel (1984) suggested that psychological distress may contribute to immune suppression. Moreover, support groups can serve useful functions for people with immune suppression since it allows them to share many common feelings and experiences and hence, provide peer support and reinforcement for health conscious behaviours (Morin et al, 1984; Martin, 1989). In self-help groups, the client not only obtains support from the group but is also given the opportunity to be of assistance to others. This in turn, promotes an improved sense of self-esteem as well as confronting the client's view of himself as a helpless individual. The group can also serve to reduce social isolation, and furthermore counsellors can encourage socialization and interaction among the members apart from the group (Dilley, 1990).

Coping with an initial HIV+ test result. Research has suggested that traditional crisis intervention techniques should be considered when clients are first diagnosed (Dilley, 1990). This may include, helping the client contain his/her fear and anxiety, and trying to help them avoid making any hasty decisions they might regret later (Macks, & Turner, 1986). A positive test result initiates an immediate catastrophic response (Martin, 1989). This period of crisis is usually seen by many as a death sentence. Seropositive individuals are fearful about subsequent development of chronic symptoms or AIDS, the potential pain and disfigurement, and the likelihood of death as a result of their infection. Feelings of being dirty, contaminated, or otherwise undesirable, and hence vulnerable to rejection, discrimination, or isolation are common concerns (Martin, 1989).

During the initial stage of diagnosis many clients might tend to isolate themselves. As a result, one task can be to help them reach out to those people they feel close to, or at least help them find services that can serve as lifelines for them at times of crisis (Macks & Turner, 1986).

It has also been reported that individuals who acknowledge their disease, comply with medical treatment, and are able to accommodate to their illness while maintaining an active life seem to cope most effectively (Dilley, 1990). This may be a very important determining factor regarding the onset of HIV related symptoms, since medical experts are now saying that this period of asymptomatic illness can last as long as 15 years (Hockings, 1989).

#### Chronic Symptomatic HIV infection

Currently, the term, chronic symptomatic HIV has been used as an equivalent to AIDS-related complex (ARC), which has fallen into disuse with the development of HIV tests (Olivier & Thomas, 1989).

The increase in physical problems in clients with symptomatic HIV infection, particularly the appearance of serious but not life-threatening infections, is associated with increased psychological distress (Catalan, 1988; Sheridan & Sheridan, 1988; Tross & Hirsch, 1988). Much of the distress experienced during this stage is due to the persistent uncertainty about the potential course of the HIV disease (Mandel, 1986; Massie, Tross, Price, Holland, & Redd, 1987; Morin & Batchelor, 1984; Morin, Charles, & Maylon, 1984).

Many factors have been identified that mediate between psychological reactions and a HIV+/symptomatic diagnosis. These may include a persons' health status and symptom severity, attributions regarding their illness, self disclosure of health problems, awareness about the disease, and available social supports (Kelly & Lawrence, 1988). Many studies find that HIV symptomatic clients' are even more distressed than persons with an AIDS diagnosis (Catalan, 1988; Sheridan, et al., 1988; Tross, et al., 1988). At this stage, counselling clients with chronic symptoms often involves helping them find ways to deal with their own uncertainty, and that of the medical profession. Everything seems uncertain which makes it very difficult for these individuals to feel any sort of control over anything (Hockings, 1989). For some clients this uncertainty can be so intense that they are actually relieved when their diagnosis changed from HIV+/symptomatic to AIDS. The ambiguity and uncertainty about their diagnosis and its treatment increases clients' psychological, emotional, and social needs. For example, many clients at this stage experience issues of loss in regards to various aspects of life including their physical status, self-esteem, sexuality, relationships and other social and financial support systems (Acevedo, 1986).

HIV related symptoms can range from being relatively minor to severe and life-threatening which may result in hopelessness, depression, anxiety, anger, and emotional exhaustion. In addition to these reactions, it has been suggested that there is a high prevalence of other psychological reactions associated with symptomatic HIV infection,

which include somatization, interpersonal insensitivity, hostility, avoidance, and intrusive preoccupations about AIDS (Tross et al., 1988).

Lamping (1990) found that one of the most distressful mental health problems associated with this stage of affliction is concerns about increasing physical disability (e.g., fear about loss of mental abilities, getting sick or sicker, concern about not being able to take care of themselves, and side effects of HIV medication). Consequently, people at this stage may often need help around medical issues, such as whether or not to take certain drugs like AZT. These decisions have both practical and emotional implications regarding one's state of health (Hockings, 1989). It has been proposed that counsellors working with these symptomatic clients may need to assist them in finding constructive ways of asserting themselves, in finding jobs or positions that accommodate their disability for example, may help preserve their sense of self-sufficiency (Martin, 1989).

Research investigating individuals with symptomatic HIV infection support clinical observations that psychosocial and psychological distress is highest during this stage of the illness. Gay and/or bisexual men with chronic symptoms show higher levels of distress and a higher prevalence of psychiatric disorders than men with AIDS (Atkinson et al., 1988; Chuang, Devins, Hunsley, & Gill, 1989; Tross & Hirsch, 1988).

These adverse psychological consequences may also affect physical health status. It has been hypothesized, for example, that psychosocial distress may exacerbate disease progression through immune suppression (Coates et al., 1984; Coates, Stall, et al., 1987; Levingston, 1988). Thus, there does appear to be empirical evidence to suggest that

distressing psychological and psychosocial issues can encourage the advancement of ones' HIV symptomatic status to the progression of an AIDS diagnosis sooner than anticipated (Glaser & Kiecolt-Glaser, 1988).

### AIDS Diagnosis

The diagnosis of AIDS, because of the prognosis associated with the disease, is catastrophic (Morin et al., 1984). The development of each new clinical syndrome, including opportunistic infections, central nervous system disease, and rare cancers, creates a different kind of stress, leading to a variety of adverse psychological reactions. These include shock following diagnosis and fears of death and dying, feelings of powerlessness to change circumstances, and consequent frustration and anger; reduced physical functioning; fear of loss of physical attractiveness due to declining health; anxiety about the reactions of others with subsequent social withdrawal; loss of social support; reduced cognitive functioning due to anxiety, depression, obsessional worries and possible intellectual impairment; reduced sexual functioning; concerns and confusion surrounding treatment options; fear of infecting others particularly lovers; and fear of being infected by them; fear of being deserted and of dying alone; and social, domestic, and occupational disruptions and losses (Christ, Siegel, & Moynihan, 1988; Miller & Green, 1985; Morin et al., 1984).

In the final stage of AIDS, patients usually shift their anxiety from anticipating disease progression to anticipating death and dying. Patients often fear the possibility of extreme life supporting measures, which compromises their dignity, and possibly

encourages a lingering, prolonged suffering or disfigurement before their death (Kelly & Lawrence, 1988). The most predominant fears reported at this stage were fears of disability, loss of body control, pain, and death (Dilley, Ochitill, Perl, Volberding, 1985).

In anticipation of death, however, patients often describe fear of dependency more readily than they do fear of dying. At this stage, it has been suggested that patients should be encouraged to vent such emotions and, when possible, to resolve unfinished business involving personal, business, or family relationships (Selwyn, 1986). This may involve attempts to resolve conflicts or resentments with loved ones and to make decisions about concrete matters such as wills, powers of attorney, and directives to physicians (Macks, & Turner, 1986). The final stage of adjustment however, should be spent preparing for death. When patients are comfortable talking about death, they should be encouraged to share their feelings/decisions regarding where, how, and when to die, as well as how they would prefer arrangements handled after their death (Nichols, 1985). For gay men in particular visiting privileges and next of kin issues may pose particular problems when immediate family members are not accepting of male lovers and friends (Selwyn 1986; Siegel, & Hofer, 1981).

Sadness and depression are common emotions experienced, as well. Patients experienced multiple losses throughout their ordeal including loss of health, employment, and, at times, even relationships, they mourned their loss of physical stamina and tried to maintain an attitude of optimism in the face of such a grim prognosis (Dilley et al., 1985).

In a study conducted by Namir (1988) to assess what people with AIDS considered to be their most pressing concerns, existential issues were first priority, second came issues concerning work and finances, followed by self-esteem issues, friends, and social existence. As mentioned earlier it is very common for patients at this point to begin an existential contemplation of their lives, the significance of death, and finally the meaning of life itself (Kelly & Lawrence, 1988). It was found that many conduct a "life review", taking stock of past achievements, failures, and relationships and reevaluating them in the light of this disabling and almost invariably terminal illness (Dilley et al., 1985).

Frierson and Lippmann (1987) reported that the major psychological issues identified in this stage include changes in body image, feelings of helplessness and isolation, sexual concerns and the grief process. In addition, they asserted that management should be aimed toward maintaining a nonjudgmental stance, providing liaison with other care-givers and securing appropriate information and grief counselling for patients, with provisions for patients' loved ones. Kelly and Lawrence (1988), argued that persons with AIDS differ from other HIV/AIDS sub-population groups in their social and environmental support needs. Some patients have close, supportive social networks and are adequately cared for by family and/or lovers during this final stage, others however are homeless and have few supports and resources for sufficient care (Kelly & Lawrence, 1988). Additional research indicates that social support can indeed reduce psychological distress. For example, the stress of AIDS is only exacerbated when friends, family, and other health care providers are not supportive (Coates, Stall, Mandel, Bocellari, Sorensen,

Morales, Morin, Wiley, & McKusik, 1987; Billings, Moos, 1982; Kaplan, Robbins, Martin, 1983).

AIDS patients frequently must undergo painful and frightening diagnostic and medical treatment procedures. Treatment failure and/or the recurrence or development of symptoms of infections can readily precipitate an emotional crisis, in which suicidal features may become more common. As a result a client often experiences emotional exhaustion and a profound sense of hopelessness (Macks & Turner, 1986). It is at this stage more than ever before, that the patient is confronted with the fatality of AIDS.

Suicide risk may be an important mental health consideration in persons with AIDS. Although early reports indicated a low risk of suicide among persons with AIDS (Holland & Tross, 1985), subsequent clinical reports suggested an increasing number of AIDS-related suicides (Faulstich, 1987; Frierson & Lippmann, 1988). Thus, the assessment of suicide risk appears to be an important component in the psychological care of HIV/AIDS infected persons (Hall & Stevens, 1988).

Counselling people with AIDS involves dealing with all the issues that have arisen since their diagnosis as well as looking at "who they are" today as a result of this affliction (Hockings, 1989).

### Conclusion

AIDS and its precursor HIV has been described as one of the most pressing medical, psychological and social problems of this century. According to the Center for Disease Control (CDC) HIV/AIDS will continue to spread and affect millions of people



worldwide. Currently, because of new promising treatment advancements the time of latency between infection and actual onset of opportunistic infections is being lengthened. Furthermore, the length of time one lives with the actual disease of AIDS is being extended considerably (Anderson et al., 1991; Douce, 1993).

Moreover, it has been hypothesized that psychological distress contributes to immune suppression thus enhancing the development of an AIDS diagnosis (Coates, Temoshok, & Mandel, 1984; Flach, 1988; Herek, 1990; Hoffman, 1991). This evidence has lead researchers to investigate the potential psychological impact of this growing health crisis. As a result it has been established that psychology plays an important role in dealing with the progression of pervasive physical, emotional, and societal reactions surrounding this illness (Dilley, 1990).

For example, becoming aware of the many different psychological issues and concerns that exist across the continuum from an initial diagnosis to HIV symptomatic infection to AIDS will enable the counsellor to be further prepared to deal with these complex issues in a more helping manner. Therapists who are familiar with these most important psychological concerns can better assist their clients to sufficiently deal with the psychological and emotional impact of the disease, and in that way, partially resist further immune suppression. Counsellors who foster positive attitudes in their clients and help them explore their feelings and deal with their concerns can ultimately help them to improve the functioning of their depressed immune system.

The purpose of the present study is to focus on identifying the specific psychological issues introduced across each stage of the HIV/AIDS continuum. More specifically, this study was designed to answer the following research questions; Do clients in their different stages of affliction place more emphasis on certain psychological issues than others? And if so, which psychological issues were rated as more significant for each of these stages. As a result, it is hypothesized that clients in their respectful stages of affliction will indeed place more emphasis on certain issues than others.

The rationale for this study was based on previous research that asserts that different psychological issues are considered to be more significant for distinct population groups across the HIV/AIDS continuum (Anderson et al., 1991; Chuang et al., 1990). This study was designed to use a more quantitative approach in determining what specific psychological issues were considered to be more significant across three different stages of affliction. Such a quantitative approach was accomplished through the administration of a specific questionnaire (see methodology section).

Thus, this study compliments previous research, in that, it systematically examines the relationship between clients' particular stage of affliction and what they consider to be significant psychological issues. In view of this, it is anticipated that such results will help develop psychotherapeutic interventions that incorporate these differing issues to patients across the full spectrum of the HIV/AIDS continuum.

## Chapter II

### Methodology

This study was conducted in order to answer the research questions outlined in the previous section. More specifically, this study was designed to investigate which psychological issues were considered to be significant for the different HIV/AIDS populations.

### Subjects

Since homosexual and bisexual men represent the majority of individuals currently affected by the HIV epidemic, participants in this study were limited to that particular population.

Subjects were delineated according to the classification system set forth by Olivier and Thomas (1993); (1) HIV positive yet asymptomatic, (2) HIV positive with chronic symptoms, and (3) individuals who have been diagnosed as having the AIDS syndrome.

The first group, HIV positive/asymptomatic, is defined as infected individuals who have developed antibodies to the virus but have not yet manifested any symptoms (infections). This is considered the latent period during which the virus remains inactive in the infected cells, and may last anywhere between several months to many years.

The second group, HIV positive with chronic symptoms, is defined as being infected persons with presenting signs, symptoms, or blood anomalies that do not allow a diagnosis of AIDS. Such symptoms may include: A) lymphadenopathy, B) chronic or recurrent fever, C) fatigue, D) involuntary weight loss (>10%), E) night sweating, F)

diarrhea, G) wasting, and H) multiple mucocutaneous problems i.e., fungal infections, herpes, dental problems, mouth ulcers, and so on.

Finally, the third group consisted of persons who are diagnosed as having the AIDS syndrome, which is the most severe form of HIV infection. This is characterized by 1) opportunistic infections i.e., pneumocystis carinii pneumonia, candidal oesophagitis, infections of the central nervous system, a range of infections that attack the eyes, digestive system, and skin, and, 2) rare cancers i.e., Kaposi's sarcoma, lymphoma, and other manifestations.

A total of 37 individuals served as subjects for this study, 10 of whom were in the asymptomatic group, 16 were in the chronic symptomatic group, and 11 were in the AIDS diagnosis group. Certain specific criteria have been set forth in order for subjects to participate in the study. In addition to meeting the specific symptomatology requirements for each group as outlined above, all subjects consisted of homosexual or bisexual men, between the ages of 18 to 65 years old who contracted the HIV virus through sexual contact. This distinction needs to be made since it has been found that other groups who contracted the HIV virus (i.e., through IV drug use, or blood transfusion, etc.) constitute different population groups with distinct patterns of impairment (World Health Organization, 1990). The subjects in this study were recruited through the AIDS Community Care of Montreal (ACCM) organization, and their affiliated support groups. ACCM was selected primarily because it is a non-profit, non-discriminating community

organization. Its members are dedicated to providing the highest possible quality of support, service and information to people affected by HIV/AIDS.

### Instruments

Two instruments were employed in this study: the Personal Information Questionnaire (PIQ) and, the HIV/AIDS Client Concerns (HACC) questionnaire.

The PIQ is a demographic questionnaire that includes questions related to one's serostatus, history of their illness, means of contraction, and sexual orientation. It was used in order to obtain demographic information and an accurate history of subjects' HIV/AIDS status. This questionnaire was necessary in order to ensure that all participants met the specific criteria for inclusion in this study and to assure homogeneity of the subject pool in terms of their position in relation to the three specific stages of infection (see Appendix A).

The HACC is composed of 40 statements, each one describing a specific psychological and/or psychosocial issue that subjects may be dealing with currently. Subjects will use a 5-point Likert scale (1=never to 5=always) to respond to each statement in terms of how significant or typical it is for them at the present time (see Appendix B).

The HACC is an adapted version of a questionnaire currently being used by ACCM for intake purposes. It was designed by Cassidy (1990) who was the director of social services for ACCM. This questionnaire was designed to detect the major problems, concerns, challenges and needs that subjects may be facing as a result of their HIV/AIDS

status. It was adapted in order to include additional questions concerning certain psychological issues that the clients may also be experiencing and which were not previously outlined in ACCM'S version. More specifically, statement #1 "I find it difficult to disclose my HIV/AIDS status to people I feel close to?"; statement #3 "I am deeply concerned with the future in terms of loss of control due to physical ailments which may lead to dependency?"; statement #6 "I usually experience feelings of being contaminated?"; statement #17 "I experience conflicting feelings when I think about having sex with a new partner?"; statement #22 "I fear infecting other people through casual contact?"; statement #28 "I have experienced feelings of being discriminated against by others (i.e., employer's, colleagues, & acquaintances)?"; statement #29 "I am often concerned about confidentiality in relation to my HIV/AIDS status?"; statement #32 "I have often thought about the issue of euthanasia and possible implications it might have in my life?"; statement #33 "I have thought about life after death and/or my own spiritual concerns?"; statement #35 "I am very concerned about my physical appearance/attractiveness and it's possible deterioration?"; and finally, statement #40 "As a result of my condition I am now much more concerned with my financial situation?" were among the specific statements on the HACC that were considered to be significant and consequently needed to be addressed. The HACC questionnaire was developed for the purposes of this research, therefore tests of reliability and validity have not yet been established. However, since the HACC was an adaptive version of a previously used intake questionnaire by ACCM, it does hold face validity. In addition, in order to verify the appropriate content of this questionnaire, face

validity was also achieved through an extensive review and analysis of the literature, and through consultations with numerous mental health professionals who have had experience counselling HIV/AIDS populations. For example, Barrows & Halgin (1988) and Bor & al., (1991) asserted that an extensive review of the literature revealed that issues regarding one's spiritual beliefs, physical appearance in relation to their HIV/AIDS status, and the possibility of societal rejection were among several psychological concerns that were considered likely to surface in psychotherapy. Therefore, the HACC questionnaire was designed to include such issues in order to achieve the most accurate profile of the many distinct psychological concerns that exist for this particular population.

#### Procedure

A brief statement describing the nature of the study and its objectives was given to all participants to read. Subjects were then given the choice of continuing in the study or declining to participate (see Appendix C). Those who agreed to participate were given a consent form to fill out (see Appendix D) followed by the two instruments; (1) the Personal Information Questionnaire (PIQ) and (2) the HIV/AIDS Client Concerns (HACC) inventory, in that particular order.

These instruments were distributed in a group with specific instructions to complete them individually, at their own convenience. Since the complete set of these instruments requires no more than one hour to complete, the subjects were requested to complete them at one setting. Once the subjects completed all the questionnaires they were

instructed to place them in an envelope, seal it, and return the envelope to their group facilitator/animator, who in turn handed them over to the researcher.



## Chapter III

### Results

Data analysis were performed by using a two-way factor (Group & Items) analysis of variance (ANOVA). The two independent variables were: 1) GROUPS, separated into three levels; i) HIV Asymptomatic, ii) HIV Symptomatic, iii) AIDS diagnosis. and 2) ITEMS, which includes the 40 questions on the HACC inventory. The dependent variable was the subjects' responses to all the questions. Post-hoc Tukey HSD tests were then performed on those specific questions/items where a significantly difference was found.

What follows is a presentation and statistical analysis of the descriptive statistics for all variables including demographic variables, such as; age, education, employment, income, means of contraction, and experience with any kind of psychotherapy. This will be followed by a presentation of the results for the inferential statistics.

#### Demographic Descriptive Statistic

Groups. The sample was composed of a total of 37 self-identified homosexual men, who were currently living in the Montreal area. The results indicated that all 37 subjects contracted the virus through sexual contact with persons of the same sex. These subjects were separated into three groups: 1) Asymptomatic, 2) Symptomatic, 3) AIDS Diagnosis. The exact number of participants in each group were; 11 in group one, 16 in group two, and finally 10 in group three.

Age. The participants' ages for group #1 ranged from 20 to 40 years, for group #2 they ranged from 28 to 51 years, and for group #3 they ranged from 27 to 64 years. Table

1 illustrates the descriptive statistics (mean and standard deviation) for the age variable across each of the three groups.

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Insert Table 1 about here  
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Education. Within the asymptomatic group 36% reached or completed a University degree, 27% completed a technical training/Cegep program, 9% received a high school diploma, and 27% did not complete high school. Within the symptomatic group, 56% had reached or completed a University degree, 25% completed a technical training/Cegep program, and 19% had completed high school. Finally, within the AIDS Diagnosis group, 90% had reached or completed a University degree, and 10% completed a technical training/Cegep program. Furthermore, there were no subjects in this group that did not complete high school.

Employment. Forty six % of the asymptomatic group were employed full-time, 9% were employed on a part-time basis, and 45% were not currently working (either due to unemployment, welfare recipient, disability, or retirement). With respect to the symptomatic group, 19% were employed full-time, 36% were employed on a part-time basis, and 44% were not currently working (either due to unemployment, welfare recipient, disability, or retirement). Furthermore, 10% of the AIDS Diagnosis group were employed full-time, 20% were employed on a part-time basis, and 70% were not currently working (either due to unemployment, welfare recipient, disability, or retirement).

Income. In terms of the average income level earned in the past year for the subjects in the asymptomatic group; 45% earned \$9.000 or less, 18% earned between \$10.000 to \$19.000, 9% earned between \$20.000 to \$29.000, and 27% earned over \$30.000. The average income level the subjects obtained in the symptomatic group ranged from; 56% earning \$9.000 or less, 19% earning between \$10.000 to \$19.000, 13% earning between \$20.000 to \$29.000, and 14% earning over \$30.000. Moreover, the percentages for the income level earned by the subjects in the AIDS diagnosis group were; 30% earned \$9.000 or less, 30% earned between \$10.000 to \$19.000, 30% earned between \$20.000 to \$29.000, and 10% earned over \$30.000.

Counselling. In addition, the results indicated that a total of 30% of the subjects in group one (asymptomatic), 50% of the subjects in group two (symptomatic), and 70% of the subjects in group three (AIDS diagnosis) sought counselling since their HIV diagnosis.

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Insert Table 2 about here  
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Summary of demographic data. Observations of the demographic data indicated that the age variable revealed a wide distribution of ages which for all three groups ranged from a minimum of 20 yrs. to a maximum of 64 yrs. of age. With respect to the education variable the data indicated that the AIDS diagnosis group reached the highest level of education, while the asymptomatic group revealed the lowest level of education. In terms of the employment variable the asymptomatic group were most likely to be employed full

time. This average decreased significantly however, as the level of diagnosis changed from asymptomatic to symptomatic to AIDS. For the income variable the majority of subjects in the asymptomatic and symptomatic groups earned \$9,000 or less as their annual income. On the other hand, the majority of participants in the AIDS diagnosis group earned between \$10,000 to \$30,000. Finally the demographic data for the counselling variable indicated that subjects tend to be most likely to seek counselling as their diagnosis changes from asymptomatic to symptomatic to AIDS.

### Statistical Analyses

The statistical procedure used to analyze the data was a two factor analysis of variance, which includes one repeated measure (items). The results of the ANOVA showed that there was a significant difference among the 40 items in the questionnaire,  $F(48, 1632) = 10.676, p = 0.000$ . In addition the ANOVA indicated that there was a significant interaction effect between items and groups,  $F(96, 1632) = 1.709, p = 0.000$ . The following table illustrates the results of the analysis of variance.

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 Insert Table 3 about here  
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### Post-Hoc Analysis

A series of Post-hoc Tukey HSD tests were then performed on all 40 questions on the HACC in order to determine which combination of group and item variables accounted for the significant interaction effect. Consequently, the results of the Post-hoc tests

indicated that a total of 8 statements were rated significantly different between the 3 groups. The specific statements that indicated a significant difference in terms of ratings between the groups were: statements #2 "I feel guilty/ashamed of myself", #16a "I often experience feelings of shock", #16d "I often experience feelings of depression", #16f "I often experience feelings of fear", #16j "I often experience feelings of loneliness", #22 "I fear infecting other people through casual contact", #26 "I often think about planning for my future care (e.g., living will, life support etc.)", and #29 "I am often concerned about confidentiality in relation to my HIV/AIDS status". What follows is a more detailed analysis of each questions' content and its significant ratings.

Statement #2. The post-hoc analysis of variance revealed that there was a significant difference in terms of ratings between the groups ( $p=0.017$ ). More specifically, statement #2 "I feel guilty/ashamed of myself", was rated significantly lower by the AIDS diagnosis group ( $p=0.015$ ) than the symptomatic group. No significant difference however, was reported for the asymptomatic group in comparison to the other two groups. Consequently, this indicates that the AIDS diagnosis group reported a much lower degree of concern with feelings of guilt and shame than the symptomatic group. The following tables will include the results of the post-hoc tests and a matrix of the pair wise comparisons probabilities.

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Insert Tables 4 & 5 about here

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Statement #16a. The post-hoc analysis of variance also revealed that there was a significant difference in terms of ratings between the groups for statement #16a "I often experience feelings of shock", ( $p=0.012$ ). This statement was rated significantly higher by the symptomatic group than the asymptomatic group ( $p=0.033$ ) and the AIDS diagnosis group ( $p=0.031$ ). That is, the symptomatic group reported experiencing stronger feelings of shock than both, the asymptomatic and AIDS diagnosis groups. Tables 5 and 6 illustrate the results of the post-hoc ANOVA, and the matrix of pairwise comparison probabilities for this question.

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Insert Tables 6 & 7 about here  
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Statement #16d. A post-hoc analysis of variance revealed that there was a significant difference in the groups' ratings for statement #16d "I often experience feelings of depression", ( $p=0.016$ ). That is, the symptomatic group responded significantly higher than the AIDS diagnosis group for this question ( $p=0.012$ ). There were no significant differences however, in terms of subjects' ratings for the asymptomatic group in comparison to the other two groups. These results indicate that the symptomatic group considered feelings of depression to be a much more significant concern than the AIDS diagnosis group (see table 8 and 9).

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Insert Tables 8 & 9 about here  
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Statement #16f. The post-hoc analysis of variance showed a difference in the groups' responses to statement #16f "I often experience feelings of fear", ( $p=0.048$ ). More specifically, the matrix of pairwise comparisons probabilities indicated that the symptomatic group rated this question significantly higher than the AIDS diagnosis group ( $p=0.048$ ). The asymptomatic group did not show any significant differences in their ratings compared to the other two groups. In other words, the symptomatic group experienced stronger feelings of fear than the AIDS diagnosis group (see tables 10 and 11).

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Insert Tables 10 & 11 about here  
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Statement #16j. Moreover, for question #16j "I often experience feelings of loneliness", the post hoc test indicated that there significant difference between the groups' responses to this statement ( $p=0.009$ ). Subsequently, the matrix of pairwise comparisons probabilities showed that the symptomatic group rated this question significantly higher than the AIDS group ( $p=0.007$ ). No difference in subjects' ratings was observed for the asymptomatic group in comparison to the other two groups. That is, the symptomatic

group experienced considerably higher feelings of loneliness than the AIDS diagnosis group (see tables 12 and 13).

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 Insert Tables 12 & 13 about here  
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Statement #22. The post hoc analysis of variance revealed that the groups responded differently to statement #22 "I fear infecting other people through casual contact", ( $p=0.000$ ). More specifically, the matrix of pairwise comparisons probabilities for this question indicated that the symptomatic group responded significantly higher than the asymptomatic group ( $p=0.000$ ), as well as the AIDS group ( $p=0.000$ ). Hence, these results indicate that the symptomatic group are much more concerned with the possibility of infecting other people through casual contact than both the asymptomatic and the AIDS diagnosis group (see tables 14 & 15).

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 Insert Tables 14 & 15 about here  
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Statement #26. The post hoc analysis revealed that there was a difference in the groups' ratings for statement #26 "I often think about planning for my future care, e.g. living will, life support etc.", ( $p=0.031$ ). The matrix of pairwise comparisons probabilities indicated that the AIDS diagnosis group rated this question significantly higher than the asymptomatic group (0.024). The symptomatic group did not show any significant



differences with respect to their ratings compared to the other groups. These results suggest that the AIDS diagnosis group are considerably more likely to be concerned with issues about planning their future care than the asymptomatic group (see tables 16 & 17).

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 Insert Tables 16 & 17 about here  
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Statement #29. The post hoc test also revealed that the three groups responded significantly differently in relation to statement #29 "I am often concerned about confidentiality in relation to my HIV/AIDS status", ( $p=0.049$ ). The matrix of pairwise comparisons probabilities specifically pointed out that the AIDS diagnosis group rated this question significantly lower than the asymptomatic group ( $p=0.039$ ). The symptomatic group did not show any significant differences in their ratings in comparison to the other groups. Subsequently, these results indicate that the asymptomatic group are much more concerned with issues surrounding confidentiality in relation to their clinical status than the AIDS diagnosis group (see table 18 & 19).

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 Insert Tables 18 & 19 about here  
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### Overview of Data Analysis

What follows is a brief summary of how the results obtained in this chapter can be applied to the subsequent research question; 1a) Do clients in their different stages of

affliction place more emphasis on certain psychological issues than on others? 1b) If yes, which psychological issues were rated more significant for each of these three groups?

In response to the above mentioned research questions, the results indicated that clients in their different stages of HIV affliction appeared significantly more concerned with different psychological issues. More specifically, the results indicate that the asymptomatic group was more concerned about confidentiality regarding their HIV/AIDS status at a significantly higher level than the AIDS diagnosis group. The symptomatic group on the other hand was significantly more concerned with issues related to feelings of guilt/shame, shock, depression, fear, loneliness, and anxiety of infecting other people through casual contact when compared to the asymptomatic and AIDS groups. Finally, clients with the AIDS diagnosis were significantly more concerned with issues surrounding the planning of their future care (e.g., living will, life support, etc.) when compared to the asymptomatic group.

In conclusion, the results obtained indicated that the three groups differed in their responses as to what they considered to be significant psychological issues. That is, each of the three groups expressed unique concerns with distinct issues as a result of their HIV/AIDS status, hence, supporting the experimental hypothesis.

## Chapter IV

### Discussion

The purpose of this study was to investigate the complexities of clients' psychological reactions across the spectrum of the HIV/AIDS illness. More specifically, the aim of this study was to determine if clients in three different stages of affliction place a higher degree of concern on certain psychological issues than on others. These stages of affliction range from HIV positive but asymptomatic to HIV symptomatic and fully developed AIDS. The results obtained supported the research hypothesis that clients in their different diagnostic stages place more significance on certain psychological issues than others. This chapter will discuss these results and relate their implications for researchers and practitioners alike. A discussion of the limitations of this study, and suggestions for future research will then be addressed.

### Overview of Research Hypotheses

This study was designed to identify the various psychological issues that exist across the HIV/AIDS continuum. Such research extends on recent evidence which hypothesizes that different psychological issues will emerge over the course of the HIV infection (Anderson et al., 1991; Chuang, et al., 1990). Consequently, the objective of this study was to answer the following research question; 1a) Do clients in their different stages of affliction place more emphasis on certain psychological issues than on others? 1b) If yes, which psychological issues were rated more significant for each of these groups? As such, in order to determine the level of significance placed on these different psychological

issues, three specific sub-groups of this general population were examined. These three sub-groups include; (1) HIV+ asymptomatic, (2) HIV+ with chronic symptoms, and (3) AIDS diagnosis.

#### Interpretation of Significant Results

As previously mentioned in the methodology chapter the HACC questionnaire was administered to the subjects in all three groups. The HACC consisted of 40 statements, each one of which was related to a particular psychological issue that clients may be dealing with currently in their lives. Subjects were then asked to rate each statement according to how significant it is for them at the present time. The results obtained indicated that there was a significant difference in terms of the three groups' responses to several statements. More specifically, the post-hoc analysis of variance indicated that a total of 8 particular statements were rated significantly different by the three groups. In other words, one can infer that each of the three groups placed a significantly higher degree of concern with particular distinct psychological issues. What follows is a brief outline concerning the interpretation of the particular issues that were rated significantly higher for each of the three groups.

Asymptomatic group. The results indicated that statement #29 "I am often concerned about confidentiality in relation to my HIV/AIDS status?" was rated significantly higher for this group in comparison to the AIDS diagnosis group. The symptomatic group however, did not show any significant differences in terms of their responses compared to the other groups for this question. In other words, this finding suggests that the

asymptomatic in comparison to the AIDS diagnosis group, was significantly more sensitive with regards to the possibility that other people will learn about their HIV status. Many clients at this stage are particularly concerned with this issue because they are afraid of the stigma associated with HIV, and as a result, experience a greater fear of the possibility of non-acceptance or rejection by loved ones. In support of this finding, Lo et al (1989) and Buckingham (1987) also contend that many clients at this stage have a substantial concern regarding the confidentiality of their status. In addition, research indicates that such findings may be attributed to the fact that many individuals at this stage experience great concern with confidentiality because they have not previously disclosed their sexual orientation, and thus, face the added burden of "coming out" to their family and friends (Nichols, 1983). As a result, in order to develop a therapeutic alliance and provide the client with a safe environment to deal with their specific concerns, counsellors need to be sensitive to this particular issue and address it early in their clinical interventions.

Chronic symptomatic HIV infection. The statistical analyses indicated that the symptomatic group rated statement #2 "I feel guilty/ashamed of myself" significantly higher than the AIDS diagnosis group. No significant difference was reported between the asymptomatic group versus the other two groups. This finding suggests that clients in this chronic stage were much more likely to blame themselves for the illness and felt significantly higher levels of shame than clients in the AIDS diagnosis group. This finding may be a result of clients' feelings of guilt and self-blame over their previous lifestyle (Dilley, 1990). Accordingly, previous research has reported that issues of guilt, shame, and

self-pity are often experienced within this sub-population (Nichols, 1985). Nichols (1985) further contends that clients at this point may obsessively review their past in an attempt to determine what they might have done to “deserve this fate”. As a result, clinicians can help alleviate such concerns by pointing out the existence of the disease in other groups. This will ultimately help the client realize that their sexual orientation was not the cause of or a punishment for the contraction of the virus. In addition, the fact that this virus is no longer solely occurring within this discrete sub-group (sexually active gay men), but appears to be growing in other groups (heterosexual men & women) further helps alleviate some of this guilt/shame. Contradictory to these results however, Dilley (1990) reported that feelings of guilt and self-blame over previous lifestyle were most prevalent within the asymptomatic group. She asserted that this was due to the fact that HIV infection is associated with a highly negative social stigma and thus leading to a greater sense of social isolation. Consequently, counsellors should be aware that previous research has indicated that, such issues were found to be significant concerns not only for HIV symptomatic individuals but also for HIV asymptomatic population groups. In addition it has been reported that experiencing support is an important contributing factor to whether or not the client will experience feelings of guilt and self-blame. If support is not experienced by the client then such feelings can become destructive and debilitating to the point where the client becomes emotionally and physically withdrawn (Hamilton & Morris, 1988). Consequently, the counsellor should help the client deal with these particular issues directly as soon as possible.

Moreover, statement #16a "I often experience feelings of shock" was rated significantly higher by this group than either the asymptomatic group and the AIDS diagnosis group. That is, it appears that when clients at this stage begin to experience chronic symptoms, their reactions of shock regarding their current status are intensified. This may be due to the fact that clients' are now forced to face the reality that the illness is affecting their physical well-being, and therefore, can no longer deny the existence of the medical symptoms associated with the progression of the virus. This finding challenges previous research which has specifically linked this issue to clients who have just recently received their HIV antibody positive test result (Grant & Anns, 1988; Pohl et al., 1990). Such a finding indicates that when clients first learn of their serostatus a crisis ensues that manifests their feelings of shock and disbelief. As a result, counsellors should be aware that clients may experience feelings of shock during the early stages of diagnosis as well as during the onset of chronic symptoms. Thus, shock may result from two different sources, that experienced in the initial stage were one first learns of his HIV status, and later on when one first experiences his first HIV related symptoms/infections. As such, counsellors should recognize that assisting clients with these particular reactions consists of crisis intervention techniques. These techniques may involve helping the client to slowly come to terms with their feelings, and then move on to issues of quality of life and ways of empowering themselves (Grant et al., 1988; Namir, 1988; Winiarski, 1991).

Statement #16d "I often experience feelings of depression" was rated significantly higher for the symptomatic group compared to the AIDS diagnosis group, while no

significant difference was observed for the asymptomatic group. In other words, the HIV symptomatic group reported experiencing higher levels of depression concerning their HIV status than the AIDS diagnosis group. This finding is supported by research which reports that this stage of the illness is associated with increased psychological distress including depression (Catalan, 1988; Sheridan et al, 1988; Tross et al, 1988). It has been suggested that such a finding may be a result of clients' anxieties regarding the persistent uncertainty about the potential course of the HIV virus (Mandel, 1986; Massie et al., 1987).

Consequently, introducing the client to a supportive health care team is essential in responding to patients' questions and needs during this stage. In addition, it has been found that clients at this stage benefit greatly from participating in ongoing support systems (Selwyn, 1986).

In addition, the symptomatic group rated statement #16f "I often experience feelings of fear" significantly higher than the AIDS diagnosis group. No significant differences however, were reported from the asymptomatic group in comparison to the other two groups. In association with this outcome several researchers have reported similar findings. For example, Hockings (1989) and Lamping (1990) asserted that one of the most distressful mental health issues associated with this particular stage of affliction is fear related to increasing physical and mental disability. This fear may be a consequence of the increased uncertainties regarding the nature of the possible physical progression of the illness. As such, the critical counselling issues in helping this particular group is reducing their fear and underlying physical stresses. This can be accomplished through a supportive,



nonjudgemental atmosphere whereby the client feels comfortable to discuss any issue which will ultimately help lower their levels of inner distress.

Statement #16j "I often experience feelings of loneliness" was also rated significantly higher within this subgroup in contrast to the AIDS diagnosis group. The asymptomatic group did not produce any significant differences in comparison to the other two groups. This may be due to the fact that clients at this stage demonstrate great difficulty in coping with the onset of the physical symptoms of the virus. Patients often experience severe social withdrawal, resulting from their refusal to deal with the disease. This manifests itself in their avoidance of friends, family, and even physicians, ultimately contributing to their feelings of loneliness. Grant and his colleagues (1988), Namir (1988), Nichols (1985), and Tross and his colleagues (1988) report similar findings and furthermore, note that counsellors should be aware that clients at this particular stage might greatly benefit from peer support groups or informal "buddy" systems. This will help alleviate their feelings of loneliness and isolation by allowing them to restructure their social interactions by engaging in effective communication with others, who are experiencing similar issues, in a safe and supportive environment. It has also been reported that gay men at this stage often experience feelings of loneliness and isolation because of the stigma of being gay and having the disease (Dworkin et al., 1993). As a result it has been suggested that it is often helpful to encourage gay male clients at this point to participate in various AIDS work projects (Macks & Turner, 1986). This opportunity will help promote positive feelings about contributing to society and giving to others, as well as, increase one's sense of pride

in their own identity (Dworkin et al., 1993). In addition, supportive counselling can help the client build his self-esteem as well as, assist him in developing coping skills, in order to deal with the stigmatization and further limitations associated with this virus. The results also indicated that the symptomatic group rated statement #22 "I fear infecting other people through casual contact" significantly higher than the asymptomatic group, as well as the AIDS diagnosis group. This may be due to the fact that as the onset of physiological symptoms of the HIV infection begin to surface, clients become more sensitive to their physical condition. Although they may be aware that casual contact does not lead to transmission of the virus, their irrational reactions may be derived from their fear regarding the physical changes that are becoming more apparent. Thus, it appears that they are adopting the unrealistic fear of transmission that is so prevalent in the society at large (Beckett & Rutan, 1990). Similarly, several researchers have confirmed this finding by suggesting that clients at this early stage of diagnosis often experience significant anxiety regarding fear of transmission (Lo et al., 1989; Buckingham, 1987). Consequently, counsellors should inform or remind clients at this particular stage, that the virus is not transmitted through casual contact. In addition, living with this kind of uncertainty is extremely stressful, thus a counsellor will need to help clients express their fears and anxieties regarding the physical progression of the virus in an ongoing and realistic manner. For example, this can be accomplished by having clients become more aware of good health practices which can ultimately, assist them in fostering a stronger sense of personal control in their lives (Fietz, 1991).

AIDS diagnosis group. The results indicated that the AIDS diagnosis group rated statement #26 “ I often think about planning for my future care (e.g., living will, life support etc.) ” significantly higher than the asymptomatic group. No difference was observed for the symptomatic group compared to the other two groups in relation to this question. This particular finding might be due to the fact that clients in this final stage often experience significant concerns regarding issues of unfinished business and preparation for death (Martin, 1989). For example, attempts to resolve personal and business conflicts with loved ones, and issues of where, how, and when to die, as well as how they would prefer arrangements handled after their death have been found to be of great concern to this sub-population (Macks & Turner, 1986; Martin, 1989; Nichols, 1985; Selwyn, 1986). As such, this final stage of adjustment is primarily spent in dealing with issues surrounding the preparation for death. In addition to addressing such issues, counsellors should encourage clients to ventilate their feelings concerning their own mortality and when possible help them work towards resolving any personal or family relationship issues they might still be dealing with. As such, the main aim at this stage might be to help clients realize that they still have choices in their lives and encourage them to actively pursue these choices (Hockings, 1989).

Summary of significant results. The results obtained support previous findings that there are distinct psychological issues that exist across the HIV/AIDS continuum (Anderson et al., 1990). More specifically, these results further endorse the conviction that certain psychological issues appear to be more relevant in terms of counselling for clients

within different sub-populations of this illness (Chuang et al., 1990; Dilley, 1990).

Consequently, the results suggest that individuals within each stage of affliction will face distinct psychological issues and thus require different clinical interventions.

Observations of the significant results indicate that only one statement (statement #29) was rated significantly higher for the asymptomatic group compared to the other two groups. Similarly, the AIDS diagnosis group rated only one statement (statement #26) significantly higher in comparison to the other two groups. The symptomatic group however, rated a total of six out of the eight statements that produced significant results substantially higher than the other two groups. Subsequently, the data suggests that the symptomatic group placed considerably higher levels of concern on several different psychological issues than the other two groups. The results of the study suggest that the symptomatic group may experience higher levels of psychological distress than the other groups along the HIV/AIDS continuum. These findings are supported by previous research that asserts that clients within this group are particularly susceptible to increased levels of anxiety and distress (Catalan, 1988; Acevedo, 1986; Atkinson et al, 1988). Further research asserts that this is a result of increased ambiguity and uncertainty about their diagnosis and possible treatment interventions which ultimately increase clients' psychological, emotional, and social needs (Atkinson et al., 1988; Chuang et al., 1989; Tross et al., 1988).

### Limitations of the Study

Certain constraints were inherent in the methodological design of this study. These include; a) small sample sizes, b) unequal number of subjects, c) self-selected participants, d) content validity of the HACC.

One limitation that is intrinsic to the present and other similar studies is small sample sizes (Nott & Vedhara, 1990). The social context of this illness often makes the selection of subjects difficult and further interferes with attempts to establish adequately large sample groups. In the context of this study, this type of constraint can easily have an effect on power and generalizability of the results. The fact that data from only 37 subjects was available for analysis may have resulted in a weak statistical relationship between the groups and their responses to certain statements. More specifically, the small sample size might have produced results that ignored particular differences between the groups ratings of certain psychological issues. That is, had there been a greater subject pool to analyze, more significant differences might have been detected between the groups responses to the remaining statements that were not found to be significant on the HACC.

Another limitation of this study may involve the unequal number of subjects to each of the three groups. That is, the inability to obtain an equal number of subjects within each group might have further contributed to inconclusive statistical relationships described above, and perhaps at times led to an unwarranted rejection of the research hypothesis. In other words, the unequal number of subjects within the three groups may have generated

results that did not detect possible significant differences between the groups ratings of certain psychological issues.

A further constraint of this study may have been the fact that the subjects were self-selected participants. All of these participants were involved in a support group for homosexual men who were in similar situations to their own. Consequently, because all the subjects were present in either support groups or active members of a HIV/AIDS community care organization, their configuration of their psychological concerns may differ from other homosexual men representing the remaining HIV/AIDS population. More specifically, since all the subjects were already seeking help from support groups or from the community organization, they were more likely to use active coping methods to deal with certain issues than avoidance, which would most likely have contributed to higher degrees of concern with certain psychological issues. As a result the subjects in the present study constituted in some ways a very homogeneous group, which ultimately lowered the statistical power of the results, and perhaps presented a biased perspective of clients interpretations of significant psychological issues.

Finally, another limitation of the present study might involve the content validity of the HACC questionnaire employed to assess clients concerns of the various psychological issues that may exist throughout the HIV/AIDS continuum. Since this instrument was adapted for the purposes of this study, tests of reliability and validity have not yet been established. As previously mentioned in the method section reliability tests were performed on the HACC through its distribution to other homosexual men in order to determine it's

relevance and comprehensiveness, but no statistical tests of reliability and validity were performed on the statements themselves in order to determine their intercorrelation coefficients and their discriminant power. However, since the HACC was an adaptive version of a previously used intake questionnaire by ACCM, and since the relevance for its content was verified through an extensive review of the literature and through consultation with numerous mental health professionals who have experience counselling this HIV/AIDS population, face validity was established.

#### Future Research

The findings previously mentioned consisted of the statistical analysis performed on the three groups' responses to all the statements on the HACC. Since the focus of this thesis was to determine what particular psychological issues were specific to each of these three groups, the statistical analysis consisted of the interaction effect between the groups and the statements. No post-hoc analysis was carried out on the statements themselves, even though inferential statistics indicated that there was a significant main effect for statements. That is, the analysis indicated that there was a significant difference in the subjects' responses to the statements for all three groups, regardless of what particular group subjects' belonged to. As such, further studies concerned in evaluating the significance of the different psychological issues that may exist for the HIV/AIDS population as a whole might benefit from expanding on the analysis of the various questions on the HACC. In other words, a more stringent analysis of which specific statements were rated significantly high or low for all three groups can be further investigated. This type of analysis can assist

researchers to identify which issues are considered important for clients within this special population. Ultimately, this type of knowledge will help clinicians provide more effective counselling.

Future research should include the administration of the HACC or similar questionnaires on different population groups, such as women, i.v. drug users, etc. This will enable the standardization of these types of questionnaires for such special population groups. In addition, this type of investigation can provide pertinent information regarding the distinct profiles of significant psychological issues for each of these population groups.

In addition, future recommendations might include performing longitudinal research studies that incorporate a more developmental approach in understanding the psychological changes that occur for the population sampled in this study over time. In other words administering the HACC or similar questionnaires to clients as they progress along the HIV/AIDS continuum and monitoring what significant changes might develop in their responses to these questions may ultimately provide a more accurate profile of clients' transient needs. This in turn, will assist both the therapist and the client to conceptualize the various psychological concerns that arise as the illness progresses. In addition, this type of developmental approach will help the client cope with concrete issues.

Moreover, future research should also focus attention on identifying the specific psychosocial issues and adaptive demands that are prevalent across the course of the HIV/AIDS illness. It has been reported that such issues and demands play an important role in clients' overall impression of themselves in relation to their illness (Dilley, 1990).



Consequently, this can be an important area of investigation to further explore since it may ultimately effect clients' interpretations and judgements of what they consider to be significant psychological issues. Although research to date has focused mainly on psychosocial distress among infected clients (Chuang et al., 1989), it does not necessarily provide an accurate indication of their overall psychosocial adjustment. As such, studies which focus on investigating both clients' psychosocial well-being and their psychological distress level may provide a more balanced assessment of their relevant psychological concerns.

Future recommendations may also include an explicit investigation of the reliability and validity of the HACC questionnaire. This may be established through different statistical procedures, such as test re-test reliability, inter-group reliability, internal consistency reliability, as well as other measures. In addition, in order to measure construct validity one can compare the HACC questionnaire to other similar standardised instruments that might have been developed to assess similar client concerns. This may be difficult to determine, since a review of the literature has determined that such standardised questionnaires are non-existent as far as the researcher can determine. It is recommended that future research should concentrate on developing specific norms to assist researchers in administering more refined instruments.

## Conclusion

HIV/AIDS has been described as one of the most urgent medical, psychological, and social problems of this century (Douce, 1993). Its psychological effects are felt by individuals, families, and mental health care workers (Silverman, 1993). This together with the nature of the illness, a potentially fatal, incurable, and transmissible disease, heightens the need for counselling of HIV infected individuals and AIDS clients to that of a major priority, and makes the tasks of the counsellor complex and challenging (Bor et al., 1991).

According to Gutierrez and Perlstein (1992) it is helpful for counsellors to conceptualize some of the psychological difficulties their clients are facing from a developmental framework. This research study attempts to assist the counsellor with the understanding of the complexities of clients' psychological reactions in dealing with the continuum of conditions ranging from HIV positive but asymptomatic to HIV symptomatic to AIDS. This type of developmental approach will help familiarize counsellors with the diversity of subgroups that exist within this HIV/AIDS population and ultimately create a practical understanding of the various psychological needs of these subgroups.

The purpose of this study was to highlight the different psychological issues that clients are most concerned with across these three sub-group populations. As such, it was hypothesized that clients within their different stages of affliction will place more significance with certain psychological issues than others. The results obtained supported the hypothesis of this study. More specifically, the findings demonstrated that the

asymptomatic group was most concerned with issues of confidentiality in relation to their HIV status. The symptomatic group on the other hand was most concerned with issues surrounding feelings of guilt/shame, shock, depression, fear, loneliness, and fear of infecting others through casual contact. Finally, the AIDS diagnosis group was most concerned with issues dealing with their future care (e.g., living will, life support, etc.). Subsequently, the results indicated that among the three groups the symptomatic group showed the most numerous significant concerns, all of which dealt with particular feelings as opposed to social, cognitive, and/or financial concerns. Studies tend to support this finding in that they assert that individuals with symptomatic HIV infection show the highest degree of psychological and psychosocial distress during this particular stage (Atkinson et al., 1988; Chuang et al., 1989; Dilley, 1990; Tross et al., 1988).

In summary, counsellors should place closer attention to the numerous yet distinct psychological consequences experienced by individuals across the full spectrum of the HIV/AIDS infection. This can help provide interventions that can alleviate, to the greatest degree possible, the emotional and social distress that often follows a HIV positive test result. The listing of psychological issues presented in this particular study is hardly exhaustive, but rather serves as a device to assist the psychotherapist to anticipate what may arise in counselling sessions with a HIV+/AIDS person. Each person, of course, will provide personal aspects of these issues, and is likely to add numerous others.

A comprehensive analysis of the various psychological issues that clients are confronted with across the different sub-population groups is beyond the scope of this

research thesis. However, by addressing some of these distinct psychological concerns it is hoped that a more detailed discussion will ensue. Such discussions can assist the counsellor in providing a service to both clients and professionals by inspiring discussions of these issues before they actually present as clinical crises.

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## Appendix A

### Personal Information Questionnaire (PIQ)



## Personal Information Questionnaire (PIQ)

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_/

d      m      y

Your Age: \_\_\_\_

Your Mother Tongue: \_\_\_\_\_

Your Ethnic Background: \_\_\_\_\_

Your religious affiliation: \_\_\_\_\_

Your Education Level: \_\_\_\_ (completed University  
post-graduate degree)  
\_\_\_\_ (completed a University  
degree)  
\_\_\_\_ (some University)  
\_\_\_\_ (completed a technical  
training program)  
\_\_\_\_ (completed Cegep)  
\_\_\_\_ (some Cegep)  
\_\_\_\_ (completed High School)  
\_\_\_\_ (not completed High School)

Employment Status: ☐ Full-time  
☐ Part-time  
☐ Unemployed  
☐ Retired  
☐ Other (i.e., welfare recipient,  
on disability, etc.

---

(please specify)

Current Income: ☐ 9,000 or less  
☐ 10,000 to 19,000  
☐ 20,000 to 29,000  
☐ 30,000 to 39,000  
☐ 40,000 or more

Your Sexual Orientation: ☐ Homosexual  
☐ Bi-sexual

How do you believe you contracted HIV/AIDS?

\_\_\_\_\_through sexual contact with persons of the same sex.

\_\_\_\_\_through sexual contact with persons of the opposite sex.

\_\_\_\_\_through blood transfusions

\_\_\_\_\_through sharing needles during intravenous drug use.

\_\_\_\_\_others (please specify)\_\_\_\_\_.

\_\_\_\_\_I don't know.

When did you first learn of your seropositivity status?

\_\_\_\_\_Less than six months ago.

\_\_\_\_\_between 6 months and 1 year ago.

\_\_\_\_\_between 1 to 2 years ago.

\_\_\_\_\_over 2 years ago.

What is your most recent t-cell count\_\_\_\_\_.

Date:\_\_\_\_\_.

Have you sought professional counselling or psychological/psychiatric help since your HIV diagnosis?

\_\_\_\_\_no

\_\_\_\_\_yes. For how long?\_\_\_\_\_

What predominant HIV-related symptoms have you experienced thus far?

\_\_\_\_\_Lymphadenopathy

\_\_\_\_\_Chronic or recurrent fever

\_\_\_\_\_Fatigue

\_\_\_\_\_Involuntary weight loss (>10%)

\_\_\_\_\_Night sweating

\_\_\_\_\_Diarrhea

\_\_\_\_\_Wasting

\_\_\_\_\_Multiple mucocutaneous problems: i.e., fungal infections, herpes, mouth ulcers.

\_\_\_\_\_other (please specify) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Do you have the diagnosis of AIDS? Yes\_\_\_\_\_ No\_\_\_\_\_  
Don't Know\_\_\_\_\_

If Yes, what predominant AIDS-Related symptoms have you experienced?

Main opportunistic infections:

\_\_\_\_\_Pneumocystis carini pneumonia

\_\_\_\_\_Candidal oesophagitis

\_\_\_\_\_Infections of the central nervous system

\_\_\_\_\_A range of infections that attack the eyes,  
digestive system, and skin.

\_\_\_\_\_other (please specify)\_\_\_\_\_

Rare cancers:

\_\_\_\_\_Kaposi's sarcoma

\_\_\_\_\_Lymphoma

\_\_\_\_\_other (please specify)\_\_\_\_\_

**Appendix B**

**HIV/AIDS Client Concerns Questionnaire (HACC)**

### HIV/AIDS Client Concerns Inventory (HAAC)

The following questionnaire contains an extensive list of questions pertaining to specific issues/concerns that you may be facing. Please read all these statements carefully, and by using the scale provided below, rate each statement in terms of how significant or typical it has been for you at this stage of your life.

- 1 Never (doesn't apply)
- 2 Very few times
- 3 Sometimes
- 4 Fairly Often
- 5 Always

(N.B): For your convenience you will find an answer sheet attached to the back of this questionnaire. Please feel free to separate this form from the questionnaire and while reading each statement carefully, record your answers directly on this sheet.

1                      2                      3                      4                      5

--+-----+-----+-----+-----+--

Never                                      Sometimes                                      Always

- 1) I find it difficult to disclose my HIV/AIDS status to people I feel close to?
- 2) I feel guilty/ashamed of myself?
- 3) I am deeply concerned with the future in terms of loss of control due to physical ailments which may lead to dependency?
- 4) I often think about the possibility of death?
- 5) I feel angry and/or frustrated at the health care system?
- 6) I usually experience feelings of being contaminated?



1                      2                      3                      4                      5  
-----+-----+-----+-----+-----  
Never                                      Sometimes                                      Always

- 7) I typically experience feelings of rejection from significant people in my life?
- 8) I feel sad most of the time due to loss of friends to HIV/AIDS?
- 9) I feel there is some sort of connection between my sexual orientation and my present condition?
- 10) The possibility of loss of social or relationship supports concerns me?
- 11) I am very uncomfortable telling someone I have just started dating that I have the HIV/AIDS virus?
- 12) I am preoccupied with my illness and fearful of it's possible progression?

1                      2                      3                      4                      5  
-----+-----+-----+-----+-----  
Never                                      Sometimes                                      Always

13) I feel that the possibility of being  
romantically involved with a "significant other" is  
now virtually impossible?

14) I feel that I am just as good as other  
people?

15) I have often used drugs/alcohol as a coping tool?

16) I often experience feelings of:

- a) shock \_\_\_\_\_
- b) confusion \_\_\_\_\_
- c) anger \_\_\_\_\_
- d) depression \_\_\_\_\_
- e) anxiety \_\_\_\_\_
- f) fear \_\_\_\_\_
- g) sadness \_\_\_\_\_
- h) helplessness \_\_\_\_\_
- i) resentment \_\_\_\_\_
- j) loneliness \_\_\_\_\_

1                      2                      3                      4                      5  
--+-+-----+-+-----+-+-----+-+-----+-+--  
Never                                      Sometimes                                      Always

- 17) I experience conflicting feelings when I  
think about having sex with a new partner?
- 18) I am as interested in sex as I used to be?
- 19) I feel comfortable with safe sex practices?
- 20) Assuming my partner is unaware of my condition  
I would still comply with a request for an unsafe  
sexual act?
- 21) I find that I am so worried about my  
physical problems that I cannot think about  
anything else?
- 22) I fear infecting other people through casual  
contact?
- 23) I feel that the future is hopeless and that  
things cannot improve?

1                      2                      3                      4                      5  
--+-----+-----+-----+-----+--  
Never                                      Sometimes                                      Always

24) I frequently think about suicide?

25) I am able to speak openly about my feelings  
when I am angry or worried?

26) I often think about planning for my future  
care (e.g. living will, life support etc.)?

27) I feel that I am now unable to realize life  
goals (e.g. completing my education, obtaining  
career goals)?

28) I have experienced feelings of being  
discriminated against by others (i.e. employer's,  
colleagues, & acquaintances)?

29) I am often concerned about confidentiality in  
relation to my HIV/AIDS status?

1                      2                      3                      4                      5  
--+-----+-----+-----+-----+--  
**Never**                                      **Sometimes**                                      **Always**

- 30) I feel that I have a satisfying, secure support system (friends, family) in my private life?
- 31) I sometimes feel that life and being alive is somehow not worth it any more (why even continue trying)?
- 32) I have often thought about the issue of euthanasia and the possible implications it might have in my life?
- 33) I have thought about life after death and/or my own spiritual concerns?
- 34) I feel I am a person of worth and have a lot to be proud of?

1                      2                      3                      4                      5  
--+-----+-----+-----+-----+--  
Never                      Sometimes                      Always

- 35) I am very concerned about my physical appearance/attractiveness and it's possible deterioration?
- 36) I often experience feelings of nervousness and restlessness?
- 37) I tend to isolate myself from others (avoid being with people)?
- 38) Generally, I feel that I have control over maintaining or improving my life?
- 39) I feel that I have enough information/knowledge about HIV/AIDS?
- 40) As a result of my condition I am now much more concerned with my financial situation?

**Answer Sheet**

1 \_\_\_\_\_

21 \_\_\_\_\_

2 \_\_\_\_\_

22 \_\_\_\_\_

3 \_\_\_\_\_

23 \_\_\_\_\_

4 \_\_\_\_\_

24 \_\_\_\_\_

5 \_\_\_\_\_

25 \_\_\_\_\_

6 \_\_\_\_\_

26 \_\_\_\_\_

7 \_\_\_\_\_

27 \_\_\_\_\_

8 \_\_\_\_\_

28 \_\_\_\_\_

9 \_\_\_\_\_

29 \_\_\_\_\_

10 \_\_\_\_\_

30 \_\_\_\_\_

11 \_\_\_\_\_

31 \_\_\_\_\_

12 \_\_\_\_\_

32 \_\_\_\_\_

13 \_\_\_\_\_

33 \_\_\_\_\_

14 \_\_\_\_\_

34 \_\_\_\_\_

15 \_\_\_\_\_

35 \_\_\_\_\_

16 \_\_\_\_\_

36 \_\_\_\_\_

17 \_\_\_\_\_

37 \_\_\_\_\_

18 \_\_\_\_\_

38 \_\_\_\_\_

19 \_\_\_\_\_

39 \_\_\_\_\_

20 \_\_\_\_\_

40 \_\_\_\_\_

## Appendix C

### Introduction



### Introduction

This is a questionnaire directed towards homosexual and bisexual men as part of a study of the HIV/AIDS virus in the Montreal region. More specifically, this study will explore the various psychological and psychosocial issues and concerns that individuals experience across the whole spectrum of HIV/AIDS infection.

Along with the consent form you will find two questionnaires which you will be asked to complete. The process of filling out these two questionnaires should not take longer than approximately 20 minutes.

If you are interested in participating in this study, please sign the attached consent form. You may then proceed to respond to the Personal Information Questionnaire (PIQ), followed by the HIV/AIDS Client Concerns Inventory (HAAC).

Thank you for your participation in this study,  
your cooperation is greatly appreciated.

Angelo Paraskevopoulos (M.A)

SIGNATURE: \_\_\_\_\_

Appendix D  
Consent Form

**Consent Form**

This is to state that I agree to participate in a research study conducted by Angelo Paraskevopoulos (counsellor in training) under the supervision of Anastassios Stalikas, Ph.D (clinical psychologist, assistant professor) in the department of Educational & Counselling Psychology of McGill University.

I understand that the purpose of this study is to determine the significance of various psychological and psychosocial issues and concerns that homosexual or bisexual men experience across the HIV/AIDS continuum.

I understand that my participation in the study is totally anonymous and that all the material collected will remain strictly confidential.

I understand that I can have a full description of the results of this study after its completion and that I will be able to ask any questions regarding my participation in this study.

I understand that my participation in this study may be published, with no mention of individual names or cases.

I understand that for reasons of completion and scientific validity I must answer all the questions truthfully and to the best of my ability.

**I HAVE CAREFULLY READ AND I UNDERSTAND THIS AGREEMENT, AND  
THEREFORE CONSENT AND AGREE TO PARTICIPATE IN THIS STUDY.**

**NAME (Please Print)**\_\_\_\_\_

**Signature**\_\_\_\_\_

**Date**\_\_\_\_\_

**TABLES**

Table 1

Means and Standard Deviations for the Demographic Variable: Age, in All Three Groups

<u>Dependent Variable</u>	Groups					
	Asymptomatic		Symptomatic		AIDS Diagnosis	
	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation
Age	38.1	11.3	31.1	6.8	41.1	6.6

**Table 2****Mean Percentages for Demographic Variables: Education, Employment, Income, and Sought Counselling for all three groups**

	Groups		
	Asymptomatic	Symptomatic	AIDS Diagnosis
<u>Education</u>			
• Completed High School	36%	56%	90%
• Completed Technical Training/Cegep	27%	25%	10%
• Received High School Diploma	9%	19%	0%
• Did Not Complete High School	27%	0%	0%
<u>Employment</u>			
• Full Time	46%	19%	10%
• Part Time	9%	36%	20%
• Not Working (unemployment, welfare, disability)	45%	44%	70%
<u>Income</u>			
• \$9,000 or less	45%	56%	30%
• \$10,000 - \$19,000	18%	19%	30%
• \$20,000 - \$29,000	9%	13%	30%
• \$30,000 or more	27%	14%	10%
<u>Sought Counselling</u>			
• yes	30%	50%	70%
• no	70%	50%	30%

Table 3

Analysis of Variance for the Effects of Subjects' Level of Diagnosis (Groups) on the Dependent Variable (Questions, 1-40 on the HACC)

Questions 1-40 on the HACC				
Source	<u>df</u>	<u>ms</u>	<u>F</u>	<u>p</u>
<u>Between Subjects</u>				
Groups (A)	2	20.608	2.585	0.090
Error	34	7.970		
<u>Within Subjects</u>				
Items (B)	48	14.102	10.676	0.000*
A x B	96	2.258	1.709	0.000*
Error	1632	1.321		

p<0.05

Table 4

Results of Post-Hoc Analysis of Variance for Question #2 "I Feel Guilty/Ashamed of Myself"

Source	Question #2			
	<u>df</u>	<u>ms</u>	<u>F</u>	<u>p</u>
Groups	2	6.405	4.625	0.017*
Error	34	1.385		

\*p<0.05



Table 5

Matrix of Pairwise Comparison Probabilities Between All Three Groups for Question #2 "I feel Guilty/Ashamed of Myself"

	Groups		
	Asymptomatic	Symptomatic	AIDS Diagnosis
<u>Groups</u>			
Asymptomatic	1.000		
Symptomatic	0.875	1.000	
AIDS Diagnosis	0.072	0.015*	1.0000

\*p<0.05

Table 6

Results of Post-Hoc Analysis of Variance for Question #16a "I Often Experience Feelings of Shock"

Source	Question #16a			
	<u>df</u>	<u>ms</u>	<u>F</u>	<u>p</u>
Groups	2	6.832	5.025	0.012*
Error	34	1.360		

\*p<0.05

Table 7

Matrix of Pairwise Comparison Probabilities Between All Three Groups for Question #16a "I Often Experience Feelings of Shock"

	Group		
	Asymptomatic	Symptomatic	AIDS Diagnosis
<u>Groups</u>			
Asymptomatic	1.000		
Symptomatic	0.033*	1.000	
AIDS Diagnosis	0.996	0.031*	1.000

\*p<0.05

Table 8

Results of Post-Hoc Analysis of Variance for Question #16d "I Often Experience Feelings of Depression"

Question #16d				
Source	<u>df</u>	<u>ms</u>	<u>F</u>	<u>p</u>
Groups	2	5.617	4.654	0.016*
Error	34	1.207		

\*p<0.05

Table 9

Matrix of Pairwise Comparison Probabilities Between All Three Groups for Question #16d "I Often Experience Feelings of Depression"

	Groups		
	Asymptomatic	Symptomatic	AIDS Diagnosis
<u>Groups</u>			
Asymptomatic	1.000		
Symptomatic	0.394	1.000	
AIDS Diagnosis	0.248	0.012*	1.000

\*p<0.05

Table 10

Results of Post-Hoc Analysis of Variance for Question #16f "I Often Experience Feelings of Fear"

Question #16f				
Source	<u>df</u>	<u>ms</u>	<u>F</u>	<u>p</u>
Groups	2	4.435	3.321	0.048*
Error	34	1.335		

\*p<0.05

Table 11

Matrix of Pairwise Comparison Probabilities Between All Three Groups for Question #16f "I Often Experience Feelings of Fear"

	Groups		
	Asymptomatic	Symptomatic	AIDS Diagnosis
<u>Groups</u>			
Asymptomatic	1.000		
Symptomatic	0.236	1.000	
AIDS Diagnosis	0.710	0.048*	1.000

\*p<0.05

Table 12

Results of Post-Hoc Analysis of Variance for Question #16j "I Often Experience Feelings of Loneliness"

Source	Question #16j			
	<u>df</u>	<u>ms</u>	<u>F</u>	<u>p</u>
Groups	2	8.013	5.452	0.009*
Error	34	1.470		

\*p<0.05



Table 13

Matrix of Pairwise Comparison Probabilities Between All Three Groups for Question #16j "I Often Experience Feelings of Loneliness"

	Groups		
	Asymptomatic	Symptomatic	AIDS Diagnosis
<u>Groups</u>			
Asymptomatic	1.000		
Symptomatic	0.175	1.000	
AIDS Diagnosis	0.375	0.007*	1.000

\* $p < 0.05$

Table 14

Results of Post-Hoc Analysis of Variance for Question #22 "I Fear Infecting Other People Through Casual Contact"

Question #22					
Source		<u>df</u>	<u>ms</u>	<u>F</u>	<u>p</u>
Groups		2			
Error	34	0.870	11.695	13.441	0.000*

\*p<0.05

Table 15

Matrix of Pairwise Comparison Probabilities Between All Three Groups for Question #22 "I Fear Infecting Other People Through Casual Contact"

	Groups		
	Asymptomatic	Symptomatic	AIDS Diagnosis
<u>Groups</u>			
Asymptomatic	1.000		
Symptomatic	0.000*	1.000	
AIDS Diagnosis	0.987	0.000*	1.000

\*p<0.05

Table 16

Results of Post-Hoc Analysis of Variance for Question #26 "I Often Think About Planning for My Future Care (e.g., Living Will, Life Support, Etc)."

Source	Question #26			
	<u>df</u>	<u>ms</u>	<u>F</u>	<u>p</u>
Groups	2	4.821	3.846	0.031*
Error	34	1.254		

\*p<0.05

Table 17

Matrix of Pairwise Comparison Probabilities Between All Three Groups for Question #26 "I Often Think About Planning for My Future Care (e.g., Living Will, Life Support, Etc.)"

	Groups		
	Asymptomatic	Symptomatic	AIDS Diagnosis
<u>Groups</u>			
Asymptomatic	1.000		
Symptomatic	0.257	1.000	
AIDS Diagnosis	0.024*	0.332	1.000

\*p<0.05

Table 18

Results of Post-Hoc Analysis of Variance for Question #29 "I Am Often Concerned About Confidentiality in Relation to My HIV/AIDS Status"

Source	Question #29			
	<u>df</u>	<u>ms</u>	<u>F</u>	<u>p</u>
Groups	2	5.212	3.291	0.049*
Error	34	1.584		

\* $p < 0.05$

Table 19

Matrix of Pairwise Comparison Probabilities Between All Three Groups for Question #29 "I am Often Concerned About Confidentiality in Relation to My HIV/AIDS Status"

	Groups		
	Asymptomatic	Symptomatic	AIDS Diagnosis
<u>Groups</u>			
Asymptomatic	1.000		
Symptomatic	0.321	1.000	
AIDS Diagnosis	0.039*	0.375	1.000

\*p<0.05