

**HEALING AND HIV/AIDS: SIX STORIES**

by

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## Abstract

The subject of this thesis is healing, which is conceptualized herein as enhancing the subjective experience of one's quality of life. Drawing from ethnographic principles I interviewed five people with HIV or AIDS in order to report their stories of healing and from which to draw implications for counsellors. A further aim of the research has been to tell the stories of people who are typically stigmatized and whose interests have often been ignored.

In presenting the participants' stories I aimed to be as faithful to the telling as possible. From the stories, I identified various themes that I perceived to capture the essential features of each story and to enable comparing stories. These themes are: circumstances around the HIV seropositive diagnosis and its impact; the journeys; acceptance and letting go; healing; beliefs, death and illness; self-responsibility; people; and reflections on the journey so far. These themes also provide the structure within which comments and suggestions for counsellors are presented.

The stories of Michel L, Richard, Jim, Michel G, and Michel T affirm that some people experience an enhanced quality of life following an HIV/AIDS diagnosis. Common to their journeys is evolving self-awareness and a greater trust in their intuition, particularly with regards to knowing what they need for themselves. Our society devalues intuition in favour of knowledge that comes from external authorities. Counsellors can address this imbalance by encouraging clients to explore their intuitive knowledge and by showing faith in their clients for knowing best what they need for their own healing. Notwithstanding, counsellors can also offer information at their disposal, whilst allowing clients to come to their own conclusions. By so doing, counsellors will foster their clients' self-responsibility. For counsellors to maximally enhance their clients' healing, I conclude that it is imperative for them to care for their clients, to honour them for being who they are, and to support them in their own ways of caring for themselves. To this end counsellors need to care for themselves and be aware of their own beliefs, expectations and assumptions, all of which could interfere with honouring their clients. Finally, because hope is so essential for people with HIV/AIDS, it is of paramount importance that, whether or not counsellors expect that their clients will die from HIV/AIDS, counsellors treat their clients as living people.

**I dedicate this thesis**

**to all who are questing for healing and personal truth**

**“How might your life have been different if, as a young woman  
struggling to find your voice ... in despair that you might never  
be able to say what you knew inside ... there had been a place  
for you to begin to speak ...?”**

**Duerk, 1993, p. 24**

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## Introduction

Carol's doctor tells her that there is nothing more they can do. Carol has advanced HIV disease. A series of infections has necessitated her hospitalization. Her body no longer responds favourably to medication and her immune system is steadily weakening. Carol asks to go home. Carol is an Ojibway Native. She returns home and requests a healing ceremony from the spiritual elders. The healing ceremony transforms her. Now, four years after the diagnosis of AIDS Related Complex, Carol travels across North America educating First Nations people about AIDS. Carol not only defies her prognosis, but enjoys an improved quality of life (LaFavor, 1991).

Carol LaFavor (1991) is one person who chose not to accept blindly the popular belief that Acquired Immune Deficiency Syndrome (AIDS) is a death sentence. I found her story inspiring. As a volunteer counsellor with AIDS Vancouver, I have spoken to many others who are responding to having AIDS or conditions of Human Immunodeficiency Virus (HIV) by making significant changes to improve the quality of their lives. Having AIDS or HIV has provided an impetus for these people to reflect on their lives. This reflection has led to personal growth and transformation, and they have reported greater happiness than previously experienced. A peer volunteer counsellor at AIDS Vancouver has also observed that many who are confronted with their own mortality "rise to the challenge and begin the healing journey toward wholeness. The HIV syndrome may or may not lessen the quantity of their lives but it has been instrumental in greatly increasing the quality of their lives" (Oram, 1991, p. 14).

As well as Carol's story, these observations of enhanced quality of life following an HIV/AIDS diagnosis are substantiated by other self-reports (e.g., Callen, 1990; Larkin, 1991; Mehl, 1990; Melton & Garcia, 1988; Mignone, 1988; Nungessor, 1986), and further anecdotal evidence (e.g., Bamforth, 1987; Callen, 1990; Goldner, 1988; Matousek, 1993; Nichols, 1986; Owen, 1987; Pohl, 1988; Salisbury, 1987; Schultz, 1988; Serinus, 1986; Walker, 1991). A paucity of academic research exists, however, exploring the relationship between HIV/AIDS and increasing quality of life (the few exceptions are Kendall et al., 1989; Pachuta, 1990; Solomon, Temoshok, O'Leary, & Zich, 1987). To a large degree researchers have ignored the psychosocial aspects of AIDS—that is, the aspects where both psychological and social factors are assumed to play a role—but rather have focused on the physical epidemiology and pathophysiology of the

disease. The smaller percentage of the AIDS research literature which has addressed psychosocial aspects have been mainly limited to descriptions of negative psychosocial consequences experienced by people with AIDS (e.g., Atkinson, 1989; Beckett, & Rutan, 1990; Dilley, Ochitill, Perl, & Volberding, 1985; Dilley, Pies, & Helquist, 1989; Douglas, Kalman, & Kalman, 1985; Dunphy, 1987; Green, 1989; Kelly, 1989; Macks, 1989; Nelson, & Jarrett, 1987; Snowden & Cassidy, 1989; Spector, & Conklin, 1987).

There are indeed profound difficulties associated with facing infection with a virus that has precipitated the death of at least hundreds of thousands of people worldwide (statistics from Health & Welfare Canada—HIV/AIDS Division, 1993). In spite of these difficulties, there exists the possibility for people with HIV/AIDS of experiencing improved quality of life.

Improving the quality of life may be equated with a broad conceptualization of “healing.” The circumstances of this disease are such that there is as yet little chance of survival and yet many persons with HIV/AIDS seem to be living longer as new therapies and new approaches to treatment are successful. As used in this thesis, therefore, “healing” and “physical curing” are not synonymous. A broader conception of healing as enhancing the subjective experience of one’s quality of life will be argued for, in preference to the conventional definition of “healing” in terms of an objectively measurable improvement in physical health.

### **Purpose of this research**

Healing is the subject of this thesis. I chose to explore the subject of healing because healing is my main purpose in life. My own healing and contributing to that of others gives my life meaning. This thesis is part of my training to be a counsellor, a profession that I expect to be maximally fulfilling because it will allow me to concentrate on healing. I argue that people themselves know intuitively—or can come to know—what they need for their own healing, because no one else has the same opportunity to know another’s subjective experiences. Yet people may benefit from including counsellors on their journeys and so I aim in this research to tap into the wealth of information that those currently with HIV/AIDS have to offer, thereby learning more about how to effectively counsel them and possibly others with HIV/AIDS.

The purpose of this research project is to record and report people's stories of healing. To this end, I have interviewed five persons with HIV or AIDS. The threefold rationale for this study is to contribute to the well-being of participants in the research, to that of other people with HIV/AIDS, and to theoretical and practical knowledge for counsellors. Firstly, there is reason to believe that giving expression to the participants' stories of healing validates and encourages their process of healing (e.g., Melton & Garcia, 1988; Walker, 1991). Secondly, such stories may be inspirational and empowering to others in their search for healing (Kremer, 1988). Thirdly, counsellors can learn from the participants about how they might better facilitate healing with their HIV/AIDS clients. I know of no academic research which reports people's stories of healing in the HIV/AIDS context. It is a wealthy source from which to draw theoretical and practical implications for counsellors. I am explicitly subjective in my approach. For the literature review I have chosen which material to read and write about, although I have attempted to fully report the literature on counselling people with HIV/AIDS. In reporting the participants' stories I have tried to be faithful to their intents as I understood them.

This research aims to serve the interests of people who are typically stigmatized and whose interests have often been ignored. Many researchers (e.g., Kirby and McKenna, 1989) recognize that knowledge and research has not served the interests of all people; rather, they have typically been used to maintain oppressive relations. Furthermore, knowledge production is organized so that the views of the small, but dominant group of people are presented as "The Truth" and that the majority of people are excluded from participating as either producers or participants in the creation of knowledge. By contrast, my research is consistent with Mies' directive: "Research, which so far has been largely the instrument of dominance and legitimization of power elites, must be brought to serve the interests of dominated, exploited and oppressed groups" (cited in Kirby & McKenna, 1989, p. 15). It is possible to affirm people who have been dominated, exploited and oppressed by participating in naming their social reality in a way that remains faithful to that experience and does not further exploit it (Kirby & McKenna, 1989).

Why is healing so important to me and why have I selected a stigmatized group of people as participants in my research?

At the age of 28 I went to see a counsellor because, probably unbeknownst to most people in my acquaintance, I felt profoundly unhappy yet had hope that I could become happier. I spent most of my early sessions in tears, in touch with the pain and grief I had been storing up over my lifetime. What a relief it was to feel and speak about what was *really* going on for me! The rewards were immediately apparent ... experiencing intensely whatever pain and grief was present at the time seemed to free me from it. At times, however, the pain and tears seemed frighteningly bottomless and I spent much of the subsequent few years feeling overwhelmed by feelings of grief and lack of worth. Now, ten years later, I *am* considerably happier, and I attribute that shift to the time and energy that I, along with friends and some counsellors, have spent on my healing. I do not know how best to describe the kind of emotional, psychological, and spiritual healing that I am talking about, except to say that it has primarily involved a deepening self-awareness, of feelings, thoughts, and behaviours, and has paralleled greater self-acceptance and self-responsibility.

If my memory serves me well, as a child I was generally happy, full of energy, and successful in my schoolwork, play and friendships. That changed when I was 10 ... when my family migrated from England to Australia. I was teased and bullied mercilessly by my new schoolmates, with whom I so desperately needed friendship and acceptance and with whom I would spend the remaining seven years of school. I was cruelly teased simply because I was a "Pom" or "Pome" (Prisoner of Mother England). I did not interpret it so simply at the time. I internalized the belief that there was something fundamentally wrong and unlikeable about me, and that this had been failed to be noticed in England. My self-esteem suffered drastically. I thus experienced harassment and oppression on the basis of my cultural background yet felt powerless to change it.

It is now almost three decades since I moved to Australia and globally there is greater awareness about harassment, discrimination, and oppression. Despite its censure in Human Rights Codes, harassment and discrimination still exist, especially against lesbians, gay men and bisexuals. Because AIDS and the gay community have been so linked in our society, my volunteer work at AIDS Vancouver (half a day per week for 17 months) and the choice of participants for the present research have both been driven in part by my personal experience of ostracism and thus an

identification with the oppression experienced by gay men, lesbians and bisexuals, and in part by my appreciation of my many lesbian and some gay male friends. It has been an opportunity to make a statement against homophobia and thus oppression generally.

To conclude this section on the purpose of the present research, the social context is fivefold. (The idea of making explicit the social context of research comes from Kirby & McKenna, 1989). First, there is the academic context. The thesis is being written as partial fulfillment of a Masters degree in Counselling Psychology and therefore needs to be accredited by supervisors and examiners. Second, there is a political context. I have chosen a population of stigmatized people to be participants in the research, thereby recognizing their typically unacknowledged experience. I acknowledge, however, the power differential between me the researcher and the researched, and aim to minimize that disparity. Third, there is a public context. I aim to make visible the experiences of some people on the margins who have been typically kept invisible, thereby filling a gap in public knowledge. Fourth, there is a community context. The research is for the participants and other people who may benefit from hearing about stories of healing. I believe, as do Kirby and McKenna (1989), that research should aim to be empowering for the people who are usually merely the objects of research. Fifth, there is a personal context. The research is also for myself—it is an opportunity for me to explore and express my views on a topic of prime personal interest.

### **AIDS Background**

In 1979, doctors in Los Angeles and New York first noticed an increase in cases of an unusual pneumonia and a rare cancer in homosexual men. These patients had severely diminished immunity. Cases were also noticed in intravenous (IV) drug users, hemophiliacs, and sporadically in other patients. The syndrome appeared to be caused by a transmissible agent, probably a virus. Records now show that there were cases of HIV infection in the U.S. IV drug community as early as 1976. As the incidence of AIDS increased in the U.S., the disease was being reported in Europe and elsewhere. Many of the affected people in Europe were immigrants from central Africa. Upon further investigation in Africa, researchers were able to see an already existing epidemic which, again, looked as though it went back to at least 1976. However, where the American cases were

mostly among homosexual men, and to a lesser extent IV drug users, the African cases were among heterosexuals, and the split was more even between men and women (Frutchey, Christen, & Rittinger, 1987).

By the beginning of 1983, shortly after the name AIDS was given to the disease, the recorded death toll in Canada had reached 36 (Health & Welfare Canada—HIV/AIDS Division, 1993). The growth rate of the epidemic peaked in Canada between 1986 and 1987 and has since declined; that is, the proportion of new cases to existing cases is presently decreasing, even though the number of new cases continues to rise each year. As of July, 1993, the Health & Welfare Canada—HIV/AIDS Division in Ottawa reports 8232 known cases of AIDS in Canada—7721 adult males, 427 adult females, 43 boys and 41 girls. 1973 of these people are alive. Most reported cases of male and female adults are in the 30-39 years range and most children (less than 15 years) are less than a year old.

Worldwide, the World Health Organization reports 745,426 known cases of AIDS (Health & Welfare Canada—HIV/AIDS Division, 1993). The *actual* number of cases is thought to be far greater. Within Canada, the province of British Columbia has the highest incidence per capita (of 69 per million in 1990), with 1502 reported cases (July, 1993). The British Columbia Centre for Disease Control (1993, July) which is responsible for HIV antibody testing reports 6,619 people who are HIV positive.

In the early 1980s, the prognosis for those with HIV disease was poor. In most cases, the infection was not diagnosed until serious disease had already developed, and most people died within a year of diagnosis (Federal Centre for AIDS, 1992). Many died of diseases such as pneumonia. Few lived long enough to develop the AIDS-related dementia which has since become an increasingly common manifestation of HIV disease (Federal Centre for AIDS, 1992).

The nature and course of HIV disease has changed. With testing, many individuals are being diagnosed while they are still well. Nowadays, many people with HIV disease can maintain their health and live 10 years or longer with the illness. For most of that time, they will be well and free of clinical symptoms, but still coping—psychologically and socially—with a communicable disease that remains potentially life-threatening (Federal Centre for AIDS, 1992).

Even for those who become ill, prognosis is much better. With available treatments, many will find illnesses more manageable. They will likely require less hospitalization and will, instead, seek treatment and support in the community. They will continue to work and be active socially. Thousands of Canadians are confronted with the challenge of living, knowing they are infected, and trying, by every means available, to slow the progress of the disease and find happiness in their lives. However, some also face the prospect of being seriously ill for prolonged periods of time (Federal Centre for AIDS, 1992). In conclusion,

changes in the diagnosis, treatment and progression of HIV have also changed the impact of the illness and the needs it creates. With the advances in managing HIV, many people no longer see HIV as a death sentence; they have hope for their future (Federal Centre for AIDS, 1992, p.1).

More and more people are coming into contact with HIV/AIDS, through infection or threat of infection, by knowing someone, or through being more aware of HIV/AIDS generally. I believe that HIV/AIDS affects everyone of us, directly or indirectly. While the focus of the present research is on individual persons with HIV/AIDS and their healing, individuals do not exist in isolation. Mehl (1988), a Native Indian shaman, expresses the notion of interconnectedness well: "All parts of the world are interconnected, on all levels of reality, so that whatever happens to one individual affects all others and whatever happens to the others affects the individual, at every level from the physical to the spiritual" (p. 129).

HIV and AIDS invoke cultural taboos—sex, homosexuality, drugs, death—thereby attaching to HIV/AIDS a profound stigma. This is an epidemic of discrimination (Blendon & Donelan, 1988). "People are being denied insurance as well as their fundamental rights to employment, housing, education, etc." (Pachuta, 1990a, p. 148). This stigma and discriminatory treatment of people with HIV/AIDS can play a significant role in their adaptation and response to their conditions. The Federal Centre for AIDS Working Group on HIV Infection and Mental Health (1992) has observed that the stigma, secrecy, religious taboos, heterosexism and discrimination are more devastating than the virus itself in terms of mental health. That is, the psychosocial environment needs changing. They write:

The mental health challenge in the second decade will be ending the isolation and breaking down the social, cultural, economic, psychological, organizational and structural barriers that

keep people affected by HIV from openly seeking and receiving the care, comfort and services they need (p. iii).

The language used to speak about HIV/AIDS is powerful because it can reinforce or breakdown the stigma. Anyone who talks about AIDS, particularly someone seen to have authority, must retain an awareness that how they speak about AIDS affects the way an individual with AIDS conceives the disease. And how an individual thinks about AIDS influences that person's response to it. Hence, for example, preferred terminology is persons or people with AIDS (PWAs), not "cases," not "sufferers," not "carriers," or any other impersonal, negative, or value laden term. As long-term AIDS survivor and political activist Callen (1990) writes: "We condemn attempts to label us as 'victims,' a term which implies defeat, and are only occasionally 'patients,' a term which implies passivity, helplessness and dependence upon the care of others. We are 'people with AIDS'" (p. 8).

### Organization of the Thesis

This thesis is for and about people with HIV/AIDS. The physical, psychosocial, and spiritual impact of HIV and AIDS are addressed in the following chapter, thus providing some background information for understanding the main issues facing people with HIV/AIDS. Chapter 3 is devoted to a discussion on healing. A review of the literature on counselling people with HIV/AIDS is the subject of Chapter 4. Chapter 5 describes the method of the present research. Chapter 6—five stories—is in two parts. The first part presents the stories of the participants in this research. The second part of the chapter is an analysis of the stories, primarily examining emergent themes. Implications for counsellors from the participants' stories, together with a reconsideration of the relevant literature, form the concluding chapter.

My philosophy on doing research concurs with that of Kirby and McKenna (1989) in the conviction that "we must include our own experience and understanding as part of doing research. This means that we must invest part of ourselves in the process of creating new information. We are an ingredient of our own research" (p. 7). Consequently, my own experiences, understandings, and assumptions are explicitly referred to throughout the thesis.



## HIV and AIDS—The Physical, Psychosocial and Spiritual Impact

AIDS does not inevitably lead to death, especially if you suppress the cofactors that support the disease. It's very important to tell this to people who are infected. Psychological factors are critical in supporting immune function. If you suppress this psychological support by telling someone he's [sic] condemned to die, your words alone will have condemned him [sic]. It simply isn't true that the virus is one hundred percent fatal.

Luc Montagnier (1988, p. 102), co-discoverer of HIV.

This chapter explores the physical, psychosocial, and spiritual impact of HIV and AIDS on people living with HIV/AIDS. The physical manifestations of HIV infection, the (variable) progression of HIV to AIDS, and HIV transmission are discussed. The comparative paucity of knowledge regarding women with HIV/AIDS is noted. The psychosocial issues are complex. Emotional responses experienced by people with HIV conditions are viewed in the context of the issues which set AIDS and HIV apart from other diseases. The impact of HIV and AIDS is also considered with regards to spirituality. The widespread belief that HIV infection is a death sentence is questioned. The media and heterosexism are seen as contributing to the stigma of AIDS and HIV and are therefore important to discuss.

### Physical Impact

**Physical manifestations of HIV infection.** The human immunodeficiency virus (HIV) was identified as the cause of AIDS in 1983 (International Development Research Centre, 1988). While HIV as the sole cause of AIDS has been challenged and further strains of HIV have been identified, it is generally believed that the virus attacks and progressively causes the body's immune system to fail. As the body's immune system is gradually disabled, the infected person becomes vulnerable to a range of opportunistic infections. Some of these, although not usually fatal, become lethal to a person with a compromised immune system.

People's response to the virus is variable. Some people with HIV infection decline quickly and die; some decline gradually with long periods of relative stability between acute episodes of illness; some regain good health after a serious illness; and some have not shown symptoms (AIDS

Vancouver, 1990). Nevertheless, the progression of HIV infection to AIDS is typically viewed in terms of stages along a continuum:

HIV infection    —>    HIV disease    —>    AIDS  
(no symptoms)            (with symptoms)

HIV may remain dormant for months or years; during this time infected persons may have no symptoms and show no signs of infection. For some, however, signs may become apparent soon after infection: fatigue, fever, swollen lymph glands, and perhaps a skin rash are typical symptoms in men (International Development Research Centre, 1988). These symptoms may disappear and subsequent stages may include the following: chronically swollen lymph nodes produced by hyperactivity of B cells; symptoms such as fevers, night sweats, weight loss, and oral thrush, and severe or persistent viral or fungal infections of the skin and mucous membranes; onset of opportunistic infections; a reduced T cell count; and organic mental disorders (delirium or dementia), with symptoms ranging from mild confusion, memory loss, and deteriorating thought processes to personality change, premature senility, and incontinence (International Development Research Centre, 1988). Additional cognitive and neurological deterioration may include lack of insight, poor judgement, disinhibition, and lack of co-ordination (Federal Centre for AIDS, 1992).

The onset of an opportunistic infection, indicative of a problem of underlying cellular immune deficiency, is the stage at which a diagnosis of AIDS is given. AIDS is the acronym for Acquired Immune Deficiency Syndrome, a syndrome being a number of symptoms and signs that occur together and constitute a distinct clinical picture. The terms HIV/AIDS and HIV condition are used to cover the gamut of manifestations of HIV infection, from asymptomatic (HIV disease) to AIDS.

Most AIDS experts agree that infection with the HIV virus alone will usually not result in full blown AIDS. Physical cofactors that appear to promote disease progression include drug use (legal and illicit), stress, excessive smoking, poor nutrition (Frutchey, Christen, & Rittinger, 1987), repeated exposure to HIV, and other concurrent viral infections (Kiecolt-Glaser & Glaser, 1988). Some of these factors may need to be present for a seropositive person (someone who has tested positive to the antibodies for HIV) to develop symptoms or AIDS. The co-discoverers of HIV—Luc Montagnier and Robert Gallo—support the notion of cofactors being necessary for

disease progression of HIV, and for transmission to be effective in the first place (Pachuta, 1990b). They also discuss multiple strains of HIV with differences in infectivity and virulence.

While HIV does not appear to be a sufficient condition for developing AIDS, recent evidence suggests that neither is HIV even a necessary condition for developing AIDS. The most provocative talking point at the 8th International AIDS Conference in 1992 was the reports of some men with AIDS who have no trace of HIV (Wong, 1992). According to Cohen (1993), the absence of a cure for AIDS has forced researchers to reexamine assumptions they once held without question and led to an open-mindedness in AIDS research. Aside from the lack of conclusiveness regarding the cause(s) of AIDS, a further limitation of the research cited above, like most research on the physical aspects of HIV/AIDS in North America, has been conducted with men.

**Women.** Women have been diagnosed with AIDS and HIV infection since the inception of the epidemic (Ybarra, 1991) yet they have been fewer in number in North America and less visible. Women are still excluded from most HIV/AIDS biomedical and psychosocial research, therefore we know only a limited amount about their unique concerns (Ickovics & Rodin, 1992). Women experience different symptoms to men (Denenberg, 1991a). Women also develop different opportunistic infections that are often not recognized as AIDS related and therefore many doctors do not suspect HIV infection (Byron, 1991). For example, Mitchell (1993) reports that HIV infected women appear to have high rates of pelvic inflammatory disease, chronic vaginitis and cervical cancer, which are not suspected of being related to AIDS. As a result many women are not diagnosed early and are not treated adequately. Many women with AIDS have been misdiagnosed during a series of illnesses and complaints and died without an AIDS diagnosis (Denenberg, 1991a).

The relatively scarce research attention on women with AIDS has no doubt contributed to ignorance about the impact of HIV/AIDS on women. Ickovics & Rodin (1992) advocate a critical need for more research with women, as sex differences in genetic and endocrine variables are likely to influence both viral exposure and the disease process. Furthermore, Denenberg (1991b) reports that women are prevented from participating in experimental drug studies either because

they do not have the social support required to make participation possible, or through restrictive entry criteria. Lack of women in experimental drug studies means that the effects on women—good or bad—which these drugs may have, remain unknown until women are prescribed these treatments, when they may be the only treatment option which exists for the specific condition, or for the underlying HIV infection (Denenberg, 1991b).

**Transmission.** Any human being is a potential host for HIV. HIV is carried in the blood and body fluids of infected persons. It can be passed from an infected person if the HIV-infected fluid enters the bloodstream of another individual. It is transmitted by: penetrative anal and vaginal intercourse; through unsterilized, contaminated hypodermic needles or instruments, through transfusion of infected blood or blood products; from an infected mother to her infant before or during childbirth, or through breast milk; and through transplanted organs or donated semen (International Development Research Centre, 1988).

### **Psychosocial Impact**

According to the Federal Centre for AIDS (1992), knowing that one is infected with HIV upsets the sense of balance that is crucial to mental health. Individuals with HIV/AIDS must face all the stresses associated with chronic and life-threatening illnesses, including concerns about their future, longevity and quality of life (Federal Centre for AIDS, 1992). As with any life-threatening disease, the individual will be coping with potential loss: of a future, bodily comfort and customary social roles and activities (Federal Centre for AIDS, 1992). According to Dilley et al. (1985), the most common and significant emotional reactions to receiving the diagnosis of AIDS are nearly identical to those of patients who are told they have other life-threatening illnesses, that is, feelings of numbness, betrayal, anger, sadness, and concerns about unfinished tasks in their lives which arise from life reviews.

However, because of the nature of the disease—the uncertainty that surrounds it in terms of progression and cure, the high mortality rate, and the fact that HIV can be a sexually transmitted disease—HIV has been seen to cause more distress than other life-threatening illnesses (Federal Centre for AIDS, 1992). Furthermore, about 44% of those diagnosed with AIDS are in their

thirties (Federal Centre for AIDS, 1991); many are at the beginning or peak of their careers and as yet have not accumulated wealth. Some may be forced to abandon their source of income and social support from the workplace, leading to poverty and a loss of self-esteem. People with less severe HIV/AIDS face decisions about taking care of their health at the expense of income. The reality is that most persons with AIDS become poor (McKillop, 1990). Those in the homosexual community may see many of their friends die of AIDS and thus experience the grief of multiple losses. For some, fear of revealing their lifestyle in relation to sexuality or drug abuse contributes to emotional distress. Kelly (1989), professor of psychiatry and chief, division of psychology, at the University of Mississippi Medical Centre, paints a vivid picture of HIV infection as different to other diseases:

In the case of most other illnesses a person with a serious illness will turn to other people. Those other people may make awkward responses, but they usually intend to be of help. With this illness, something else often happens. An individual who turns to a partner, friend, or family member, may find that potential source of support doing 180 degrees and leaving that support network.

Related to isolation are fear of abandonment and feelings of unloveability.

And there is anger. Anger at other people. Anger because someone gave me the virus. Anger at myself. Why did I do the things that I should not have done? Anger at the government and researchers and institutions. Frustration. Why are they not doing more? Why are the politics that affect us so greatly being developed by people who have never seen anybody with AIDS?

People become preoccupied with symptoms and hyper-vigilance. I've got a cough. Is it a cold or the beginning of pneumocystis pneumonia?

My life is being determined by a virus that I can't even see. I may feel well. What can I do? .... Do I have any influence over anything that is going on with me any longer? Feelings of helplessness are common (pp. 71,73).

In summary, while having HIV/AIDS involves facing a life-threatening situation as do some other diseases, the following issues sets HIV/AIDS apart: uncertainty about the course of the disease, treatment and curability; that it is sexually transmissible; the comparably young age of those contracting HIV, and associated financial concerns; the grief of the death of friends; the stigma; and heterosexism (to be discussed later). Because of the social stigma associated with HIV, infected individuals are often denied the comfort and support society gives to those who are seriously ill and this may negatively intensify the psychosocial consequences (Federal Centre for AIDS, 1992).

The psychosocial consequences experienced by men and women with HIV/AIDS as reported by the academic literature include depression, anxiety, suicidal ideations, fear of death and dying,

guilt associated with lifestyle and possible infection of others, frustration, anger, isolation and relationship disruption, preoccupation with symptoms, grief around loss of health, body image, sexuality, and childbearing potential, and perceived loss of control and a sense of helplessness (Atkinson, 1989; Beckett, & Rutan, 1990; Dilley, Ochitill, Perl, & Volberding, 1985; Dilley, Pies, & Helquist, 1989; Douglas, Kalman, & Kalman, 1985; Dunphy, 1987; Green, 1989; Kelly, 1989; Macks, 1989; Nelson, & Jarrett, 1987; Snowden & Cassidy, 1989; Spector, & Conklin, 1987; Ybarra, 1991).

Siegel and Krauss (1991) reframe psychosocial consequences into challenges. From their in-depth study that involved focussed interviews with 55 seropositive men, they identified three broad challenges covering eight issues representing adaptive challenges for HIV+ men. These challenges and issues are: [A] dealing with the possibility of a curtailed lifespan: (1) dealing with a sense of urgency to attain life goals, (2) deciding to what extent to invest in the future; [B] dealing with reactions to a stigmatizing illness: (3) deciding to whom to disclose their serostatus, (4) feelings of shame and contamination; and [C] developing strategies for maintaining physical and emotional health: (5) the need to take control of their health, (6) preoccupation with their body and health, (7) treatment decision making, (8) and maintaining emotional equilibrium.

The majority of men interviewed by Siegel and Krauss viewed their disease as likely to be progressive but not likely to follow a predictable timetable. They therefore felt the need to pick up their pace in trying to attain goals. Some of these men seemed to feel that attaining these goals would ensure that their life had meaning if they died. A number of the respondents questioned the value and the sense of investing time and energy in future goals. "These men typically reduced their career aspirations because of an unwillingness to expend energy and effort necessary to create opportunities to get ahead at some point in the future" (pp. 21-22). Many of the men seemed to have assimilated the societal stigmatization of the disease and felt devalued by their condition.

**Variability of emotional responses.** The responses and corresponding needs of people with HIV conditions vary depending on the HIV condition. The needs upon immediately learning of HIV infection will likely change over time. New needs may emerge if HIV-related symptoms

appear. Needs change with alternating periods of better health and deteriorating health, and when facing imminent death (Kelly, 1989).

People with HIV infection who are asymptomatic live with the fear of becoming ill. Without denying the reality of HIV, they must find a way to live fully. Many will have to change sexual and other behaviours to safeguard the health of themselves and others (Federal Centre for AIDS, 1992). When people living with HIV disease develop symptoms, the stresses change again. At this stage, some individuals become immersed in their medical care and most are looking for any treatment that may control the virus and prolong their lives (Federal Centre for AIDS, 1992). Many may also develop worries about housing, money, and legal affairs. In spite of the stress of being symptomatic, some individuals experience a sense of well-being (Federal Centre for AIDS, 1992).

Atkinson (1989) suggests that the emotional needs of people with HIV disease may be greater than those with AIDS because of the even greater uncertainty about what the future holds for them. Higher levels of depression, anxiety, somatization, hostility and lower global well-being have been found for people with HIV disease compared to people with AIDS (Tross & Holland, cited by Atkinson, 1989). Kelly (1989) has observed that persons with HIV infection who are asymptomatic tend to show greater anxiety and depression than people with symptoms. Responses and needs may also be affected by whether or not HIV positive persons suspected their infection and by the severity of HIV condition when they learn of their infection (Oram, 1990).

People with HIV/AIDS and their needs vary depending on life resources and stressors as well. This is not only a stage in the HIV continuum, but also in the individual's life. The Federal Centre for AIDS (1992) reports that being female, younger, less educated, a student, unemployed or unable to work, dependent on welfare or unemployment insurance, living with family of birth and not living in one's own place are significant factors for high psychosocial distress. Among people with AIDS in the United States, women are more likely than men to be poor, minority, and less connected to community organizations (Mays & Cochran, 1988) and thus more likely to be disadvantaged.

From her counselling of HIV positive gay men, Templeton (1990) reports that when gay men test HIV positive, many of the issues that confront them are not new, but the resolution of these

issues tends to become more compelling. Bor, Miller, Scher and Salt (1991) also view HIV/AIDS as "the entree to other problems, such as relationship problems. AIDS ... need not necessarily be the main problem nor the enduring problem" (p. 135). Prior and co-existing problems and social support are major factors in how people respond to HIV/AIDS. In general, the better people's existing social supports the better they cope with major life stressors, including HIV/AIDS (Kelly, 1989). People's ability to cope also depends on their belief systems (Federal Centre for AIDS, 1992).

### **Spiritual Impact**

The spiritual impact of HIV and AIDS on the people living with HIV/AIDS has been addressed by the Federal Centre for AIDS Working Group on HIV and Mental Health (1992):

HIV raises deeply spiritual questions about the nature of pain, the meaning of suffering, the connection between action and punishment, control, community, death and life after death. As with any terminal illness, HIV and AIDS highlights the human need for hope, empowerment and meaning in life....

Spirituality can be a source of strength, helping people with HIV ... deal with emotional stresses such as alienation, despair, fear of death, and meaningless, and with feelings such as a sense of belonging, presence, gratitude, joy and love.

HIV has caused spiritual turmoil and confusion ... [which] threatens the integrity of the self. Individuals must choose to either live with HIV disease or see it as a death sentence (p. 12).

Individuals with HIV are often torn between the desire to survive and the desire to die quickly, before the illness robs them of health, vitality and control. Living with HIV, individuals are often led to confront their existing systems of belief—and often they find them wanting. Although some religious institutions are responding to the needs created by HIV, many of those affected find their needs are not being met (and perhaps experience outright condemnation) and are looking to alternate sources of spirituality for support (Federal Centre for AIDS, 1992).

Whereas the majority of research literature documents people's negative experiences with HIV/AIDS, evidence is emerging that people with HIV/AIDS may also have positive experiences. These are addressed in the subsequent chapter on healing. The responses of people with HIV/AIDS influence and are influenced by societal attitudes. I now discuss three important related social issues: the conception that HIV infection is a death sentence; the role of the media in contributing to this conception; and heterosexism.



## HIV Infection as a "Death Sentence"

A disease once viewed as an automatic death warrant, is now in the process of becoming a chronic, potentially long-term treatable illness.

Zurlo & Lane (1990, p. 165), National Institute of Allergy and Infectious Diseases, Bethesda.

The widespread belief is that HIV infection inevitably leads to AIDS which inevitably leads to death. While many HIV-infected people have developed AIDS and subsequently died, this progression may not be inevitable.

According to John-Roger and McWilliam (1989), the initial prediction that everyone infected with HIV is destined to get AIDS was based on a biased cohort from San Francisco. In 1978, blood was taken from thousands of patients and stored as part of a study on hepatitis. When, in 1984, the test for the HIV antibody status was discovered, an experiment was begun on 5,000 homosexual men whose 1978 stored blood showed the presence of the HIV antibody. By 1988, 48% of the people who had the HIV antibody in their blood in 1978 had developed AIDS (John-Roger & McWilliam, 1989; Pachuta, 1990b). That is, more than half of the men studied had not developed AIDS after ten years. As John-Roger and McWilliam point out, a disease tends to affect the weakest and/or most susceptible portions of a population first. Furthermore, the majority of the people in the study had a history of sexually transmitted diseases, higher drug use, and possibly repeated exposure to the virus before the risk of unsafe sex was known. These factors are likely to have exacerbated disease progression. Moreover, for six years these particular men did not have the awareness of their HIV infection, a knowledge which *might* have inspired health-promoting changes. On the basis of these considerations, John-Roger and McWilliam conclude that it is erroneous to say that HIV inevitably progresses to AIDS.

Various studies have attempted to estimate the time interval between HIV seroconversion and AIDS, despite the limitation of uncertainty about when seroconversion actually occurred with many subjects. The most recent estimate of the median incubation period is 9.2 years, based on 348 homosexual and bisexual men (Hendriks, Medley, van Griensven, Coutinko, Heisterkamp, & van Druten, 1993). The authors state that their results are in agreement with other homosexual/bisexual cohort studies, yet a median as high as 11 years has been reported, based on 1861 homosexual men (Munoz et al., 1989).

A study of hemophiliacs found the incidence of AIDS to be 26 percent eight years after antibody seroconversion (Eyster, Ballard, Gail, Drummond, & Goedert, 1989). Another study found the incidence to be 25 percent after nine years (Goedert et al., 1989). The latter study showed a marked difference with age, the incidence being higher with increased age, suggesting the influence of age-related immune functioning and/or cofactors. The cofactor theory of AIDS infers that an HIV-infected person is not necessarily doomed to develop AIDS.

Nowhere in the scientific literature did I find any statement or evidence that progression to AIDS is 100% likely. The conclusion of Hendriks et al. (1993) is that there is "insufficient information to be able to estimate accurately the probability of never progressing to AIDS" (p.237). Lui, Darrow, & Rutherford (1988) state that the *maximum* likelihood estimate for the percentage of infected homosexual men developing AIDS is 99%. This implies that almost all HIV-infected men will eventually develop AIDS if they do not die from other causes, but not all. At the very least, some people are remaining healthy 10—15 years after HIV infection (Buchbinder, Mann, Louie, Villinger, Katz, Homberg, 1993).

Regarding the progression from AIDS to death, the following report was mailed to every U.S. household from the Surgeon General:

**AIDS: The present situation**

[A]bout half ... [of] the number of persons known to have AIDS in the United States ... have died of the disease. Since there is no cure, the others are expected to also eventually die from the disease (Callen, 1990, p. 18).

While the prevalent belief is that AIDS is invariably fatal, this prediction has clearly been, and continues to be questioned. There are a small but growing number of individuals who are alive and well three or more years after an AIDS diagnosis (Callen, 1990; Solomon, Temoshok, O'Leary, & Zich, 1987). Having lived with AIDS for three or more years is how the U.S. Centres for Disease Control (CDC) define a long-term survivor. The choice was somewhat arbitrary, basically a doubled median survival, which was around 18 months (Callen, 1990). More recent figures (Lundgren et al., 1993) give a median survival of 17 months, with an estimated 3 year survival of 16%.

As a long-term survivor of AIDS himself, Callen (1990) has researched the issue extensively. He is one of twenty-five out of 1,049 Americans diagnosed with AIDS during 1982

who were alive when he published his book on long-term survivors in 1990. After carefully investigating the three major studies of long-term survivors in the U.S., the only figures Callen confidently reports, are 9.7% of those diagnosed in San Francisco between 1980 and 1985 survived three or more years; that is, one out of every ten earned the title of long-term survivor. The percentage drops to 3% surviving five or more years. Callen concedes that these percentages are low, but expects them to rise as our knowledge about managing the disease increases. In a national CDC study, a few of the long-term survivors were found to have immune functions in the normal range. Many of the others were doing well, even though they still had continued evidence of T-helper cell depression. Most of them were totally functional (Callen, 1990). The longest living person with AIDS in my knowledge is a New York man who was reported in 1992 as having lived a full productive life since diagnosis nearly ten years ago (Pfeiffer, 1992).

Statistically, the long-term prognosis for people with AIDS is poor, but not absolutely hopeless. Regarding the expectation that HIV inevitably leads to AIDS and consequently death, Gallo, co-discoverer of HIV, cautions against the unscientific practice of making predictions without proof, *especially considering the impact it may have on people with HIV/AIDS* (Pachuta, 1990b).

## The Media

The media has contributed to the conception that HIV infection and AIDS are invariably fatal. An editor's or reporter's choice of words can emphasize doom.

When virtually every newspaper and magazine article, every radio and television broadcast about AIDS explicitly or implicitly reinforces the message that AIDS is invariably fatal, the media clearly bears a responsibility for the public's perception of AIDS as an automatic death sentence (Callen, 1990, p. 52).

Sensationalist, fear-invoking stories on HIV/AIDS in newspapers have become less frequent, but not absent. The fatalism is reinforced by headlines such as "AIDS kills three who received transplants from infected man" (Associated Press, 1991, May 17). The article was grossly misleading because it failed to report crucial information; firstly, the donor had twice tested negative for HIV (not conclusive, however); secondly, organ recipients usually receive a blood transfusion during or after such an operation and when the transplants took place, in 1985,

transfusions were a risk factor for AIDS; and thirdly, highly immunosuppressant drugs are given to all donor recipients (Nicholson, 1991). Nicholson asserts that such irresponsible journalism contributes to the belief in the vastly oversimplified equation of HIV = AIDS = DEATH, thereby adding to the burden of those with HIV/AIDS.

In a detailed critique of the media's response to AIDS, Kinsella (1989) states that the media would typically feed on the public's fears and misinform with errors of omission and misguided emphasis. Such misinformation is particularly alarming because, according to a recent telephone survey, people in Vancouver and the Lower Mainland get their information on AIDS from the newspaper more than any other source (Wagman, 1991). Furthermore, the ineffectiveness of the early drinking and driving campaigns indicated that fear fuels denial, rather than increasing awareness (Poole, 1990). Seen in this light, such media coverage is dangerous and irresponsible, leading individuals to deny their own sense of risk of HIV contraction.

A more recent article marking a decade of AIDS inspired greater hope at first glance. Prompted by Rick Marchand, education coordinator at AIDS Vancouver, a Vancouver Sun reporter tells some of the story of a long-term survivor (McMartin, 1991). Joe Ford was diagnosed with AIDS seven years ago, in 1984, and exhibits no outward signs of disease. However, upon closer examination, the story could have been more optimistic (and less sensationalistic) if it had begun with something other than "He is the anomaly" (p. 1). The truth is that there is more than one such anomaly. In addition to the misconception that HIV conditions are inevitably fatal, another aspect of the mythology that surrounds HIV/AIDS appertains to heterosexism.

## Heterosexism

While other sexually transmitted diseases are stigmatized, what exaggerates the stigma for persons with AIDS and HIV infection is heterosexism. Heterosexism is prejudice or discrimination against non-heterosexuals on the grounds of sexual orientation. The term heterosexism is used in place of a perhaps more commonly invoked notion of homophobia—the dislike or fear of homosexuals and homosexuality and characterized by negative attitudes and behaviours towards gays and lesbians (Canadian AIDS Society, 1989). Preference for the term heterosexism over homophobia is well-argued by Neisen (1990): Heterosexism identifies more accurately the

problem—discrimination and prejudice against gay men and lesbians—and the origin of the prejudice, “forcing heterosexuals to confront their own bigotry” (p. 37). Heterosexism is also more consistent with the language of oppression (e.g., sexism, racism, etc.). Furthermore, homophobia is not a true phobia. Finally, Niesen argues, use of heterosexism leads the way from victimization to survival for lesbians and gay men, by directing their anger outward to heterosexual individuals and institutions rather than inward, where it can lead to self-destruction.

Heterosexism is pervasive in all aspects of contemporary Canadian society. In a survey of 36,000 young Canadians, for example, 50 percent of male adolescents felt that homosexuality was “wrong” (Federal Centre for AIDS, 1992). In a position paper on homophobia and AIDS, the Canadian AIDS Society (1989) states that AIDS in fact was originally defined within a context of homophobia and racism.

Overcoming homophobia and clearing up the predominant misconception that there is a link between homosexuality and AIDS are two of the difficult tasks that must be undertaken in order to ameliorate the impact of AIDS (p. 1).

The paper points out that individual attitudes and responses to people with AIDS reflect deep-seated cultural and historical assumptions about the relation of disease to otherness and deviance:

Plagues and epidemics have always been read as metaphors for evil ... It is hardly surprising that AIDS is frequently seen as punishment for ‘violators of morality.’ Furthermore, disease has regularly been seen through history as inseparable from *other-ness*, from *foreign-ness*, from the *not us*. (pp. 7-8).

Results from Los Angeles Times polls found that about about a quarter of the people who responded agreed that AIDS is God’s punishment for a homosexual lifestyle (Herek & Glunt, 1988). As more of the public has come to recognize that AIDS affects all of us—HIV is not selective—concern, education, and government funding have increased. In the North American media, interest and coverage increased only when AIDS was perceived as a threat to “mainstream” citizens (Kinsella, 1989).

Numerous studies and polls have reported heterosexist attitudes and behaviours in the AIDS context (e.g., Dowell, Lo Presto, & Sherman, 1991; see Herek & Glunt, 1988). Males are found generally to be more homophobic and less empathetic than females (Dowell et al., 1991). Not only has heterosexism negatively affected the general public’s view of people with HIV/AIDS, but it has also influenced the health professionals who are caring for these people. Studies conducted in the

United States have consistently shown negative attitudes among health care workers towards homosexuality, ranging from indifference to outright hostility (e.g., Fish & Rye, 1991). A 1982 study of physicians indicated strong homophobic attitudes among nearly one quarter of respondents; 30% would not admit qualified homosexual applicants to medical school; 40% would discourage homosexuals from pediatrics and psychiatry; and 40% expressed discomfort with gay and lesbian patients (Duprey & Margo, 1988).

Kelly, St. Lawrence, Smith, Hood and Cook (1987) also found significant levels of homophobia among health care workers. 157 physicians responded to two case vignettes which were identical except that one was a heterosexual patient suffering from leukemia and the other a homosexual diagnosed with AIDS. Physicians reported much less willingness to interact with the AIDS patient, even when there was no risk of HIV transmission; the AIDS patient was considered more responsible for and deserving of the illness, and less deserving of sympathy, than the leukemia patient. A similar, more complex study found that homosexuals were perceived as being more personally responsible for their illness and less interactionally desirable than were heterosexual patients regardless of the diagnosis (Triplet & Sugarman, 1987). Nearly 10% of physicians and nurses in another study agreed with the statement that homosexuals who contract AIDS are getting what they deserve. 32% acknowledged that patients with AIDS receive inferior care compared to patients with other illnesses (Douglas, Kalman, & Kalman, 1985).

Gaining treatment in the first place may also be a problem. The results of a recent survey of 548 Toronto medical students are disturbing (Toughill, 1990). Not only were 70% found to have a negative view of homosexuals, but almost half felt that medical students have the right to refuse to treat HIV-infected patients. Most of these medical students had an unrealistic fear of being infected.

These attitudes do not go unnoticed by AIDS patients (e.g., Dilley, Ochitill, Perl, Volberding, 1985; Rosse, 1985). Feelings of isolation may be magnified for AIDS patients in a hospital:

... several patients saw their worst fears mirrored in the exaggerated behaviour of some of the staff: doctors standing at arm's length when talking to them, nurses shying away from anything but brief physical contact. Some patients even became aware of staff members who at times refused to come into their rooms at all (Dilley et al., 1985, p. 84).

Treatment has improved since Dilley wrote the above description in 1985, but the heterosexism evident from the studies cited earlier suggest that ignorance is still present. All people with HIV/AIDS may be affected by heterosexism. Individuals who, because of their sexual orientation or drug use, were already marginalized have become more so (Federal Centre for AIDS, 1992). Heterosexual women and men may be reluctant to seek help from community based HIV/AIDS organizations for fear of being identified with the gay community (Federal Centre for AIDS, 1992). Atkinson states the case clearly: "These attitudes must be identified and overcome if truly humane health care is to be provided and to be seen to be provided for people who have reason to be wary of the institutions of society" (p. 132).

A change in attitude may be effected through education. In a study that examined the effects of an educational film on AIDS, Pryor, Reeder, and McManus (1991) found that attitudes toward interacting with an HIV-infected co-worker became more favourable as a result of the film, but only among prohomosexual subjects. The attitudes of homophobic subjects did not change. This research implies that homophobic attitudes will need to be vanquished in order for AIDS education to be maximally effective.

Heterosexism and homophobia are not limited to heterosexuals. Gay men, lesbians and bisexuals may accept and internalize the negative stigmatized view of homosexuality that they find perpetuated in society. Internalized homophobia is characterized by turning negative attitudes, emotional responses and behaviours against oneself (Canadian AIDS Society, 1989). Gay men, lesbians and bisexuals may therefore devalue themselves and not expect the fair treatment that is their right.

Expressions of homophobia have increased since the advent of AIDS (Dowell, Lo Presto, & Sherman, 1991; Douglas, Kalman, & Kalman, 1985). Lesbians, bisexuals and gay men may suffer as a result of "AIDS-assisted homophobia" (Douglas, Kalman, & Kalman, 1985). It is possible that the outward expression of heterosexism may contribute to the movement toward acceptance and validation of the gay, bisexual and lesbian reality. On this more positive note I turn to the next chapter, on healing. Bear in mind the physical and psychosocial issues discussed above, thus describing the context of healing for people with HIV/AIDS: the characteristic, yet

variable, physical and emotional responses; that HIV infection is widely believed to lead to AIDS and then death; and heterosexism.



## Healing

Like some rabid animal, AIDS picked me up by the scruff of my neck, shook me senseless, and spat me out forever changed. I am today a totally different person than I was when the decade and the epidemic began. AIDS has been a cosmic kick in the ass—a challenge to *finally* begin living fully (p. 2).... While I would never have wished for AIDS, the plain truth is that I'm happier now than I've ever been. Having AIDS has been like going through ten years of therapy—every week (Callen, 1990, p. 10).

AIDS is new; healing is not. The concept of healing has been around for centuries, but what is it? This chapter explores that question. Healing is here viewed within the context of health and disease as defined by Western medicine and alternatives. Scientific and intuitive approaches are considered with respect to the question: What do you do for your own healing? The final part of the chapter reviews the research into long-term survivors and others who report doing well with AIDS.

### What is Healing?

The verb to heal is defined by the Oxford dictionary as, "become sound or healthy again, cause to do this; right (differences etc), alleviate (sorrow etc); archaic cure." This definition implies physical and/or non-physical improvement. Healing may be perceived as a physical, psychological, or spiritual phenomenon, or any combination of these. Health and the phenomenon of healing have meant different things in different ages. What is meant by health and healing, Capra (1982) says, depends on one's view of the living organism and its relation to its environment. As these views change from one culture to another, and from one era to another, the concept of health and healing also change. Contemporary Western society predominantly defines health and healing in physical terms and accordingly turns to scientifically based medicine for disease treatment.

Healing may be viewed as incorporating the mind as well as the body. Research in the new medical field of psychoneuroimmunology demonstrates the connectedness of mind and body by measuring the effects of attitudes and emotions on the immune system (e.g., Kiecolt-Glaser & Glaser, 1988). The influence of psychological factors on physical health is now well documented

and being integrated into practice through such methods as visual imagery (e.g., Krippner, 1985; Achterberg, 1989). For example, measurements of the blood, saliva and urine of participants before and after experiments involving imagery, found that positive (happy) imagery increased immune functioning while negative (sad) imagery decreased immune functioning (Cousins, 1990). It is on the basis of these kinds of studies that some researchers in psychoneuroimmunology have concluded that healing may be productively understood as having significant psychological dimensions.

The concept of spiritual healing is fundamental to many cultures around the world, including many First Nations peoples. Whereas Western medicine aims to return an ill person to the state of health held prior to the illness, some First Nations shamanic healing, for instance, may aim for a spiritual transformation (Lawlis, 1988), "a change in perspective of the world, a shift in understanding of that person's role in nature and his or her relationship to it (p.140)." In Western society, pastoral care of persons with HIV/AIDS may focus on spiritual healing. As one Roman Catholic priest puts it: "Spiritually, persons with AIDS experience a profound need for meaning and hope. [If and when f]aced with physical debilitation and psychological and social losses, they must rediscover a reason for living and a sense of self-worth" (Dunphy, 1987, p. 58).

Healing may also be considered as an integration of physical, psychological, and spiritual dimensions. Thirty-seven physicians, psychologists, nurses, metaphysical healers and shamans were asked about healing by Carlson and Shield (1989). Most of the respondents indicated that healing is a movement toward wholeness, or harmony of body-mind-spirit. For example, Kübler-Ross (1989) writes: "Healing means achieving a balance between the physical, emotional, intellectual, and spiritual dimensions" (p. 129). The definition of health given by the World Health Organization in the preamble of its charter conveys the holistic nature of health [and thus healing]: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (Capra, 1982, p. 124).

The discussion so far has implicated healing as an intrapersonal experience and this may be inadequate. Duprey and Margo (1988) assert that the ongoing perceptions of deviance in the AIDS epidemic is encouraged by the intrapersonal focus of Western medicine. Alternatively, sociology

considers disease as an outcome of a social system. Healing, therefore, may involve the entire social world of any particular person.

Capra (1982) acknowledges that the biomedical model of Western medicine does not govern all practitioners and that the "art of healing" is still widely practised both within as well as outside medicine. However, healing is not explicitly acknowledged in our medical institutions and thus the major arenas of research. "The phenomenon of healing will be excluded from medical science as long as researchers limit themselves to a framework that does not allow them to deal significantly with the interplay of body, mind, and environment" (p. 141). Given the lack of attention that healing has received in medical science and the various ways that it may be construed, healing is difficult to define in an academic paper. Achterberg (1988) speaks on another aspect of the disfavour of the word healing:

The word *heal* and all its derivatives are naughty words in modern medicine, where *healer* is synonymous with *quack* ... a person's own natural abilities to heal ... are given scant recognition in terms of research, nor are they generally credited with bringing about recovery. Spontaneous remission is shrugged off as an anomaly, the placebo effect is viewed as a pest in research, and any disease that does not conform to statistics is widely classified as a misdiagnosis, a temporary remission, or just plain hysteria. Healing, indeed, is not popular (pp.118-119).

Discomfort with the word healing in medical science and academia arises because it tends to be viewed as incorporating more than the physical dimension and is therefore less amenable to scientific scrutiny. Present day scientific inquiry may not be equipped to consider the complex range and variety of factors contributing to healing. Perhaps what may prove as important as purely organic factors will be what healing means to those seeking to cultivate it. It is from this standpoint that I here define healing in broad terms, allowing for subjective construction. Allowing the assumption that subjective experience may be a significant constitutive factor in health promotion, for the purpose of this study healing will be defined as enhancing the subjective experience of the quality of life. That said, one aim of the present research is to gain an understanding of what healing means to the participants. Knowing this may give clues as to how counsellors can facilitate healing with these and other clients with HIV/AIDS.

Healing addresses fundamental issues of health and disease. It may be conceptualized within the context of a broader philosophy, which includes how we understand health and disease. While

disease is a universal experience, each social group classifies it as to cause and cure. In Western medicine, the dominant paradigm aims to cure disease with drugs and surgery, although alternatives exist and are gaining popularity.

### Western Medicine and Alternatives

The film "Men Don't Leave" is the story of a Western suburban family. The movie opens with a young boy running home from school, fearing the coldness of the snow, the descending darkness, and being alone. He arrives home, collapses into a big chair by the open fire; his Mum brings him a hot drink while his Dad massages his feet—"And I was saved," he says to himself. The boy looks to his family for security and safety. As we grow older we can continue to look outside of ourselves for salvation. Medical doctors have been targeted as saviours in Western society. Capra (1982) writes that the notion of the organism's inherent healing power is minimally acknowledged in medical science. Trust in one's own organism is rarely promoted, but rather we are encouraged to give away our power to doctors; society generally is "spellbound by the mystique that surrounds the medical profession" (p. 158). Yet modern medicine has limitations.

**Disease.** Western medicine typically views diseases as problems to be repaired, much like an auto mechanic deals with a broken down car (Friedman & DiMatteo, 1989). According to Capra (1982), the influence of the Cartesian paradigm on medical thought resulted in the biomedical model. Within the biomedical model, the human body is regarded as a machine that can be analyzed in terms of its parts; disease is seen as a malfunctioning of biological mechanisms which are studied from the point of view of cellular and molecular biology; the doctor's role is to intervene, either physically or chemically, to correct the malfunctioning of a specific mechanism.

Capra speaks of the limitations of this model:

By concentrating on smaller and smaller fragments of the body, modern medicine often loses sight of the patient as a human being, and by reducing health to mechanical functioning, it is no longer able to deal with the phenomena of healing.... Although every practising physician knows that healing is an essential aspect of all medicine, the phenomena is considered outside the scientific framework; the term "healer" is viewed with suspicion, and the concepts of health and healing are generally not discussed in medical schools (pp. 123-124).

The reason for the exclusion of the phenomena of healing from biomedical science, Capra argues, is because it cannot be understood in reductionist terms. This applies to the healing of

wounds, and even more to the healing of illnesses, "which generally involve a complex interplay among the physical, psychological, social, and environmental aspects of the human condition" (p. 124). Nonbiological circumstances are thus commonly ignored in the practice of medicine from the biomedical approach, thereby limiting the large network of phenomena that influence health.

Some health professionals, however, interpret the concept of fixing disease as going against the body itself and suggest that disease may be seen as a signal for attention, as a way of making us aware of imbalance in our lives. Dafter (1990) argues that in many different arenas—earlier Western civilization, Buddhist cultures, First Nations cultures, and Jungian mind-body healing—sickness and suffering are considered to be a normal part of life that force constructive reevaluation. "Healers from these ancient traditions worked compassionately to help patients undergo a transformative journey, during which a new relationship to life was acquired" (p. 29). The zeal to cure physically was not as great as in Western society today; spiritual factors, which were thought to have a more permanent, eternal quality, were held to be equally important to, if not more than, one's physical condition. Yet it may be argued that the unavailability of alternatives made spirituality the primary focus of intervention (deCastell, 1991). Dafter asserts that as medicine evolved into its present form the soul and personality variables were discarded in favour of pharmacologic and surgical treatments.

**Drugs.** The search for a cure and an effective vaccine against HIV have not yet been successful. The hope of success in Western medicine lies in attacking and destroying the virus itself. Occasionally a "miracle treatment" hits the media; for example, a blood heating treatment claimed promise in 1990. In the meantime, medical treatment of HIV/AIDS tends to be of three types: preventive treatment of disease (e.g., PCP prophylaxis), drugs aimed at slowing down immune system deterioration (e.g., AZT), and treatment of opportunistic infections as they arise (e.g., antibiotics for cryptococcosis).

The effectiveness of drugs is limited. Owen's (1987) opinion is that: "All a drug can do is make you more comfortable. Temporarily. For a little while. But the drug can't heal you. Only your body can do that" (p. 200). Consider how freely many pain killing drugs are prescribed and ingested. Such drugs may conceal pain without correcting the underlying cause, by deadening the

mechanism in the body that alerts the brain that something is wrong. The conditioned response to pain in our society is to get rid of it by reaching for the painkiller, as if the pain were evil. An alternative perspective on pain, as with disease, is to consider it as an integral indicator of health. Cousins (1979) considers pain to be, "part of the body's magic... both the warning system and the protective mechanism that enables an individual to defend the integrity of his [or her] body" (p.107). Capra (1982) sees the limitation of the biomedical model exemplified in how it deals with pain:

To understand pain, and to be able to alleviate it in the process of healing, we must see its wider context, which includes the patient's mental attitudes and expectations, belief system, emotional support from family and friends, and many other circumstances. Instead of dealing with pain in this comprehensive way, current medical practice, operating within the narrow biomedical framework, tries to reduce pain to an indicator of specific physiological breakdown. Most of the time pain is dealt with by means of denial, and is suppressed with the help of pain killers (pp. 142-143).

Aside from obscuring a potential message, some drugs may be destructive. When malformed babies were born to mothers who had ingested thalidomide to relieve morning sickness, people questioned the benefits of drugs. Drugs may be administered without full knowledge of their effects. The comparative newness of AIDS and the desperate time-pressured search for a cure makes people with HIV/AIDS more than usually willing to risk experimental drugs.

**Challenging the assumptions and procedures of Western medicine.** For centuries it was believed that drawing blood from patients was essential for recovery from virtually every illness. Now we see the ignorance in such a practice. Which of the present medical practices will be viewed as useless or even destructive one hundred years from now? In *AIDS, the straw on Western Medicine's back*, Rossoff (1988) expects that the present AIDS crisis will force people to look deeper into the meaning of "sickness," "healing," and "health."

Lewis Mehl (1988) has an interesting story to tell. He grew up observing Cherokee and traditional Appalachian folk medicine. Later in medical school, he was amazed to learn that healings which seemed commonplace in his background were viewed as miraculous from the contemporary Western medical perspective. The professors simply did not believe his childhood experiences. Mehl concluded that modern medicine was lacking an adequate concept of healing and the spiritual base from which healing occurs.

There are progressive physicians who are no doubt frustrated by the pervasiveness of the biomedical dogma amongst the public (Capra, 1982). Doctors who try to explain their patients' symptoms to them and relate illness to their living habits may find patients not satisfied with that approach. Many patients may not be content until they have a prescription in their hands. To change the dominance of the biomedical model, which, according to Capra (1982) has acquired the status of a dogma, he writes:

To adopt such a holistic and ecological concept of health, in theory and in practice, will require not only a radical conceptual shift in medical science but also a major public reeducation. Many people obstinately adhere to the biomedical model because they are afraid to have their lifestyles examined and to be confronted with their unhealthy behaviour (p. 162).

Because AIDS is life-threatening and at present has no medical cure, many persons with HIV/AIDS are searching beyond the bounds of Western medicine with its limited focus on the physical realm. Consider again the case of Carol, the Ojibway Native whose story was briefly told in the opening chapter. Carol's doctors concluded that medical technology could not keep Carol alive. Carol and the millions of other people infected by HIV worldwide pose a profound challenge to the medical community. I believe that meeting the challenge will involve reassessing the fundamental assumptions and procedures of Western medicine.

Lying at the roots of Western medicine is the tradition of Hippocratic medicine that was developed twenty-five hundred years ago (Capra, 1982). Modern Western medicine has departed from Hippocratic philosophy—a philosophy which emphasizes the fundamental interrelation of body, mind, and environment. Health, according to the Hippocratic writings, requires a state of balance among environmental influences, ways of life, and the various components of human nature (Capra, 1982).

As far as healing was concerned, Hippocrates recognized the healing forces inherent in living organisms, forces he called "nature's healing power." The role of the physician was to assist these natural forces by creating the most favourable conditions for the healing process (p. 312).

In 1982 Capra wrote that he was observing a holistic systems approach to health and health care re-emerging. This approach is in harmony with many spiritual traditions and the Hippocratic tradition and seems to be gaining favour. It recognizes health as a multidimensional phenomenon involving interdependent physical, psychological, social, and environmental aspects. The systems

concept implies continual activity and change, reflecting the organism's response to environmental challenges. A systems perspective implicates that what is unhealthy for the individual is generally unhealthy for the society and for the embedding ecosystem (Capra, 1982).

**Healing and curing.** One assumption to question is the link between healing and curing. In Western medicine, healing and curing are seen to be synonymous; they both mean the remission of physical symptoms and staying alive. Just as a mechanic aims to keep cars on the road, the major goal of Western medicine is to keep people alive (Friedman & DiMatteo, 1989). The preoccupation with keeping people alive is illustrated by the provincial health minister's placement of AIDS as twelfth on the list of health concerns; twelfth, because it was the twelfth highest cause of death in the province (Craik, 1991). The preoccupation of keeping people alive in the Western medical approach is challenged by Mehl (1988), who writes: "We do not know whose time it is to die, so no assumptions are made to that effect" (p. 127). However, Mehl asserts that healing always involves a death and transformation of some part of the person.

Furthermore, healing and curing may be two different entities. In many First Nations cultures, healing bears little resemblance to the remission of physical symptoms. It refers, rather, to establishing harmony with the world—intuitively perceiving the interconnectedness of all beings in the universe (Houston, 1987; Achterberg, 1987). When this happens, physical healing may or may not be observed, and the patient may well die. "The course of life or death is irrelevant, for these are only different experiences along the continuum of existence" (Achterberg, 1988, p. 119).

A similar view is held by Stephen Levine (1987), who adopts an Eastern meditative approach for working with the dying. Levine speaks of healing into life *or* death, having observed numerous people finding peace through a spiritual healing, some of whom became physically healthier, while others died. Healing may mean a miraculous remission of the illness or it may involve dying with a sense of peacefulness.

**The cause of HIV/AIDS.** The cause of HIV/AIDS can also be viewed from different perspectives. While the prevalent belief is simply that a physical entity—HIV—invades the body, some theories focus on a spiritual explanation. According to Dossey (1988), modern medical



science is based on "an outmoded mechanistic view of reality in which the only worthwhile causal explanations are regarded as purely physical ones, whereas shamanism offers a more realistic appreciation of the role of many levels of reality in the process of illness" (Dossey, 1988, p.86).

Achterberg (1988) writes:

disease is inevitable if life loses meaning and one forgets the feeling of belonging and connection (disharmony). Similarly, a chronic sense of fear will cause a person to lose the love, joy, and trust which are basic foundations of health and without which the force of life itself seems to begin withdrawing from the body.

Soul loss is regarded as the gravest diagnosis in the shamanic nomenclature, being seen as a major cause of illness and death. It is not referred to at all in our modern Western medical books. It is becoming increasingly clear that what the shamans refer to as soul loss—that is, injury to the inviolate core which is the essence of a person's being—does manifest as despair, immunological damage, cancer, and a host of other very serious disorders (p. 121).

A shamanic approach to healing will therefore address these metaphysical concerns and be less interested in expelling the virus by physical means. The body is, however, a source of great wisdom, according to the medical practitioner and shaman, Mehl (1988):

When we walk too far afield from our own true nature, illness arises as an alarm that we must get back onto our own path of destiny. Healing produces that return. The body is wonderfully wise. It is modern culture that has taught us to ignore our bodies. Shamanic treatment requires listening to the unique wisdom of each individual body, not blindly following rules made by the mind... For the body is a part of the earth. The body is the earthly home of our soul. It knows more about life on earth than the mind. When in doubt, ask the body (p. 137).

Attending to the individual's sense of subjective well-being rather than just emphasizing biomedical changes, appears to be gaining in popularity and credibility. Now, many health care providers are taking a holistic perspective and seeking to consider the total person. Dafter's (1990) writes: "Modern-day biomedicine is rediscovering the soul as an important factor in the treatment of cancer and other physical diseases" (p. 24). Blum (1985) reports that the potential for patients' physical health improvement is greater when the health provider's perception extends beyond the focus on physical symptoms and disorders and includes attention to the patients' psychological and emotional needs. As a medical practitioner, Owen (1987) speaks of his frustration with being trained only to treat symptoms instead of root causes. Owen is one of many physicians who have incorporated alternative/complementary treatments with their patients.

**Alternative/complementary treatments.** During the past two decades, the term holistic has been applied to refer to medical therapies and therapists emphasizing the whole person,

including body, mind and spirit, in contrast to the emphasis in Western medicine on the body. Acknowledging that no one treatment may be the total answer, some practitioners call themselves practitioners of complementary medicine, implying that these approaches may be added with benefit to Western medical methods. A treatment that does not fall within mainstream Western medicine may be referred to as an alternative treatment.

Complementary therapies are characterized by: (a) existing outside the Western medical repertoire, (b) requiring a relatively active participation by the consumer, and (c) taking into account the whole person as the context for the illness being treated (Strawn, 1989).

Complementary therapies attempt to tap human resources for healing that are often ignored by Western medicine. The focus is on improving the quality of life; cure is not guaranteed and not necessarily the primary goal. The responses of physicians to complementary therapies range from wholehearted endorsement to disregard. The majority view them as harmless treatments which may, however, result in physical or psychological advantage (Maryland Medical Journal editorial board, 1990). This suggests that any physicians may be disinclined to advocate such therapies simply in view of their expectation of negligible physical effects.

The shift towards a holistic approach to treating people is congruent with Capra's (1988) understanding of a change in worldview that he suggests is currently underway. Capra asserts that the epistemological paradigm that is under review and is now receding has dominated Western culture for several hundred years. Among other ideas and values, this paradigm incorporates a view of the universe as a mechanical system and the view of the human body as a machine. Capra argues that the high value this worldview places on separateness is a serious error in perception of reality, because it fails to reflect the harmonious interrelatedness physicists observe in nature. The new paradigm that is now emerging, says Capra, is a holistic worldview, regarding the world as an integrated whole rather than a disassociated collection of parts.

The effectiveness of alternative treatments has been reviewed by Reuben (1986), who gives evidence of the beneficial effects for persons with HIV/AIDS of: acupuncture; vitamin C and other supplements; chiropractic; diet (e.g. macrobiotics); exercise; herbs; homeopathy; psychotherapy; spirituality; massage, acupressure and other forms of touch techniques; and visualization and

guided imagery. Other treatments cited elsewhere include humour, expressing emotions, dreamwork, drawing, writing, meditation, biofeedback, progressive relaxation, hypnosis, yoga, crystals. How do you choose amongst all these alternatives? What works? What works for a particular individual? There seems to be no single treatment or behaviour that is universally valuable (Callen, 1990).

### **What To Do For Your Own Healing?**

How do you know what to do for your own healing? The two perspectives explored in this chapter are a scientific approach and an intuitive approach. A scientific approach relies on positivism—randomly select from the population of interest, experiment against a control group, and compare the results of the two groups. On the other hand, an intuitive approach relies on personally directed decisions based on an internal sense. For example, to decide whether or not to use imagery as a healing strategy, a positivist might research into the comparative results of those who have used imagery versus those who have not. Those more intuitively inclined might be guided by an interest in the method and feel drawn to explore it. After trying it they will assess it by subjectively reflecting on its impact. These two approaches, of course, may reflect in part quite different conceptions of “healing.”

In accord with Belenky, Clinchy, Goldberger, and Tarule (1982), I think that a scientific approach is favoured as part of the male hegemony in our society, and an intuitive approach has consequently been undervalued and is less well understood. Evidence from persons with AIDS presented later in this chapter speaks to the value of using intuition in deciding what to do for one’s own healing. An intuitive approach respects individual differences whilst allowing for guidance by logic. Questioning the appropriateness of the scientific method implies no disrespect to science but is, in fact, part of the scientific enterprise itself. As Kremer (1988) writes,

Indeed, it would be self-contradictory for science to put its own current scientific narrative on a pedestal as the only true and legitimate story, for this would amount to the creation of a dogma and a state religion that are philosophically founded on belief and faith rather than on the reason and argument claimed by science to be its guiding principle (p. 189).

To continue with the question of what to do for your own healing, I turn to a review of what science has taught us about immune system functioning, followed by an exploration of an intuitive approach to healing.

### **A Scientific Approach—Immune System Functioning**

Because AIDS is about immunity, it is useful to look at healing from the standpoint of immune functioning. There is good evidence for psychological mediation of immune function. Psychosocial and behavioural variables are among possible cofactors that may influence HIV infection and disease progression (Kiecolt-Glaser & Glaser, 1988). George F. Solomon, who coined the term psychoneuroimmunology in 1964, and other psychoneuroimmunologists, propose that thoughts and emotions profoundly affect the course of a disease by marshalling or impairing the complex immune responses of the body (Callen, 1990). Psychoneuroimmunology builds on the implications of the placebo effect. Someone whose symptoms disappear while taking a sugar pill demonstrates that believing in the possibility of healing—and believing that one is doing something to bring it about—often has beneficial effects. By way of explanation, Pert (1990) of the U.S. National Institute of Health has zeroed in on neuropeptides as the “biochemical units of emotion.” Neuropeptides can affect a whole metabolism of a cell and link nervous, immune and endocrine systems. The action of these molecular messengers is demonstrably affected by emotion.

**Immune system suppression.** Emotions which affect the immune system by suppressing it have been explored in a number of studies. Depression, life satisfaction, and hopelessness are all linked with immunosuppression (Coates, Temoshok, Mandel, 1984). Commonplace stressful events can reduce immune functioning. Medical students’ exams, separation or divorce, bereavement, unhappy marriages, loneliness, caregiving to a friend or family member with a severe, long-term illness such as AIDS or Alzheimer’s disease, have all been associated with poorer immune function. Many of the emotions and events mentioned here are frequent psychosocial responses of people with HIV/AIDS as discussed in the previous chapter. In addition, the characteristics of compliance, conformity, self-sacrifice, denial of hostility, and non-expression of emotion appear to be related to suppression of the immune system

in both cancer and AIDS patients (Dafer, 1990). The stress of homophobic attitudes and behaviour to people with HIV/AIDS may add to the burden on the immune system. According to Cecchi (1984), the immune system breakdown may be the result of an already worn out immune system weakened by lack of self-acceptance and identity, loss of family, lack of community nurturance, and lack of supportive role models.

Many of the 55 seropositive men interviewed by Siegel and Krauss (1991) conceive of emotionality as a symptom of stress and view stress as a cofactor in disease progression. Many attempted to manage their emotions by avoiding stressors and seeking out pleasant experiences.

**Immune system enhancement.** As an example of many health researchers' focus on pathology, evidence on what enhances immune functioning is less extensive. Pennebaker, Kiecolt-Glaser, and Glaser (1988) demonstrated that writing about a traumatic experience was associated with improvements in immunological function, especially amongst those who wrote about experiences they had not previously discussed. What about verbal disclosures? The authors suggest advantages to each. Writing allows people to confront traumas at their own rates, and encourages them to devise their own meaning and solutions to their problems. Talking allows for an outside opinion, support from others, and coping information. Supporting the benefits of verbal interaction, Pennebaker et al. (1988) report that the use of mental health services is associated with fewer visits to physicians, and fewer days of hospitalization. The authors offer the explanation that inhibiting one's thoughts, feelings, and behaviours is stressful. "A significant form of stress is associated with the work of inhibiting or actively holding back the disclosure of important traumas" (p.24). Such stress may be linked with ill health. Actively confronting upsetting experiences may reduce the stressful effects of inhibition and allow for the understanding and assimilation of the experiences. In another study, measures of more emotional expression were positively correlated with a prognostically favourable host immune factor and negatively correlated with prognostically unfavourable tumor factors (Temoshok, Sagebiel, & Sweet, cited by Solomon, Temoshok, O'Leary, & Zich, 1987).

**Immune functioning and HIV disease progression.** The missing link in much of the aforesaid is how immune functioning and HIV disease progression are related. Antoni et al. (1990), have investigated immunological functioning by taking into account where people are along the HIV continuum. Differences in immunological functioning between seronegative and asymptomatic seropositive men across the anticipatory period preceding their HIV antibody testing and during the impact period following news of their antibody status, suggest that the immune systems of seropositive individuals may be compromised to such a degree that they are insensitive to psychosocial factors (e.g., anxiety). If this premise is correct, it suggests that psychosocial factors may relate to immune functioning in different ways for seropositives and seronegatives, regardless of the degree of overt symptomatology.

The authors also evaluated the effects of an aerobic exercise training program on seronegative and seropositive individuals. The immunomodulatory benefits of the program were greater for the seronegative and recently converted seropositive participants, highlighting the importance of early interventions that may help restore competence and halt HIV disease progression at an early point in the continuum. Antoni et al. conclude that aerobic exercise and other behavioural interventions (e.g., stress management, relaxation training, social support and self-efficacy enhancement) may provide some benefit, especially during the early stages of HIV infection.

Kiecolt-Glaser and Glaser (1988) reviewed the possibility that stress reduction interventions have positive consequences for HIV positive individuals. The evidence is mixed. The authors' conclusion is similar to that of Antoni et al. (1990), that the impact of psychosocial stressors and perhaps stress alleviating measures are likely to vary depending on the stage of disease, because immune function can differ widely at each step.

Antoni et al. (1990) report evidence associating stressors and psychological variables—depression, perceived loss of control, and feelings of helplessness—with the progression of HIV disease. Taking the evidence a step further: “Stressors that decrease the host’s sense of control (e.g., learning of HIV-1 seropositivity, bereavement) may lead to a cascade of psychosocial, neuroendocrine, and immunological events that may accelerate HIV-1 disease progression” (p.42). Cumulative empirical evidence suggests that perceived control can profoundly affect emotional and

physical health—possibly by influencing stress resistance, physiological response, or health behaviours (Ickovics & Rodin, 1992). In a small ( $n=21$ ), longitudinal study, Temoshok (cited in Solomon et al., 1987) compared self-report measures of control obtained 2 to 8 weeks after diagnosis of AIDS with PCP for men who had died to those of men who were still alive at 1-year follow-up. The men who were still alive had scored significantly higher on a measure of perceived control.

Psychosocial factors might also be associated with disease progression and survival indirectly. Indirect effects include those factors associated with delay in seeking medical attention, compliance, and self-management (Coates, Temoshok, Mandel, 1984). In summary, psychosocial factors have been found to affect immune functioning; there is some evidence, and more inference, linking immune functioning with HIV disease progression.

**Mind-over-matter—myth or reality?** If psychosocial factors affect immune functioning, and likely therefore disease progression, is it possible to manipulate psychological factors to achieve immune system enhancement? Achterberg (1989) claims that “the mind contributes the greatest variance to the course of health and that to ignore the role of mental factors in the treatment of disease is inhumane and perhaps even unethical” (p.93). Achterberg suggests that a specificity may exist such that there can be conscious control over, for example, subpopulations of white blood cells. She reports on a patient with a rare blood disease—autoimmune hemolytic anemia—who demonstrated repeatedly that he could alter numbers of B-cells and other blood factors. In another study, college students were trained in specific images relating to the function of either neutrophils or T-cells. Each group had significant changes in the type of white blood cell imaged, while the other type of cell remain unchanged (Achterberg, 1989). Reviewing the research on imagery and health, Krippner (1985) concludes that a cause and effect relationship is evidenced by some findings. However, other studies have revealed inconsistent or non-significant findings. It appears that imagery may play a key role for some people. It is important to bear in mind that most of the studies have focused upon people who personally believe that they can influence their immune systems with their minds (Krippner, 1985).

One of the thorniest issues in the debate on the role of psychological factors is what Dafter (1990) refers to as the “mind-over-matter myth.” As a Jungian-oriented clinical psychologist who specializes in the mind–body treatment of chronic medical and catastrophic illnesses, he acknowledges the pioneering work of those—for example, Norman Cousins, Carl Simonton, and others—who have applied psychobiological (mind-body) techniques to successfully enhance physical well-being and alleviated a number of diseases. However, he is quick to point out that their initial successes have been sensationalized in the media, so that the complexities of their healing work have been grossly over-simplified and their methods distorted. Consequently, a destructive myth has arisen, which over-emphasizes the power of psychological factors, while tending to ignore or minimize biomedical ones. According to Dafter, the recognized leaders in mind-body healing emphasize the multidimensional nature of diseases and “psychological factors are recognized as having the *potential* to become powerful triggers for healing *some* individuals through unknown biological brain-cell links, under certain circumstances that are not yet fully understood” (p.26).

This mind–over–matter myth, “tends to shift the focus of mind-body therapies from the pursuit of psychological well-being to an exhausting and sometimes futile struggle to alter one’s body with one’s mind” (Dafter, 1990, p. 26). Sontag (1977) has described how this over-simplified healing myth can become destructive by creating what she calls “blame cultures.” Here patients, their families, and health care providers develop conscious or unconscious beliefs based on the myth that the illness is the patient’s fault. In essence, people are blamed for their illness, since they really should be in better control of their minds, which supposedly host the sole cause of the illnesses (Sontag, 1977). It is important to remember that, while we have the ability to respond to disease, disease occurs in all areas of nature, seeming to be a part of life wherever there is life. Tucker (1990) criticizes the myth as reliance on a sort of magical thinking, as though a cure is simple.

According to Dafter, the result of over-emphasizing the power of mind–over–matter is that patients become overly goal oriented as they fight their physical illness, feeling terrified that they will die if they do not succeed. Because patients can fail in the fight to heal their bodies, which they



expected to win, the myth becomes painfully self-defeating. However, "all of us have the opportunity to attain peace in the soul, and when this is the emphasis, there are only winners; there are no scapegoats in this mind-body healing work, despite the life or death outcome" (p. 31).

To conclude this section on a scientific approach to immune functioning, there is ample evidence to support the claim that psychosocial factors affect immune functioning. How that can be directed in health-enhancing ways and how it affects disease progression is less understood. In any case, as Pert (1990) says: "Once considered in the realm of quacks, faith healers, and flakes, the field [of psychoneuroimmunology] is gaining credibility for coming scientifically to the same conclusions that many individuals have reached through what they consider to be common sense" (p. 34).

### **An Intuitive Approach**

What is right?  
 Right is what feels right.  
 Intuitive awareness.  
 You at this moment know exactly what's right  
 for *you* to do at *this* moment.  
 No one else knows/no facts are relevant.

Paul Williams

Whereas a scientific approach relies on knowledge claimed to be objective, that comes from outside the self, an intuitive approach depends more upon subjective knowledge. Intuition is defined by Noble (1991) as

a way of thinking or knowing that encompasses ordinary thought and intellect in something larger and more inclusive. Intuition is also body based and may come through a feeling in the physical body, a dream, or simply a complete thought that passes through the mind as information, a warning and the like (p. 43).

Supporting the value of subjectivity, which is the basis of intuition, Brooke Medicine Eagle (1988) writes,

... we need go nowhere but inside ourselves for our transformation. Focus of attention within ourselves is the first step... Too often, however, we begin by looking outside ourselves for understanding, wisdom, spirituality, and transformation, whereas the first step is always to acknowledge that what we need lies within (p. 210).

According to Mehl (1988), illness may be considered the body's message to focus attention within and to make a change in our path. He writes:

The body begins that message by an illness perhaps as “trivial” as a common cold. Cold symptoms are a sign to listen to the body and ask what is wrong. How am I ignoring my body’s needs? How am I not respecting my body? Instead, television and other advertising media in our culture train us to shut off the body’s message by taking Contac or Dristan so we can continue life as usual.

By our failure to listen, our body is disappointed. We have not heard the message. Therefore it will perhaps next try to get our attention with a knee injury or a touch of arthritis. That prompts a visit to the doctor, who prescribes aspirin or an anti-inflammatory drug. Again the body has not been heard.

Why is it so frightening for us to consider illness as a sign to examine the way we live? ... To be well may require drastic changes in our families, communities, and cultures. This task is beyond us. We go to the doctor for a succession of pills instead. When the body is not heard by the knee, perhaps it tries a migraine headache. Again no luck. The person must lie still but is drugged with morphine or Cafegot. Again no awareness. Finally a very serious illness must ensue to get the person to pay any attention to the ignored message.

Medicine needs to emphasize awareness of the body’s needs rather than the blockage of its messages with drugs. The shaman–physician can treat the physical needs of the body while responding to the needs of the soul (pp. 137-138).

How does one “focus attention within” or “listen to the body”? Drawing from more of a collective wisdom than Mehl suggests, Achterberg (1988) writes about listening through hypnosis, trance, meditation, imagery, or prayer:

... what is required is a shift into another mode of consciousness, one that can listen in an intuitive way to messages coming from one’s own body/mind/spirit complex. The shift permits an atonement with a universal mind, a higher power, a collective unconscious, or whatever dwells within that guides and gives life its meaning and substance (p. 123).

Regarding spiritual needs, the Federal Centre for AIDS Working Group on HIV and Mental Health (1992) reports that people with HIV/AIDS are looking within themselves more than looking outside to organized religious institutions, compared to previous generations. The group views the evolution of innovative or alternate expressions of spirituality as being a major impact of HIV. These expressions of spirituality are often highly personal and include visualization exercises, meditation, Tai Chi, dance, healing circles, massage and touch, “which increase awareness of dynamic inner resources.... By conceptualizing spirituality as inner strength, individuals may be empowered and enabled to access this source of power when necessary” (Federal Centre for AIDS, 1992, p. 27).

### Scientific and Intuitive Approaches

The emphasis on rational thought in our culture is epitomized in Descartes’ celebrated statement “Cogito ergo sum”—I think, therefore I exist (Capra, 1982). Capra points out that this has encouraged Western individuals to equate their identity with their rational mind rather than with

their whole organism, the effect being: "Retreating into our minds, we have forgotten how to 'think' with our bodies, how to use them as agents of knowing" (p. 40). Compared to Eastern societies, subjective knowledge is poorly valued in Western society. According to Capra (1982), Japanese doctors can accept subjective judgements—both their own and their patients—without seeing them as threats to their medical competence or integrity. Capra argues that,

Ever since Galileo, Descartes, and Newton our culture has been so obsessed with rational knowledge, objectivity, and quantification, that we have become very insecure in dealing with human values and human experience. In medicine, intuition and subjective knowledge are used by every good physician, but this is not acknowledged in the professional literature, nor is it taught in our medical schools. On the contrary, the criteria for admission to most medical schools screen out those who have the greatest talents for practicing medicine intuitively (pp. 319-320).

Acknowledging the value of intuitive knowledge will give greater credence to people's experience of their own health and healing.

The following anecdote demonstrates somewhat flippantly the two approaches discussed above—scientific and intuitive. Following his own experience of recovering from a terminal illness, Norman Cousins became involved in research to measure the physiological benefits of laughing. In response, Lynn Grasberg, who leads a workshop designed to activate humour in the treatment of HIV/AIDS, entitled "Healing Your Amuse System" writes:

This is a great joke to some of us who laugh as much as possible and notice that we feel better because of it. However, in a world suffering from 'Serious Adult Syndrome' (SAS) you need to collect serious statistics to convince people of the usefulness of laughing and playing. 'The SED rate shifted X number of points before and after giggling, and X number of points after guffawing.' Great! (Glickstein, 1988, p. 10).

The medical community recognizes the value of laughing; for example, the British Columbia Cancer Agency room has a humour room filled with joke and cartoon books, pictures, audiotapes and videos (Colcleugh, 1991). The therapeutic value of laughing and smiling have been physiologically validated. Laughing stimulates the production of endorphins—a nerve tissue hormone—relieving pain, and can exercise the cardiovascular, respiratory, and circulatory systems (Colcleugh, 1991). According to Diamond (1979), the zygomaticus (smile muscles) stimulates the thymus gland, an important contributor to the immune system. There are sound scientific reasons for other behaviours that are thought to be healing. For example, aerobic exercise stimulates the production of norepinephrine, a neurotransmitter in the brain that is associated with feelings of

well-being (Dosdall & Broach, 1986). Long before this was known about exercise, many people were intuitively convinced of its value. More recently, scientific evidence provides validation for the healing effects of some therapeutic activities. The importance of the scientific method has been blown up to the point where people may be blind to any form of treatment which lacks a scientific study. An exclusive emphasis on the need of such scientific validation may thus lead to our disregarding possibilities for healing as yet only intuitively grounded.

In support of both ways at looking at this question of “what to do,” Ornstein and Sobel (1989) assert that people are naturally drawn by the pleasure principle to many of the things which promote health. For each form of pleasure—for example, touching, music, saunas, snorkelling, aromas, sex, garlic and chili peppers, exercise, siestas, vacations, laughter, and many more—the authors offer rational explanations for the health promoting benefits of each, usually with credible scientific backing. Ornstein and Sobel’s (1989) search of the medical literature on the relationship between leisure activities and health revealed the pathological focus of medicine.:

Scores of studies exist regarding the health hazards of various hobbies and leisure activities: lead poisoning in painters and potters, high cancer rates in amateur ham radio operators, skin conditions in gardeners. There is even some mention of how various diseases can interfere with hobbies. More pages are devoted to describing the hobbies of doctors, dentists, and nurses than how intense involvement in a hobby can be good for the mental and physical well-being of patients and people (p. 189).

Because of the comparative lack of attention to health promoting factors, people may have to depend at times on their intuition to guide their decisions as to what to do for their own healing. Evidence on the mind/body connection discussed earlier provides some rational reason to the often given advice to the newly diagnosed PWA: “listen to your body.” Reuben (1986) reports that:

Again and again persons with AIDS and medical practitioners claimed that the look within was a critical loop in the rope to survival.... the healing journey begins with a look inward, toward ourselves, and a coming to know our own truths and healing powers (p. 62).

As mentioned earlier, the philosophical basis for complementary therapies emphasizes the clients’ responsibility for active participation in therapy. It calls for people to choose therapies and actions, giving them a sense of control over their treatment. Siegel and Krauss (1991) identified “the need to take control of their health” and “treatment decision making” (p. 21) as fundamental adaptive issues for HIV+ men. Taking control of their health meant several things to the men interviewed. It included seeking out medical treatment options aggressively and informing oneself

about the demonstrated efficacy and side effects of such treatments rather than merely accepting the physician's recommendations concerning drug therapy. For some, taking control meant understanding the course and the signs of the disease. Taking control also included taking responsibility for following a healthy lifestyle (e.g., avoiding tobacco, alcohol, and drugs, eating well, getting adequate rest. It also meant trying to sustain a positive and healthy attitude toward the future. Most men adopted a holistic approach to maintaining good health that emphasized mind-body interdependence.

Further to an earlier discussion, misinterpretation of the role of a person's responsibility in their health and disease has prompted the criticism that this induces blame and guilt, that they did something wrong if they are not healed. This viewpoint confuses the focus of "responsibility for participation" versus "responsibility for outcome" (Strawn, 1989). The client is responsible for applying the therapies, not making them work. "People add to the confusion of responsibility versus blame when they equate healing with cure.... Those with a certain level of spiritual understanding can comprehend that healing can occur, and the client may still eventually die" (p. 191).

One source of valuable information for continuing the investigation into what to do for healing is people who seem to be doing well with AIDS. Some people who are doing well are so-called long-term survivors of AIDS because they have outlived the prognosis which generally accompanies AIDS.

### **Long-term Survivors**

A diagnosis is an event to be adapted to, not a death sentence to be compliant with. I have offended a lot of doctors being alive. Now they are starting to call me and ask for my advice.  
Lon Nungessor (1986).

A long-term survivor is someone who has lived with AIDS for three or more years. In one of the early public statements about people recovering from AIDS, Schultz (1988) claims that despite their many differences, what long-term survivors have in common is a personal commitment to improve the way they live. Their inspiration and support in this commitment comes from many different places: teachings, teachers, and tools.

Callen (1990) is perhaps the best known long-term survivor in North America. He has been politically active and committed to PWA public relations, including numerous media events, and was the first publicly identified PWA to meet with representatives of the White House. He was one of the first to introduce the concept of safer sex. The reason for his activism, "has been a passionate belief that hopelessness kills. That is why challenging the myth that everyone dies from AIDS has become an obsession" (Callen, 1990, p. 10). According to Callen, knowing another long-term survivor is important in sustaining belief in that possibility for oneself. Callen probably knows more long-term survivors than anyone else. His book Surviving AIDS is the result of trying to understand the mystery of his own and others' long-term survival. Some researchers have put forth biological theories to account for long-term survival. All are speculative: one suggests secretion of a lymphokine which suppresses HIV infection (Levy, 1989); another suggestion is that different strains of HIV may be involved (Pachuta, 1990b); genetics may play a role (Gorman, in Callen, 1990).

Callen's book presents the collected wisdom of dozens of survivors, yet the conclusion is far from conclusive: "There are as many different ways to survive AIDS as there are survivors" (p. 183). Each survivor expressed the sentiment that persons with AIDS would have to follow their own instincts and trust their own judgements. It is not possible to prescribe for anyone else what to do. Reading and talking about what other people do may trigger ideas for someone seeking answers. Kremer (1988), for example, writes about "tales as ways of personal empowerment" (p. 189).

What stood out for Callen from the 25 interviews with long-term survivors was an "ineffable quality of *joie de vivre*—a friskiness.... These people were all fighters: skeptical, opinionated, incredibly knowledgeable about AIDS, and passionately committed to living" (p. 183). The skepticism extended to the use of drugs, especially AZT and experimental drugs. Most of them used a group of physicians to coordinate their health care. All the survivors had explored alternative approaches to healing (e.g., shiatsu massage, acupuncture, visualization), using the yardstick of how something made you feel. They tended to "suspend disbelief and do what made them feel good without first insisting on a detailed, referenced, rational explanation for precisely

*how* a particular treatment approach was supposed to work” (p. 189). No medical treatment or single holistic therapy was common to all. Openness to alternative treatments came after AIDS for most of the survivors and was indicative of a more general open-mindedness. Several had moving, near-death experiences. A sudden interest in spirituality and religion was another pattern that emerged. Finally, nearly all the survivors were involved to some extent in the politics of AIDS.

A more scientific study of long-surviving persons with AIDS is under way, by Lydia Temoshok and colleagues (Solomon, Temoshok, O’Leary, & Zich, 1987). Their intensive longitudinal psychoimmunologic study began with pilot interviews of five long-term survivors from which they formed the hypotheses that are presently under investigation. The investigation involves interviews plus physiological measure of immune system functioning. While their conclusions are yet to be published, the hypotheses are worth stating because they are well-grounded in research on the related areas of health and personality style, social support, long-term survivors of cancer, and psychoneuroimmunology. Furthermore, Callen (1990) reports that the hypotheses captured the essence of the survivors he interviewed.

Solomon et al. (1987) hypothesize that the following factors predict longevity in persons with AIDS:

- Perceiving the treating physician as a collaborator, and not interacting in a passive-compliant (nor defiant) mode.
- Having a sense of personal responsibility for one’s health, and a sense that one can influence health outcomes.
- Having a commitment to life in terms of “unfinished business,” unmet goals, or as yet unfulfilled experiences and wishes.
- Having a sense of meaningfulness and purpose in life.
- Finding new meaning as a result of the disease itself.
- A prior mastered experience with a life-threatening illness or very serious life event.
- Engaging in physical fitness or exercise programs.
- Deriving useful information from and supportive contact with a person with AIDS shortly following diagnosis.
- Being altruistically involved with other [people with] AIDS.
- Acceptance of the reality of the diagnosis of AIDS in conjunction with refusal to perceive the condition as a death sentence, or at least an imminent one.
- A personalized means of active coping that is believed to have beneficial health effects.
- Altered lifestyle to accommodate disease in an adaptive manner.
- Long-term survivors are assertive and have the ability to say “no.”
- Long-term survivors have the ability to withdraw from taxing involvements and to “nurture” themselves.
- Long-term survivors are sensitive to their bodies and their psychological/physiological needs.
- Long-term survivors have the ability to communicate openly about their concerns, including their illness (pp. 649-652)

Callen's (1990) observations support most of the above hypotheses. As predicted, survivors were realistic about the seriousness of their condition. They took responsibility for their own healing, which meant making difficult and major lifestyle changes (e.g., reduced use of drugs and alcohol, safer sex or celibacy). They listened to the messages from their bodies. Taking responsibility also meant a willingness to resolve conflict in their lives. Most of the long-term survivors quit stressful jobs and began pursuing activities that gave them pleasure. Many made it a priority to resolve emotional conflict with friends, family, and lovers; by reconciliation where possible, and separation if necessary. Most could be described as assertive, but Callen questions whether they are more so than PWAs who do not survive. A characteristic proposed by Solomon et al. (1987) that was not borne out by Callen's interviews concerns exercise. The survivors who exercised regularly were a distinct minority. Callen's conclusion was that "loving and nurturing yourself, loving life enough to fight for it, and believing that surviving AIDS is possible" (p. 189), are vital—but not necessarily sufficient—preconditions for long-term survival.

### **Quality Of Life Rather Than Quantity?**

Having survived for longer than expected does not necessarily equate with healing.

However, much of the information from long-term survivors relates to quality of life issues. The question of particular interest to the present study is: what enhances the subjective experience of the quality of life for people with HIV/AIDS, irrespective of length of life?

The research of Kendall et al. (1989) is particularly relevant to this question. They were interested in identifying factors that may help enhance the well-being of persons with AIDS. They asked three people who viewed themselves as "doing well" about their subjective experiences. Five themes emerged from the interviews: autonomy/mastery over the disease; existential/spiritual journey toward understanding; self-acceptance; staying active and involved; and positive thinking. All participants were concerned with a sense of control, or mastery, over the disease. The need to stay actively involved in their own care, as well as staying physically and emotionally active, seemed to be vital. One participant decided to participate in a hospice program, providing him "with a sense of control over his life and destiny in a way that passive followship with the



established medical program could not” (Kendall et al., 1989, p. 160). Another person felt a sense of control and mastery through visualization and guided imagery techniques.

In addition, each participant entered a type of spiritual or existential journey toward a further understanding of themselves with their disease. This led to a new perspective on the meaning of their lives. Each saw self-acceptance as important in this journey, including acceptance of their new identity of having AIDS. They viewed having AIDS as an opportunity for personal growth, self-awareness, and reassessment of personal goals. Staying active and involved was valuable, although the activities each enjoyed were different. All three participants felt that staying positive was an important motivator to continued success. They all actively sought ways to stay away from negative people and situations in order to remain positive about the direction of their lives. The most obvious observation made by Kendall et al. (1989) was the connection between meaningfulness and well-being; “perhaps the difference between those who do well with AIDS and those who do not, could lie in how well a person is able to resolve one’s own existential dilemmas” (p. 164).

The similarity of the findings of Kendall et al. (1989) with the research on long-term survivors suggests a correlation between living well and living long. This is also evidenced by anecdotal self-reports. For example, Robert Mehl’s (1990) personal philosophy of living and surviving AIDS (since diagnosis in 1986) stresses quality of life over quantity and contains all the principles of long-term survivorship contained in the research of Solomon et al. (1987). Furthermore, the conclusion from a study of 53 long-term survivors by Remien, Rabkin, Katoff, and Wagner (1993) was that a positive quality of life and minimal depression is possible (even shortly before death) with extended survival with AIDS, regardless of physical status. The authors report that their study participants exhibited considerable resilience and continued to maintain hope and goals to derive satisfaction in their lives.

### **Stories of AIDS and Healing**

There are many stories about HIV/AIDS and healing that tell of improved quality of life (e.g., Larkin, 1991; Matousek, 1993; Mehl, 1990; Melton & Garcia, 1988; Mignone, 1988; Nungessor, 1986; Bamforth, 1987; Goldner, 1988; Owen, 1987; Pohl, 1988; Schultz, 1988; Serinus, 1986;

Walker, 1991). Two long-term survivors, George Melton and Wil Garcia (1988), express greater happiness with their lives as a result of exploring the capabilities that they believe we all have within us. For them, the journey of healing began as they took charge of their own lives. The theme of taking responsibility for one's life, health, and well-being appears over and over. Another person with AIDS writes: "My healing has come from a genuine commitment to love myself. To take charge of my life, taking full responsibility for everything that has taken place in my life by getting out of the VICTIM consciousness without blame and without guilt" (Mignone, 1988, p. 3).

Matousek (1993) researched people who have had spiritually transformative experiences in response to AIDS. One person said: "You're not going to believe me but I've never been happier in my life" (p. 22); another: "While it's true that our lives have been shattered by the HIV virus, it is also true that within this destruction, profound insights have occurred, which have led to a deepening of vision, purpose, and faith" (p. 24). Matousek claims that personal growth is accelerated by the intensified climate produced by HIV/AIDS. He writes: "With nothing left to lose, risk takes on new meaning. Changes that seemed daunting before an HIV diagnosis seem like nothing compared to the prospect of dying without having done them" (p. 24). About himself Matousek says:

AIDS has actually saved my life, propelling me to change, encouraging me to confront what's difficult, urging my fascination with things divine. There is nothing pollyanna in this; it does not imply that I'd have chosen this virus, or that I would not cure it tomorrow if I could. But there have been undeniable benefits to having the myth of immortality exploded.

Matousek (1993) acknowledges that not everyone agrees about "the honey in the rock." Nevertheless, more and more stories of healing are being documented, yet few find their way into academic literature, the popular press, or the media. Why are there so many stories which have not been heard by the public?

One of the reasons so few people come out and say they are in remission or healing is that the belief system is so strong in our society that they will die. By saying you're in remission, everybody who doesn't believe it's possible and thinks it's only temporary and you will die projects the thought form at you. You have to be a really strong individual, and you have to be able to deal with stress (Serinus, cited by Reuben, 1986, p. 55).

It is like being told by your village witch doctor that you have been hexed and must die. Callen agrees that it is a struggle: "Those of us who've insisted on the possibility of surviving have been patronized, handed Kübler-Ross [i.e., accused of being in denial], sent into therapy, or faced with

the charge of AIDS dementia" (p. 68). Healthy persons with AIDS are often accused of being in denial when they talk about their well-being and their expectancy that this will continue. Perhaps the lack of acceptance of long-term survival is in part due to the added stress of uncertainty; it is easier to believe in an inevitable end, in which case the denial is by those judging—denial of the possibility of long-term survival. This attitude may be particularly destructive when it comes from those who are seen to be experts or authorities. A physician and a psychiatrist demonstrate their narrow-mindedness and arrogance regarding the issue of long-term survival in the following report on group psychotherapy: "Many of the physically healthier patients denied the lethality of the disease and avoided talking about issues of terminality.... and actually verbalized resentment at being expected to talk about the fatal nature of the disease!" (Spector & Conklin, 1987, pp. 437, 436).

That some people respond to the crisis of HIV/AIDS by improving the quality of their lives may be threatening to others. It challenges others to look at their own lives. I see healing as a natural force and a desirable goal. So why does not everybody undertake a healing journey? Lawlis (1988) explains the costs involved:

There are costs involved in transformation—costs to therapists, costs in terms of inappropriate roles within a family that must be given up; costs of giving up and surrendering a counterproductive relationship to nature that may have been possessed and valued since birth. These costs are fraught with fear of loss (p. 148).

Healing may involve intense pain and struggle. Templeton (1990a) describes the process she has observed in many of her HIV positive clients with a citation by John Sanford:

It is as though there is within each person an inner centre that knows what constitutes health. If our conscious personality becomes related to this inner centre, the whole person may begin to emerge, even though this may not bring either peace or social adaptation, but conflict and stress. The collision between the conscious personality, and its desire to conform with a minimum of pain to the collective demands and expectations of society, and the demands from the inner centre for wholeness may result in painful symptomatology as a necessary, inevitable prelude toward health (Templeton, 1990a, pp. 66-67)

Alice Miller (1991) attributes much of people's problems to repression of childhood mistreatment and asserts that "emotional access to the truth is the *indispensable precondition of healing*" (p. 143). Emotional access to the truth means reexperiencing the emotions connected with repressed memories and these emotions will probably be painful. Miller criticizes the medical community for failing to adequately look at the causes of emotional pain, just as physical pain is

often treated by quelling the pain rather than examining underlying causes: “The problem with medical pedagogy is that the majority of those involved, the institutions and specialists, in no way wish to know *why* it is people become ill” (p. 141). The reason for this is that it serves to keep repressed their own unpleasant experiences.

At a conference on AIDS in the aboriginal community, an 18-year-old ex-prostitute, Keesha Larkin (1990), talked movingly about how being HIV positive challenged her to look at her life and heal from past experiences. My understanding of her story illustrates my own comprehension of healing from past trauma. It also exemplifies the pain and courage involved in healing. Keesha has shed many tears, reliving painful childhood memories of sexual abuse. Yet the pain seems worthwhile. Each incident more fully experienced is followed by a feeling of liberation. An explanation is that it requires energy to keep emotions repressed. Reviving those emotions frees up energy, resulting in feeling more full of life. I think that repression has its place, however. Keesha was able to function and survive in the community she did because of the protective powers of denial and repression. Timing and balance are important. Emotions are repressed because they are overwhelming. I believe that when the time is right and when it feels safe—for example, when we are no longer dependent on people who may be harming us—we can explore past unpleasant memories, and heal from them. In my experience personally and from observing clients, the healing process frequently involves coming to a new understanding of the trauma. As a ten year old child I interpreted the rejection I felt from schoolmates as there being something fundamentally *wrong* with me. As I have healed from that trauma I have come to understand that, NO, there is and was not anything fundamentally *wrong* with me; I did not warrant that unkind treatment. For another example, children who are sexually abused will likely blame themselves for the abuse and regard themselves as bad or unworthy of love. In adulthood, these children may come to reassess how they perceive the abuse, rightfully laying responsibility where it is due, with the adults that abused them. Coming to such an understanding will likely relieve feelings of unworthiness and self-esteem will be enhanced. Counsellors can provide an environment that helps seekers in their healing. Learning more about how we can do so is an aim of this thesis.

In this chapter, healing was discussed within the context of health and disease. Alternative approaches to Western medicine are gaining popularity and may be viewed as complementary to medical treatments. The question of what do you do for your own healing was considered from scientific and intuitive approaches. The research into long-term survivors and others who report to be doing well with AIDS seems to support an intuitive approach to healing, while awaiting scientific validation. The research and anecdotal evidence cited in this chapter demonstrate the possibility of having HIV/AIDS and improving the quality of one's life. The present research aims to add to this awareness. I have interviewed persons with HIV/AIDS who view themselves as being on healing journeys about their journeys. Before describing the methodology for doing so, the final area of the relevant literature to review is on counselling. Counselling people with HIV/AIDS is the subject of the next chapter.

## Counselling people with HIV/AIDS

One of the joys of working with individuals who are dealing with existential issues and questions of meaning is the chance to witness them become more aware of who they are, of what is really important to them: the painter who finally starts to paint; the poet who pens his first poems; the angry young man who reveals his anger; the one who cares so much finally allowing himself to do so and experiencing his helplessness; the lover who becomes proud of his love (Templeton, 1990a, p. 65).

This chapter examines the literature on counselling people with HIV/AIDS. The counselling issues are noted and this leads into a discussion of counselling objectives, tasks and goals, and of what counselling approach(es) to take. There are, of course, no definitive answers from the academic research literature regarding how best to counsel people with HIV/AIDS, not least because of the diversity of kinds of people who contract HIV/AIDS. Notwithstanding, many professionals over the past decade have documented their experiences and recommendations, and these provide useful understandings for counselling practice in this area. Seven specific issues that bear special mention are discussed. Group counselling is considered as a feasible option. The chapter concludes with recognizing the uniqueness of individual clients, the importance of counsellors' self-awareness, and how an understanding by counsellors of the beliefs and values of their clients, particularly regarding healing, may be necessary for effective counselling and for effectively facilitating healing.

### The Counselling Issues

There are numerous counselling objectives and approaches that can address many of the issues that frequently arise for people with HIV/AIDS. As mentioned in the second chapter, these issues include: depression, anxiety, suicidal ideations, fear of death and dying, frustration, anger, isolation, relationship disruption, body image, and sexuality. While the source of these issues may (or may not) be HIV/AIDS-related, most counselling approaches offer a strategy for dealing with them. Other issues which are more specific to HIV/AIDS—medical issues, disease progression, treatments, preoccupation with symptoms, sexual behaviour, transmission and prevention of HIV, pregnancy and procreation, disclosure of HIV condition and perhaps sexual orientation, legal

issues (e.g., wills, discrimination), and early retirement—may require special attention. Therefore, being well-informed about HIV/AIDS and knowing where to find or refer for information is commonly thought to be important by counsellors (e.g., Kendall et al., 1989; Miller & Bor, 1988; Pohl, 1988; Price, Omizo, & Hammett, 1986; Templeton, 1990a).

### **The Literature on Counselling People with HIV/AIDS**

The literature on counselling people with HIV/AIDS speaks to the issues just mentioned. Authors typically report their observations and, based upon their experiences, document counselling objectives, tasks, and/or goals. These vary from counsellor to counsellor.

**Counselling objectives, tasks, goals.** Kelly (1989), for instance, outlines six counselling objectives, which are: helping an individual manage anxiety and depression; re-establishing or establishing sources of support in the client's day-to-day social environment; the adaptive direction of anger and frustration; accurate understanding of health, and accurate appraisal of one's own situation and involvement in health care planning; the implementation of behaviour changes to promote the health of oneself and other people; and changes in risk behaviour to protect others.

Similarly, Hoffman (1991) includes in her objectives: managing emotional reactions; increasing/maintaining sources of support; and increasing health promoting behaviours (which involves educating about needed changes as well as assisting clients in implementing these changes). In addition to Kelly, Hoffman aims to: examine spiritual and existential issues; assist clients in maintaining employment; and assist clients in rethinking life goals.

Bor, Miller, Scher, and Salt (1991) are more precise in describing seventeen tasks of the HIV/AIDS counsellor. These include, for example, "to create a reality with the client which fits with the client's current worldview and which will sustain him or her through periods of change which lie ahead" (p. 131); and "to talk with the client about the concept of unpredictability, which is reality for him or her" (p. 134). Other tasks, similar to some of the objectives already reported from other authors, relate to emotional responses, social support, relationships, health decisions, problem solving, and personal and spiritual growth. Nevertheless, Bor et al. advise counsellors

not to assume that HIV/AIDS or its consequences are inevitably the presenting problem. The authors have observed from the current literature on the psychosocial aspects of HIV/AIDS that many assumptions are made about the impact of HIV/AIDS on people and caution against making such assumptions. They have found that

assumptions about reactions to a diagnosis on the part of the counsellor may impede rather than facilitate the client's management. Resistance and denial may then become the focus of sessions, as counsellors and their clients 'compete' to assert their views and beliefs (p. 130).

Templeton (1990b) similarly respects the uniqueness of her clients' experiences. Her main aim is to follow and amplify whatever process is happening for them. However, she does write about what she refers to as the steps toward wholeness taken by many of the HIV+ gay men that she has counselled. In addition to steps of health-related changes in behaviour and the development of more intimate and caring friendships, two important steps are the channeling of energies and feelings into constructive work, such as service to people with AIDS and political activism and, given her clientele, disclosure to family and friends of gay lifestyle and HIV status.

Counsellors are guided by what they have observed and experienced and what they believe to be important. For example, Nelson and Jarratt (1987) believe that finding meaning enhances quality of life, and see the role of the counsellor to be to strive for understanding and empathy with the person while offering encouragement, without judgement. Enhancing quality of life is particularly pertinent to the theme of the present research. Hence, the implications offered by Kendall, Gloerson, Gray, McConnell, Turner and West (1989) from their investigation aimed at identifying factors that may help enhance the well-being of people with AIDS are relevant here. Kendall et al. suggest encouraging as much autonomy and freedom of choice as possible, by allowing for an environment that is respectful of self-judgement and autonomy. Persons with AIDS should know all the options open to them; for example, hospice, experimental treatments, treatments other than offered by mainstream medicine. All the participants questioned by Kendall et al. identified the need to recover psychologically after first hearing that they had HIV/AIDS. The way they seemed to regain their emotional balance was to enter a type of spiritual or existential journey toward a further understanding of themselves with their disease. Such a journey typically involved seeking answers to questions about the meaning of life and death, and likely involved



confronting fears, inadequacies, and losses. Counsellors can be respectful of their clients' process by supporting their quest for continued meaning and autonomy (Kendall et al., 1989).

With clients who have recently learned of their HIV seropositive status, the aims of Kendall et al. and others cited above might seem overly ambitious to Grant and Anna (1988), who argue that many recently diagnosed people with HIV would not otherwise have sought a counsellor and that support and information is enough for the majority of clients. They assert the value of an empathic and caring counsellor yet question that of probing psychotherapy. Being sensitive to the needs of individual clients seems apparent.

Hoffman (1991) raises some thought-provoking issues about how the goals of counselling clients who have HIV/AIDS might stand in sharp contrast to goals with non-HIV/AIDS clients. In particular, these goals might involve (a) a commitment to maintain (or assist the client in maintaining) a counselling relationship throughout the duration of the illness; (b) a recognition of the importance of hope and a positive attitude; "both the client and counsellor need to believe in the power of realistic hope in coping" (p. 522); (c) the value of a directive approach around issues of safety for client and others, as opposed to a non-directive approach; and (d) changing the therapeutic goal from "seeking cure" to "assuming safe passage" (p. 522); by "assuring safe passage" Hoffman means making the passing of life as positive as possible, to allay fears about death and dying by allowing the client to express these concerns in the counselling relationship. Furthermore, Hoffman suggests that the usual boundaries of the counselling relationship—setting, regularity of attendance; payment, etc—may need to change. There are clearly numerous delineations of objectives, tasks, and goals for counselling people with HIV/AIDS. Explicitly or implicitly linked with these intentions is the theoretical approach of the counsellor.

**Theoretical approaches.** According to reviews by Green (1989) and Bor, Miller, Scher, and Salt (1991), theoretical approaches described in the counselling literature related to HIV/AIDS are primarily cognitive, systemic, and psychodynamic. Some authors offer reasons for their chosen approach; for example, Bor et al. (1991) argue that a systems approach suits HIV/AIDS-related problems because of issues relating to unpredictability, relationships, interaction, complexity and secrecy which arise in the course of the illness and its management. A further

observation by Bor et al. is that "the predominant psychotherapeutic approach with clients is symptom-focused and presents psychological problems as being inevitable in the course of illness" (p. 129). Balmer (1992) reports a similar evaluation, that the counselling aims of the World Health Organization/Global Programme on AIDS have been based on a disease-centred approach and asserts that, since the parameters of the pandemic have changed, the aims need to be revised. "HIV/AIDS now represents a pandemic with broad social, cultural, political, ethical and legal dimensions. We already know that it has consequences that go well beyond the health and well-being of individuals" (p. 211). Balmer advocates a person-centred approach aimed at improving individuals' self-concept and self-esteem which "allows people to be treated in their singularity and uniqueness. This would fit with the wider social context of trying to encourage more supportive attitudes and a more open social climate associated with the pandemic" (p. 210).

Any review of the HIV/AIDS counselling literature is limited because so much of the actual counselling is not reported in the academic literature. I suggest that all theoretical approaches have scope for HIV/AIDS counselling. Some approaches more than others are focused on healing as understood in this thesis. Consider a Jungian perspective, for example. Jung maintained that the psyche has a powerful self-healing potential and that the source of the autonomous healing forces is the collective unconscious (Grof, 1988). The collective unconscious is Jung's term for that aspect of the unconscious shared by all people (Reber, 1985). From this perspective the task of the counsellor is thus not to understand rationally the problem the client is facing in order to use some specific techniques to change the situation according to a preconceived plan; but rather to mediate and facilitate the client's access to the deeper strata of the psyche. Healing then results from a dialectic interplay between the individual and collective unconscious (Grof, 1988). There are many possible theoretical approaches that can be taken by counsellors in the HIV/AIDS field. Is there a best one to take?

**The comparative literature.** Green (1989) states that the relative effectiveness of different counselling approaches needs to be established. A noble quest perhaps, but is this possible, and if so, how is it to be done? There is a huge body of literature which has unsuccessfully attempted to determine the efficacy of different psychotherapeutic approaches.

Positivistic inquiries, which have predominated in research in the social sciences, have failed to determine any one approach that is definitively superior in any given situation. Contrary to both theoretical and intuitive expectations, theoretically incompatible and technically dissimilar treatments appear to produce relatively minor differences in counselling efficacy (Luborsky, Singer & Luborsky, 1975; Smith & Glass, 1977). At a fundamental level, it is yet to be established what is indeed therapeutic and what, therefore, are valid measures of therapeutic efficacy.

The question of what approach to take for counselling people with HIV/AIDS—or more specifically, what approach to take to facilitate the healing of people with HIV/AIDS—cannot be answered simply. Perhaps the question is as difficult to answer as the question of what people should do for their own healing. I propose that counsellors can draw from the writings and research of others but must ultimately come to their own decisions, which fit their own styles, beliefs and experience, their clients (e.g., HIV condition, current concerns, etc.), and the context of counselling.

### **Some Specific Issues**

Regardless of the counselling approach taken for counselling people with HIV/AIDS, there are a number of issues that bear special mention. I am really only identifying the issues here, each of which could take a thesis on its own to deal with adequately. The issues include: counselling gay men, counselling women, disclosure of HIV status and sexual orientation, suicide, community resources, hope and denial, and encouraging self-responsibility.

**Counselling gay men.** The fact that the majority of people with HIV/AIDS in Canada are gay men bears consideration. Kathryn Templeton (1990a), who has counselled many HIV+ gay men in Vancouver, along with others (e.g., Price, Omizo, & Hammett, 1986), view it as imperative that anyone counselling gay men is knowledgeable about gay lifestyles and the particular issues that are part of their developmental and evolutionary process. They need to understand the psychosocial framework within which gay men have grown up. Of central importance here is the issue of heterosexism. Since counsellors “have an ethical responsibility to offer an accepting, validating, and affirming environment for [their] clients” (p. 77), they need to

have a heightened awareness and sensitivity to their own heterosexism. On a more positive note, "we as counsellors have an opportunity to respond in more knowledgeable, humane, and appropriate ways to the understanding of the gay experience, and through this contribute to a more accepting environment for gay men who are HIV positive" (p. 76).

**Counselling women.** Most of the HIV/AIDS counselling literature is based on experiences of counselling gay men. The issues for women may be different. For example, it may not be sufficient to counsel women about the use of condoms to prevent HIV transmission, without addressing the powerlessness that women often feel in their relationships with men. Ybarra (1991) suggests that women will be helped in their relationships if opportunities are created for role playing the negotiation of safer sex practices.

Additionally, Ybarra (1991) has observed that counselling mothers with HIV/AIDS often must focus exclusively on the issues of self-blame and hatred. If their children have HIV/AIDS, their mothers may blame themselves. If children are healthy, their mothers may feel guilty for leaving them behind. Counsellors may help these mothers to forgive themselves before they die and prepare them to leave their children behind. In addition, counsellors may need to assist in making referrals to help find proper homes for these children (Ybarra, 1991). Ybarra (1991) also points out the need for seropositive women to have neutral abortion counselling. Estimated chances of transmitting the virus from mother to infant vary: 24% to 33% according to Andiman et al. (1990, cited in Ickovics & Rodin, 1992); 50% according to Ybarra, 1991. Chances are better for infants with Caesarian than traditional birthing practice (Olin, 1993). Ybarra advises that women be presented with a realistic picture of the possibilities and implications of their serostatus on their infants, and the implications of raising an infected infant, and then be supported in their decision.

**Disclosure of HIV status and sexual orientation.** Siegel and Krauss (1991) found that most of the 55 men they interviewed had been quite selective in deciding to whom they disclosed their serostatus. Four considerations influenced whom they told: fears of rejection, the wish to avoid the pity of others, the wish to spare loved ones emotional pain, and concerns about discrimination. Templeton (1990a) suggests that counsellors provide as much encouragement and

support as possible for clients to disclose their HIV status and its physical and psychological ramifications, and homosexual orientation if homosexual. She believes it to be self-affirming because, through risking rejection, they are valuing themselves more than other people's expectations of them. Clearly, however, it is not the counsellor's conviction about the value of disclosure, but the client's, which will determine the extent to which disclosure is likely to prove "self-affirming" for them.

**Suicide.** Suicide may be a concern for people with HIV/AIDS at the initial diagnosis of seropositivity, the onset of symptoms, and the terminal stage of the disease (Ybarra, 1991). Ybarra (1991) and Werth (1992) advise counsellors to carefully assess the suicide potential of their clients and be sufficiently informed and comfortable to discuss the issue. Werth (1992) aims to preserve clients' freedom of choice, unless the ability to make a rational decision has been lost, for example, as a result of mental disease. He personally views suicide as a reasoned decision for some people with HIV/AIDS, while acknowledging that "each therapist must grapple with this issue and come to a conclusion based on his or her own feelings and values" (p. 656).

**Community resources.** Clients can benefit from their counsellors' knowledge of the various community resources available for people with HIV/AIDS in their vicinity. Through AIDS Vancouver and the Persons With AIDS Society in Vancouver, these include: financial assistance; transportation assistance; food bank deliveries; home care; buddy support; counselling; peer counselling; therapy groups; support groups; groups for lovers; groups for families and friends; and informational events.

**Hope and denial.** The importance of hope is mentioned ardently by many authors (e.g., Callen, 1990; Hoffman, 1991; Macks, 1989; ). Assessing the psychological needs of people with AIDS, Macks (1989) asserts that maintaining hope is a primary task. As a long-term survivor, Callen (1990) concurs: "it's hard to explain to those who are healthy that hope is like the air we breathe—it's that essential to survival" (p. 65). According to Macks,

Hope is fostered when individuals feel powerful and in control of their lives to as great a degree as possible. It is frequently associated with developing or maintaining spiritual practices, finding new meaning in experiences, becoming politically active, altering one's

attitude and way of thinking, maintaining significant social and familial ties, and being able to help others (pp. 6-7).

Counsellors can contribute to the maintenance of hope by reframing and redefining what feels hopeful. If hope is associated with more global or long-term achievements, a person with HIV/AIDS may become frustrated and lose hope. However, if hope becomes associated with day-to-day accomplishments and events, the possibilities of feeling hopeful are greatly increased (Macks, 1989).

Denial, an important and protective defense mechanism, is integrally intertwined with maintaining hope. Constructive denial allows for much needed cognitive and emotional breaks from HIV/AIDS, and it cushions the impact and intensity of emotional reactions. When denial helps a person with HIV/AIDS attend to daily living in the fullest way possible, it contributes greatly to feelings of hope (Macks, 1989). Denial allows people with HIV/AIDS to deal with their new realities in manageable steps (Templeton, 1990a). In summary, counsellors will best help their clients if they respect the value of denial and not force awareness on them. Planning when to give information and assessing how that information is being used may help counsellors to be sensitive to their clients' readiness for new knowledge (Price, Omizo, & Hammett, 1986).

**Encouraging self-responsibility.** Encouraging clients to take an active role in their health care is a theme mentioned as vitally important by many writers on counselling people with HIV/AIDS (e.g., Kelly, 1989; Kendall et al., 1989; Macks, 1989; Nelson & Jarrett, 1987; Price, Omizo, & Hammett, 1986; Ybarra, 1991). Ybarra (1991) has observed that methods of counselling and education that involve people in the development and delivery of their own programs are more likely to be successful. According to Macks (1989), the most important factor in maintaining hope is active participation in decision making, health care and life activities. Any intervention that enables a person with HIV/AIDS to feel in control serves to strengthen feelings of hope. This is congruent with what was seen to be important for the long-term survivors of AIDS discussed in the previous chapter. Taking responsibility for one's health has good foundations in attribution research. In order to learn more about how people decide what help is most appropriate and what the consequences of these choices are, Brickman, Rabinowitz, Karuza, Coates, Cohn, and Kidder (1982) investigated attribution of responsibility for a problem and attribution of

responsibility for a solution. They conclude that there is an advantage in believing you are responsible for solutions, regardless of whether you attribute problems to a cause for which you are not responsible or a cause for which you are responsible.

A specific examination of the impact of attributions of blame and responsibility for the cause and course of disease in persons with AIDS found that those who attributed more responsibility for improvement to themselves made more health behaviour changes (Moulton, Sweet, Temoshok, & Mandel, 1987). Attributing responsibility for self-improvement did not have the negative psychological effects of “blaming the victim” as did attributing responsibility for the cause of AIDS to the self.

### Group Counselling

The profound isolation of the diagnosis can dissolve, for some moments, in an empathic community where the unbearable is jointly borne.

Beckett & Rutan (1990, p. 28)

In addition to individual counselling, group counselling may be valuable for people with HIV/AIDS (Beckett & Rutan, 1990; Coleman & Harris, 1989; Gambe & Getzel, 1989; Getzel, 1991; Levine, Bystritsky, Baron, & Jones, 1991; Macks, 1979; Price, Omizo, & Hammett, 1986; Spector & Conklin, 1987). There are advantages to a group format. Groups allow for the enhancement of social support, which may be particularly important for people with HIV/AIDS. Because of the numerous reports of poor treatment being offered, due to a fear of catching AIDS (nowadays diminishing) and heterosexism, meeting with others gives them the opportunity to discuss experiences and express shared concerns, thereby reducing the isolating nature of HIV/AIDS. Furthermore, accurate information is needed whenever possible to maximize people's sense of control over their lives (Macks, 1989). A group provides a forum for sharing information and discussing options. Groups may also provide time for healing activities together, such as singing, meditating, the use of imagery, as well as recreational activities (Steinberg, 1990).

What sort of group format works best? Macks (1989) concludes: For individuals facing life-threatening illnesses, a short-term closed-group model can provide predictable consistency, thereby enhancing the development of social support. The structure offers a contained environment which provides models for managing overwhelming feelings and provides ongoing support which can

often lead to feelings of empowerment and hopefulness. The short-term nature also provides the best opportunity for maintaining the integrity of a group, given the fluctuation in physical status and the high mortality rate for people with AIDS (Macks, 1989).

Long-term groups can offer increased opportunities for in-depth therapeutic intervention, but there may be difficulty in maintaining consistent group attendance due to physical illness and death of group members (Macks, 1989). Drop-in groups can be especially useful for persons requiring immediate support or for those individuals whose emotional and physical state may prevent them from making a commitment to a group (Macks, 1989).

The variability of aims and strategies amongst counsellors is evident in the literature reported by counsellors of groups. For example, Gambe and Getzel (1989) focus on spiritual and existential issues in HIV support groups, assisting group members in (a) addressing the meaning of their lives with regard to themselves, their sphere of relationships, and to society as a whole; (b) assuming responsibility for any aspects of their life over which they still have control; and (c) accepting the limits of their actions. Somewhat different goals for HIV support groups are adopted by Levine, Bystritsky, Baron and Jones (1991); their goals are (a) management of group grief; (b) recognition and support during a suicidal crisis; (c) diagnosis of organic mental disorder; and (d) help to group members in coping with anxiety surrounding dying, death, and disease.

Regarding the composition of groups, Beckett and Rutan (1990) offer a number of arguments in favour of homogeneous groups: The bonding of group cohesiveness is facilitated if members of a group understand important aspects of each others' life situations. Non-HIV/AIDS members are likely to expect the death of persons with AIDS and this may threaten the development of relationships. In addition, non-HIV/AIDS members might share the unrealistic fear of contagion that is so prevalent in the society at large. Anxiety might also be aroused by confronting the issue of mortality. Conversely, HIV/AIDS members may have difficulty relating to other group members whose concerns might seem trivial in comparison to the issues of life and death that confront the HIV/AIDS members.

Homogeneity can be taken further. Kendall et al. (1989) report that long-surviving persons with AIDS do not always find support groups helpful because they have experienced other people



with HIV/AIDS focusing “excessively” on the negative. It may be important to have a separate support group for newly diagnosed people with AIDS and another for those who have already secured a new identity as a person with AIDS. The proposition of composing groups of persons at similar stages of disease is supported by Spector and Conklin (1987) who speculate about the usefulness of separating the patients with different opportunistic infections into different groups, because their prognoses, survival, and complications may be different. In summary, the sort of group that works best will be the one which meets the needs of a particular person. As well as providing an assembly for shared experiences, an effective group will also acknowledge individual differences.

### Individual Differences

As recognized in the chapter on HIV and AIDS, responses to HIV/AIDS by individuals varies a great deal according to HIV and non-HIV-related issues. Some literature addressing the psychosocial needs of persons with AIDS (e.g., Dilley et al., 1989; Macks, 1989) tends to categorize subjects as PWAs with stereotyped responses rather than *persons* with AIDS. Just how similar or different are their responses and needs? Different needs and beliefs about how these needs can be met will require different responses from counsellors. As Nelson and Jarrett (1987) point out, in order to foster the integrity of persons as individuals, their own particular situations and needs must be acknowledged and honoured. Other writers also make note of the uniqueness of individual clients (e.g., England, 1986; Kelly, 1989; Price, Omizo, & Hammett, 1986).

Within the group counselling context, Getzel (1991) has observed how differently and creatively people with HIV/AIDS have responded to their conditions. He talks particularly about people developing their own unique modes of survival and the importance of counsellors supporting the courage of group members’ self-determination. Counsellors “must defend the sanctity of each person’s survival, even if such efforts frighten others” (Getzel, 1991, p. 11).

From their research on attribution, Brickman et al. (1982) assert that disagreement between the counsellor and the client on attributions regarding responsibility will undermine effective counselling. It is therefore important for counsellors to be aware of their clients’ attributions of responsibility. Attribution is one area among many where individual differences may exist which

may impede the effectiveness of counselling. For counsellors aiming to facilitate healing with their HIV/AIDS clients, understanding what healing means to their clients may be vital.

Implicit in the earlier discussion on the nature of healing, culture is an important factor to bear in mind because beliefs vary from culture to culture. In order to provide effective health care within any culture, learning directly from the group's members about their beliefs and assumptions is suggested by England (1986). Perhaps England's suggestion can be taken a step further, by inquiring of *individuals* their beliefs regarding disease and healing. There is good reason for doing so: Beliefs may vary between subcultures and from person to person *within* a culture. Hansen and Resick (1990) report that differences in health beliefs and cultural values between the provider and the receiver of health care may become an obstacle to providing quality care.

One area where beliefs and values may influence the effectiveness of counsellors is sex-role stereotypes. A study by Broverman, Broverman, Clarkson, Rosenkrantz, and Vogel (1970) found that both female and male clinicians' judgements about the traits characterizing healthy, mature individuals differed according to the sex of the person judged. Moreover, attributes that were judged to be healthy for an adult, sex unspecified, were the same as those for an adult male; and different to those for an adult female. It appears that abstract notions of health are influenced by the greater social value of masculine stereotypical characteristics than by the lesser valued feminine stereotypical characteristics. The authors speculate that this double standard of health for men and women stems from the acceptance of an "adjustment" notion of health; that for women and men to be healthy they must adjust to and accept the behavioural norms for their gender. Furthermore, in the case of women, it means accepting behaviours that are generally less socially desirable. The authors caution clinicians to be concerned about whether the influence of sex-role stereotypes acts to reinforce social and intrapsychic conflict with their clients: "The cause of mental health may be better served if both men and women are encouraged toward maximum realization of individual potential, rather than to an adjustment to existing restrictive sex roles" (Broverman et al., 1970, p. 7). The authors' conclusion suggests that clients' mental health will be served best by counsellors who minimize the influence of what the counsellors themselves deem to be healthy behaviours and encourage their clients' individuality. Importantly, however, counsellors self-awareness may

determine the extent to which they are able to accept and encourage such individuality in their clients.

### **Self-Awareness of Counsellors**

Many counsellors have written about the need for counsellors to be aware of and confront their own judgements, values, attitudes and fears (e.g., McKusick, 1988; Nelson & Jarratt, 1987; Pohl, 1988; Price, Omizo, & Hammett, 1986; Templeton, 1990a; Werth, 1992; Ybarra, 1991). Counsellors are also challenged to deal with their own search for meaning, confronting the same existential issues as their clients (Nelson & Jarratt, 1987). Getzel calls upon counsellors of groups to express their own sense of vulnerability as group members question the meaning of life and death. Furthermore, "at times, the [counsellor] must express personal emotions and opinions immediately and clearly during the course of group process, particularly concerning self-destructive behaviours, the death of a member, and the injustice of illness" (Getzel, 1991, p. 11).

McKusick offers a suggestion as to how to enhance self-awareness:

One concrete way of bringing home the issues is for psychologists to assess their own personal risk of infection with HIV, or to imagine their own possible emotional reaction to testing positive. By developing an "inner ear" to their own questions and attitudes toward those at risk, psychologists can be alerted to potential countertransference attitudes before beginning the next therapy session or interview with a person affected by AIDS (p. 939).

Finally, counsellors need to take care of themselves and recognize the support they need (Federal Centre for AIDS, 1992; Nelson & Jarratt, 1987; Pohl, 1988).

### **Conclusion**

While positivistic research has not provided answers as to how best to counsel people with HIV/AIDS, the literature does offer recommendations. These recommendations vary amongst authors, in accordance with their own beliefs, values, and experiences. For counselling to be most effective it is likely that it must be culturally relevant to the community it serves and also respectful of individual differences. To this end, clients' beliefs must be understood. In conclusion, how healing is viewed by counsellor and client may determine what is therapeutic in their interaction. The present research aims to explore what healing means to some persons with HIV/AIDS, within the context of their own healing processes, with an intent to contribute thereby to an understanding

of how better to facilitate their healing, and perhaps that of others, through counselling. The following chapter describes the method for fulfilling this intention.

## Method

Science needs a soul which would show respect and love for its subjects of study and would stress harmony and communication with the rest of the universe.

Arditti (1979, p. 367)

This chapter outlines the method employed in the present research. The method draws upon the principles and practice of the ethnographic interview as a methodological approach. Also discussed are the research participants, the interviews, analysis of the interview data, and the impact of the research on participants.

### The Ethnographic Interview

A method renowned for exploring and describing the experiences of others is ethnography. Hammersley & Atkinson (1983) regard ethnography as the most basic form of social research: "It bears a close resemblance to the routine ways in which people make sense of the world in everyday life" (p. 2). People derive meaning for the things in their lives from interacting with one another, thereby creating their social realities (Haig-Brown, 1991). Moreover, "ethnography provides opportunity for the sensitive interviewer and the interested co-investigator (study participant) to develop mutual understanding as they work together" (Haig-Brown, 1991, p. 35). By admitting into the research frame the subjective experiences of both participants and researcher, ethnography may provide a depth of understanding lacking in other approaches to investigation (Le Compte & Goetz, 1982). Recording the personal experiences and assumptions of the researcher adds another dimension to the data, one that is always present, but rarely acknowledged (Kirby & McKenna, 1989). This information about the researcher "places her/him in relation to the research question and research process in an immediate and central way" (Kirby & McKenna, 1989, p. 21).

My primary aim in this research was to learn about people's experiences of healing. The obvious way of doing that for me was to *talk* to people about their healing. I wanted to find out about how they understand their experiences of healing. This immediately posed a personal challenge: the challenge to acknowledge and discern the mainstream bias of a positivist paradigm in

social science research and affirm my belief in a dialogic approach. A dialogic approach entails conversation between people as a means of investigating human understanding.

In principle, an advantage of living in a democratic society is being able to express ideas that do not reflect society's most dominant views. However, it is not easy to confront the dominant paradigm and not everybody has the opportunity. Chomsky (cited in Kirby & McKenna, 1989) writes:

The right to free expression of ideas and free access to information is a basic human right, and in principle it is available to all, though in practice only to the extent that one has the special privilege, power, training and facilities to exercise these rights in a meaningful way (p. 33).

Spender (1981) also recognizes that knowledge production has been organized in a way that excludes many people from participating as either producers or subjects of knowledge, even though constructing explanations of the world is a human activity. Kirby & McKenna (1989) further argue that research has not served the interests of all people but rather has typically been used to maintain oppressive relations. By contrast, the present research, that employs a dialogic approach, values and reports the experiences and knowledge of some marginalized people whose interests have usually not been considered.

The idea of knowledge emerging from a dialogic relationship between researcher and researched is proclaimed by Westcott (1979). A dialogic approach dissents from the mainstream positivist emphasis upon objectivity in social science research. It challenges the positivist principle that truth can be expressed in causal relations independent of time and place. According to Westcott, the methodological screen that typically separates researcher from subject distorts the phenomena under study. Lowering the screen through dialogue allows the researcher and researched together to shape emergent concepts.

Even in the natural sciences, the tenet of objectivity is increasingly challenged. Capra (1991) contends that scientific descriptions are no longer considered independent of the human observer and the process of knowledge. Capra writes:

In quantum physics, the observer and the observed can no longer be separated, but they can still be distinguished (p. 331).

The understanding of the process of knowledge has to be included explicitly in the description of natural phenomena (p. 330).

Furthermore, according to Capra, it is now recognized that all scientific concepts and theories are limited and approximate descriptions of reality. What is reality? This question is the subject of ongoing debate in the philosophy of science. Positivists speak of an objective concrete reality that exists "out there," independent of our beliefs about it, and that awaits discovery. For naturalists, reality means something different. Weber (1949), for example, defines concrete reality to be the individually conceptualized experience of people as they negotiate their social world. Weber also views science itself to be a social product and hence an expression of values of the society in which it is produced, and of the theorist producing the interpretation. Kuhn (1970) has been influential in affirming that, to understand scientific knowledge, one has to understand the social processes by which, and the social context in which, that knowledge is produced. Social constructionists declare a more radical view. They argue that what we observe and infer to be knowledge is more a product of our constructions of reality than an inherent property of reality per se (Palys, 1992). The evolutionary biologist Gould (1981), for example, through evaluating the research on cranial measurement, showed how indices of measurement have reflected and reaffirmed broader cultural assumptions and hierarchies of power.

So we can look back and realize misunderstandings that have since been adjusted. The process of negotiating reality is ongoing. Perhaps, as Capra (1991) proposes, science can never provide any complete and definitive understanding. He quotes Louis Pasteur: "Science advances through tentative answers to a series of more and more subtle questions which reach deeper and deeper into the essence of natural phenomena" (p. 333). Palys (1992) declares that, "'reality' is a negotiated construction and the qualitative researcher's task is to understand the processes by which such negotiation is done" (p. 375).

Our changing understanding of reality has in part been prompted by the voices of individuals, women, and minority groups who have challenged the majority view model of psychological knowledge (Palys, 1992). Various oppressed groups have claimed that much research has been biased and does not represent their experience (Kirby & McKenna, 1989). For example, the early decades of psychological research mostly did not include women as subjects yet the results

obtained were reported as representing all people (Josselson, 1992). Rich (1979) writes about the importance of correcting such ignorance:

Women have often felt insane when cleaving to the truth of our experience. Our future depends on the sanity of each of us, and we have a profound stake, beyond the personal, in the project of describing our reality as candidly and fully as we can to each other (p. 190).

In recent times women and marginalized groups have been writing and speaking more loudly about their own experiences. Consequently, the varieties of people's experiences are being recognized as such. The present research aims to present the reported experiences of some marginalized people. I acknowledge here, however, that I—the researcher—am not a gay or bisexual man with HIV/AIDS like the participants whose stories I am telling.

The philosophy of science field evaluates the criteria for determining “the truth”, and even whether truth can be determined. My views concur with those of Weber and Kuhn. We need to pay attention to how situations are perceived and interpreted by participants in context. The researcher, the “observer” is better conceived of as a participant in the research. This is fundamental to the ethnographic interview.

The principles and practice of the ethnographic interview (Spradley, 1979) provide the method of inquiry for this research. According to Spradley (1979), the ethnographic interview has three important elements that distinguish it from other forms of “speech events.” Firstly, it has an explicit purpose (compared with, for example, a friendly conversation); it necessitates ethnographic explanations (for example, reasons for tape recording an interview); and involves ethnographic questions, designed to discover information.

Haig-Brown (1991) calls ethnographic interviews “research as conversation” (p. 42). She points out that although the emphasis is on one side of the conversation, this is often the case with intense personal talks. An interview is a joint product, shaped and organized by both participants. The ethnographic interview is an interactive process; questions and answers are more than simply stimuli and responses (Mishler, 1986). Rather, meanings emerge, develop, and are shaped by and in turn shape the discourse. The value of a dialogic approach is well described by Gilligan: “If the process of coming to know others is imagined ... as a joining of stories, it implies the possibility of generating new knowledge and transforming the self in the experience of relationship” (p. 240).



The researcher can become another subject in the research process by making her thoughts and experiences explicit, thereby being vulnerable in a way that, according to Kirby & McKenna (1989), changes the traditional power dynamics that has existed between researcher and those who are researched. I aim to reduce the power differential, yet acknowledge that I am still the researcher, the people whose stories I report are the researched, and this situation inevitably sets up a power imbalance.

My aim has been to facilitate the open expression of the participants' perspective on the world. The interview questions were designed to generate information with as little influence as possible by researcher partiality. The questions were primarily open-ended, designed as prompts to stimulate the interviewee into talking about a particular broad area (Hammersley & Atkinson, 1983). In this research the broad area is the interviewees' stories of healing. I present stories of people's experiences. A difficulty, pointed out by Polakow (1985), is that experience has fallen in value, giving way to the rise of information:

In the language of contemporary social science, stories are soft—they do not constitute the *real* data of the scientific enterprise... The isolation of body, of mind, of experience, of consciousness, leads to documentation, to a mere taxonomy of facts closed in on themselves, leading us away from, not towards, the understanding of human experience (p. 826).

Polakow suggests that the criteria for evaluating good research of this genre emphasize the power of one's narrative, the rhetorical skills of the teller, and the evocation of a landscape of experience that resonates with one's audience. Polakow's criteria are a far cry from the objectivity, replicability, and predictability that govern evaluation of a positivist inquiry. Furthermore, the researcher as storyteller "is an embedded participant, not a distant, uninvolved observer of the humanscape" (Polakow, 1985, p. 831).

Like an ethnographer, I have the opportunity—and the obligation—to check out my understanding with the participants (Hammersley & Atkinson, 1983). Lather (1986) asserts that the extent to which the reported results ring true to the participants—that is, face validity—is integral to the process of establishing data credibility in openly value-based research. Face validity is established by recycling categories, emerging analysis, and conclusions, back through at least a sample of respondents. Accordingly, in second interviews the participants were given the

opportunity to correct any inaccuracies on my part and respond to how I had represented them.

Reason & Rowan (1981) support this approach:

One of the most characteristic things about good research at the non-alienating end of the spectrum is that it goes back to the subjects with the tentative results, and refines them in the light of the subjects' reactions. Then instead of a 'hit and run' approach which sucks the subject dry and leaves her by the wayside, there needs to be an involvement with the person which enables a process of correction of impressions to take place (p. 248).

In addition to respondent validation, a vital component of validity in ethnographic analysis is context. Hammersley & Atkinson (1983) speak about personnel and social context, both of which will shape the data and therefore need to be considered in order to avoid making unwarranted inferences. Personnel context refers to people's identities or social locations, which will affect the information available to people and their perspectives (Hammersley & Atkinson, 1983). While there are few guidelines to guard against oversights in regards to context, the aim is to be as aware as possible of contributing contingencies (Hammersley & Atkinson, 1983). An important aspect of social context is the societal and political environment. As discussed earlier, the present environment is heterosexist and stigmatizes people with HIV/AIDS. Another aspect of social context is the audience to which the accounts being used as data are directed—this includes the researcher and others, present or not. The audience for the present thesis consists of the research participants, the researcher, her supervisors, colleagues and friends, interested readers from AIDS Vancouver and the PWA Society, plus anyone else who seeks it once it becomes available through the university library. In interviews the very structure of the interaction forces participants to be aware of the ethnographer as audience. Furthermore, their conceptions of the nature and purposes of social research and this research project in particular may influence what they say (Hammersley & Atkinson, 1983). The participants have thoughts and experiences regarding counsellors and counselling which influenced what they said to me, a declared counsellor.

Since what is told to me is conditioned by the circumstances of this research and, in particular, the interactive dialogue between each of the five participants and myself, I am a player in their stories. Furthermore, *I* tell a story about these people's stories. For these reasons, the thesis is entitled: "Healing and HIV/AIDS: Six Stories." Bearing all of the above in mind, the procedure went as follows: Study participants were recruited and interviewed; an initial analysis of the

collective findings was performed and circulated back to the participants; second interviews took place to discuss the initial analysis; and the write up was completed.

## The Participants

Once the research proposal had been approved by my senior supervisor and the University Ethics Review Committee, participants were sought. In addition to the researcher, the study participants were persons with HIV or AIDS in Vancouver. They are stigmatized and marginalized people because of their gay or bisexual orientation and by having HIV/AIDS, in a heterosexist society. Five persons with HIV or AIDS were asked to participate through word of mouth or notices in the PWA Society's newsletter and the AIDS Vancouver volunteers' newsletter (Appendix A). I met Michel L and Richard as peer AIDS Vancouver volunteers and asked them to participate in the study. The other three participants—Jim, Michel G and Michel T—called me in response to the notice in the PWA newsletter. To minimize confusion, the three Michels are referred to throughout the analysis with the initials of their surnames.

Michel L, Richard, Jim, Michel G and Michel T are referred to as “participants” because they are indeed “subjects” of research, yet so-called subjects in social science are often treated as the “objects” of research. The five participants are not representative of all people with HIV and AIDS. They are all male and are in their mid-twenties to late-thirties. They were selected, or selected themselves, because they see themselves as on a healing journey (refer to Appendix D for brief subject profiles). No further people responded to the notice requesting participants. I had hoped to have some women participate in the study, but, despite the help of a friend who is associated with the Women's Positive Network, no women came forward.

At the initial contact (face-to-face with Michel L and Richard or by telephone with the other three) participants were invited to ask questions about the study. A convenient time and venue for the first interview was arranged. Participants were each sent the information sheet and consent form (Appendix B) and the list of questions that was to guide the interviews (Appendix C). Such informed consent procedures are intended to minimize negative consequences and serve the purpose of allowing participants to know what their participation involves and to assess the benefits and risks. Further consent was requested from those I was in contact with for including

transcripts of the interviews in an appendix to the thesis (refer Appendix E for the consent form). Subsequently, the transcript of the interview with Jim is attached as Appendix F.

## The Interviews

The first interview was with Michel L during the early stages of the project. At my request, Michel L agreed to go through my proposed procedure with him, including a taped interview, and he agreed to give me feedback about it. My initial interest was to talk with people about their views on healing. As we were talking I found myself more interested in hearing his story than in seeking answers to the questions I had prepared. My research purpose lost direction until four days later when I was analyzing the interview: I shifted from seeking a theoretical understanding of healing to a richer and more holistic exploration ... hearing and reporting stories of healing in process.

The interviews with Michel L, Jim, and Michel T took place in their homes; Richard and I met at AIDS Vancouver, and Michel G came to my home. At the beginning of each meeting the participant read and signed the information sheet. Each participant was also verbally offered a guarantee of anonymity if desired and was reminded of the right to withdraw participation at any point. Participants were asked if they had any questions. These questions were answered and then the audiotaped portion of the interview began.

I opened each interview with: "We are here to talk about your healing journey. Perhaps we could begin by you telling me when you became aware that you were HIV positive and how that impacted on you at the time?" As necessary I later asked: "What's happened since then?" I did not interrupt the participants until they had completed their answers, aiming to give a sense of unlimited time. Other questions attempted to further an understanding of healing in the context of the participants' lives.

After the tape recorder had been turned off, I asked participants, "How has it been for you to do this interview?" I also asked them what name they would like to have in the report. This debriefing segment of the interview was designed to give participants an opportunity to talk about their experience. It also provided closure for the initial interview.

A second interview took place with each willing participant to discuss the collective findings. I met with Jim over lunch in a restaurant. At time of writing this Michel L has in his possession the

collective findings yet I no longer expect him to contact me, I have been unable to track down Michel G for whom the telephone number I had is no longer in service, and the other two participants—Richard and Michel T—are no longer alive. [Some of the] participants had this further opportunity to talk about their experience. They were thanked for their contribution. Each participant was promised a copy of the thesis upon completion.

### Analysis of the Interviews

The first interviews were audiotaped, transcribed, and analyzed qualitatively. Each participant's story was condensed and is reported as a distinct entity. I present the stories (in the next chapter) as faithful to the telling as possible, as if I am completely accepting of what is being told. I assume that whatever is said is important to the speaker. Extensive quotations of the participants own words are included in writing their stories, bearing in mind Haig-Brown's (1991) caution:

Clearly moving the word from conversation where it includes a particular environment, history, body language, and expression and to transfer it to paper where it lies still, waiting for a reader in some other context, transforms it beyond recognition. Yet, I believe that the printed word can convey much of the speaker's original intent if the writer places it carefully and sensitively in its new context and seeks approval for that placement with the person who spoke. This is the truth for which the ethnographer strives (pp. 64-65).

The ease I felt in writing the stories varied considerably from one participant to another, with Jim's well-articulated and chronologically recounted story at the "easy" end and Michel G's all-over-the-place, less "factual" account at the "difficult" end. I *aimed* to stay open to the participants during the interviews yet wonder, given my struggle in telling Michel G's story, how well I was able to hear and recount stories that did not fit any preconceived perceptions I had.

At the conclusion of writing each story, I re-read it and recorded on a separate page words and phrases that I perceived to identify key elements of the story. Once all the stories were written and the key elements of each were identified, I studied the pages of key elements and grouped together those elements that seemed to be closely connected. This process resulted in a number of tentative themes, although the themes continued to evolve throughout the analysis. I went through each story and highlighted sections according to the themes; each theme having been designated its own pen colour. I then focused on each theme in turn, pulling together all the relevant sections

within and across the five stories, thereby constructing a commentary on each theme. Finally, I went back and examined sections of the stories that had not been highlighted to pick up what seemed to me to be any important information that had initially been missed.

Bateson (1989) refers to such recurrent themes as “the echoes from one life to another” (p. 16), albeit relative to my frame of reference. The stories and a discussion of the themes, having since been modified in light of the participants’ feedback, are presented in the next chapter. The discussion of the stories flowed from reflecting on both the data and the process of analyzing it.

Inherent in analysis is the act of interpretation.

All knowledge that is about human society, and not about the natural world, is historical knowledge, and therefore rests upon judgement and interpretation. That is not to say that facts and data are nonexistent, but that facts and data get their importance from what is made of them in interpretation (Said, cited in Kirby & McKenna, 1989, p. 23).

Kirby & McKenna (1989) claim that the act of interpretation underlies the entire research process:

What kind of data and facts you are able to gather will depend on the kind of questions you think are important to ask and the way in which you go about asking them. The research process is a social activity which is located in a specific historical and social context, and involves intentional activity (p. 23).

Those in power are able to decide what is researched and what is fit to report and therefore what knowledge is legitimated (Kirby & McKenna, 1989). I aimed to present the data so that the participants could see themselves reflected in it. I find it difficult, however, to fully account here for the process of analysis. It seems impossible to know exactly how words representing themes come to mind and how subsequent massaging of the data to fit within the “boxes” created might inhibit fuller expression of people’s stories. Despite good intentions of being open to what the participants said, I was no doubt influenced by my own perceptions on healing. Furthermore, the implications for counsellors, while intended to be drawn directly from the stories of the participants, are filtered by my own experience as a counsellor.

Given the above limitations that are seemingly inherent in the process of qualitative analysis, I realize that someone else, even analyzing the same set of transcribed interviews, might well come up with a different account of each person’s story. I do not think, however, that the accounts I have documented would be unrecognizable to anyone who had read the transcripts. The conclusions I have drawn *are* different to those that another researcher would arrive at. Reason &

Rowan (1981), who think in terms of the validity of knowledge in process as being tied up with a particular knower say that if the same research produces different conclusions, "this does not mean that one is right and the other wrong, the two pieces of research will probably build on each other and contribute to a binocular vision" (p. 250).

### The Impact of the Research on Participants

I propose that research be guided by the aim of empowering respondents (Mishler, 1986, p. x).

When exploring possibilities for my research project, the first criterion that I defined was that it be valuable to those who participate in the research. I cannot *know* that it *will* be valuable, only that I will do my utmost to make it so. To that end, this final section of the method chapter examines the impact of research interviews on participants.

Intrinsic to a discussion about the impact of my study on the participants is the rationale behind the study. As stated in the introductory chapter, my rationale is threefold: Firstly, giving expression to the participants' stories of healing validates and encourages their process; secondly, such stories are inspirational and empowering to others in their search for healing; and thirdly, we can learn from the participants about how counsellors can better facilitate healing with their AIDS and HIV clients.

The basis for the above rationale comes from my understanding acquired through studying and practising counselling. Regarding the first of the three aspects, I hold the assumption that people can come to know what they need for their own healing and being listened to by an attentive and appropriately empathic person can facilitate that process. In this way I hope to encourage and validate the personal experiences of each participant, hence aiming to meet the criterion that the research be valuable to its participants. The ensuing discussion focuses on this first aspect of the rationale. The latter two aspects of the rationale are less directly relevant to the participants. However, the study allows them to share their knowledge and experience in ways intended to foster healing globally. Many persons with AIDS and HIV have expressed such a desire to me.

The effects of research on participants has not been widely investigated. The effects of researchers and the procedures they use on the *responses* of the people studied have, by contrast,

been subjected to considerable investigation (see Hammersley & Atkinson, 1983, p.10, for examples). Validity has typically been concerned with the quality of the information collected. There has been considerably less attention to the effects on the *people* in the research.

One of the exceptions is the work of Sanford (1970). Sanford reported several studies in which interviews of students about their development and educational experiences catalyzed important changes in their self-perceptions, their goals, their attitudes to other groups, and their energy for doing things about their new perceptions. Mary Catherine Bateson (1989) asserts that telling one's stories can help people gain perspective on their lives and this can be particularly powerful for marginalized people. She writes: "When one has matured surrounded by implicit disparagement, the undiscovered self is an unexpected resource. Self-knowledge is empowering" (p. 5). Kirby & McKenna (1989) agree: "There is power in being able to tell your story and hear others tell theirs. Sharing experiences triggers some life, some anger, some need to create change" (p. 170). Furthermore, "when we begin to interpret ourselves and say together with others on the margins that 'this is my story, this is our story,' the power dynamics begin to shift" (p. 19).

Further evidence on the catalytic power of interviews is an examination of the effects on subsequent attitudes and behavior of participants by Brown & Tandon (1978). In their study, interviewed respondents gave less socially desirable and more extreme responses to a subsequent questionnaire, reported more involvement in the community, and were rated more active in community affairs than uninterviewed controls. The authors provide two general explanations for these differences: a "rapport effect" and an "arousal effect." A rapport effect results from the creation of a trusting relationship between the researcher and the respondent. Researchers strive to create such a relationship, on the theory that rapport provides frank answers to interview questions. The tendency to give "socially desirable" responses may be reduced by the creation of researcher-respondent rapport.

Furthermore, there may be an arousal effect as the outcome of respondent-researcher interaction around topics of importance to the respondent. "The experience of talking to a sympathetic audience about centrally important issues may result, as in [Rogerian] counselling in the reorientation of respondents' perceptions of the issue" (Brown & Tandon, 1978, p.198).



Changed perceptions that emerge from the interview experience may also include subsequent respondent attitudes and behavior. Even when the researcher's intent is to get information rather than to promote change or development in the respondent, the latter may be aroused by the experience to reconsider old attitudes and behaviors. Brown & Tandon conclude that high rapport and personally important issues promote the catalytic effect of interviews. As a counsellor trained in developing rapport, talking to people about a personally important issue, their healing—moreover, people who have elected to talk about their healing—I expect to be a catalyst in their journeys.

Whether the openness that comes from rapport is as valuable for the respondents as it will likely be for the researcher needs to be held in question. The effect of rapport was noted by Haig-Brown (1990) in her study of First Nations' control of their adult education:

Perhaps, because it is only rarely that people have the full attention of another adult human being with the sole purpose of understanding their experience, the interviews often became very intimate... This sense of intimacy may lead the study participants to take some risks in their disclosures. They may later regret this openness or they may feel very positive about having had the opportunity to talk about aspects of their lives in such detail and for a purpose (pp. 43-44).

In my study, I endeavoured to be sensitive to the participants' right to disclose what and how much they chose and trusted that they could take care of themselves in this regard. I aimed to establish a safe, comfortable atmosphere so that participants could share what they were comfortable in sharing. It was hoped that the openness of the questions allowed participants the freedom to create (with the researcher) an interview that was as valuable as possible for them.

That research be valuable to its participants is of paramount importance to Mishler (1986). Mishler calls into question the typical asymmetric power relationship in interviews and proposes alternatives intended to empower respondents. Mishler's focus is a shift away from investigators' problems, such as technical issues of reliability and validity, to respondents' problems, specifically, their efforts to achieve a meaningful understanding of their experiences and act in the world in accord with their interests. His central concern is:

whether and how different research practices and forms of interviewing may function to hinder or to facilitate respondents' efforts to construct meaning from their experiences, develop a fuller and more adequate understanding of their own interests, and act more effectively to achieve their purposes (p. 135).

Mishler points out the close link between the effort to empower respondents and the study of their responses as narratives. They are connected through the assumption that one of the significant ways through which individuals make sense of and give meaning to their experiences is to organize them in narrative form.

Various attempts to restructure the interviewer-interviewee relationship so as to empower respondents are designed to encourage them to find and speak in their own "voices." It is not surprising that when the interview situation is opened up in this way, when the balance of power is shifted, respondents are likely to tell "stories." In sum, interviewing practices that empower respondents also produce narrative accounts (pp. 118-119).

An additional implication of empowerment is that

Through their narratives people may be moved beyond the text to the possibilities of action. That is, to be empowered is not only to speak in one's own voice and to tell one's own story, but to apply the understanding arrived at to action in accord with one's own interests (p. 119).

Empowerment has been discussed above as a desirable pursuit, yet it carries some inherent shortcomings, according to Gore (1992). Gore cautions "those of us who profess and practice empowerment ... against didactic claims of 'what we can do for you'" (p. 55). The term "empowerment" presupposes an agent of empowerment, a notion of power as property, and some kind of vision or desirable end state; all three of these presuppositions may be problematic. Firstly, claims to empowerment attribute grand abilities to the agent of empowerment and may ignore limitations of the context of the empower-er-empowered relationship; for example, teaching feminist theory within a patriarchal system. Secondly, "to *em*-power suggest that power can be given, provided, controlled, held, conferred, taken away" (p. 57). And thirdly, we might be wrong in assuming we know what would be empowering for others. Yet, consistent with Foucault's rejection of conceptions of power as property, and consistent with the aims of this thesis, empowerment may be constructed as the exercise of power in an attempt to help others to exercise power (rather than as the giving of power) and then—Gore warns us—we must be humble and reflexive in our claims: "no matter what our aims or how we go about 'empowering,' our efforts will be partial and inconsistent" (p. 63). My efforts, thus, will be partial and inconsistent.

A first step in reducing the asymmetry of power between interviewees and interviewers, according to Mishler, is to view interviewees as informants or as competent observers and

interviewers as reporters. This approach is often adopted by ethnographers, who aim to report members' understandings—their cultural experiences—as faithfully as possible. By contrast, the standard interview tends to disrupt respondents' attempts to make coherent sense of themselves and their world because the interviewer typically assumes control over the structuring of meaning.

Mishler writes:

In a standard interview respondents are presented with a predetermined scheme of relevances: topics, definitions of events, categories for response and evaluation are all introduced, framed, and specified by interviewers, who determine the adequacy and appropriateness of responses. Finally, researchers through their analyses and reports define the “meaning” of responses and findings, whereas respondents have no opportunity to comment upon interpretations of their words and intentions (p.122).

Within this perspective, the issue of confidentiality bears consideration; that is, giving respondents control over whether and how they will be identified. I endorse Mishler's belief that “identification is a way through which members of the culture retain control over, that is, continue to ‘own’ their ways of ‘naming the world’” (p.124). In this way respondents are given their voices and credited for what they say and think. Respondents have a right to have their views represented as belonging to them, if they wish, just as they have the right to anonymity. Each of the five participants in this study chose to use his real name. Michel L, for example, said that using a pseudonym would take away from the power of his story.

Mishler sees a further step in the direction of reducing the power differential in an interview is to accept interviewees as *collaborators*, that is, as full participants in the development of the study and in the analysis, interpretation, and use of data. This approach is generally proclaimed by those espousing feminist research. Exemplary of a collaborative relationship is the project on women's development described by Belenky, Clinchy, Goldberger, & Tarule (1982). In the relatively unstructured interviews, the respondents were asked about what was important about life and learning from their points of view. Copies of interview transcripts were returned and reviewed together by investigators and interviewees. The work of understanding the material was a joint effort. The investigators noted certain positive effects on their respondents' lives of having participated in the study, such as a self-reported sense of change following the initial interview. For some, the interview was the first step toward “gaining a voice.” Smith (1987) also writes about the “consciousness-raising” possibilities of collaborative research.

The transformations in research practice that are proposed here—yielding control to interviewees of the flow and content of the interview, entering into a collaborative relationship, attending to what and how interviewees may learn from their efforts to respond meaningfully to questions within the context of their own worlds of experience, giving them a voice in the interpretation and use of findings—are intended to empower respondents by facilitating their efforts to learn and act. Accordingly, where possible I took a draft of the analysis to each of the willing participants in my study. I hoped to resolve any disagreements with them, by at least omitting disputed material or presenting it as such. I ended up speaking about the analysis with just one of the five participants; another one chose not to respond to it, two died before I had completed the initial draft, and I have lost contact with the other person. I incorporated Jim's feedback into the results and discussion chapters. His support of the project and his expression of appreciation of being involved in it were encouraging to me.

The empowerment of respondents advocated by the present research corresponds to Lather's (1986) concept of catalytic validity. Catalytic validity refers to the degree to which the research process "re-orient, focuses, and energizes participants ... knowing reality in order to better transform it" (p. 67). In acknowledging that value-neutral social science is impossible, Lather argues that valid research includes the catalytic.

My argument is premised not only on a recognition of the reality-altering impact of the research process itself, but also on the need to consciously channel this impact so that respondents gain self-understanding and, ideal, self-determination through research participation (p. 67).

Lather cites Gilligan's work on women's moral development as a good example of catalytic validity. Lather notes that as respondents began to examine their own thinking, a pattern developed whereby they moved from a conventional feminine construction of the moral problem (equating feminine goodness with self-sacrifice) to a recognition of the conflict between the dependence and self-sacrifice of femininity and the choice and existential responsibility of adulthood. Hence, the research provided an opportunity for respondents to grow through thoughtful assessment of their experiences.

Similar opportunities have been provided by other researchers who hold the interests of their participants in high regard. Sonneborn (Kirschenbaum, 1991) investigated widows' views of the

Vietnam war, by way of making a documentary film. Her intention was "to give these women a voice for their own grief, a chance for them to tell the stories that for years no one has asked to hear" (p. 86). Initially concerned that the effect of asking her questions might be distressing for the participants, Sonneborn reports that the women interviewed said things like "Thankyou so much for doing this. I feel a great weight has been lifted off my chest. I feel lighter now" (p. 87). Realizing that it seemed to be an incredibly healing experience for the women to be interviewed, she continued to interview as many women as possible. It seems that the film became "a receptacle for their sorrow" (p. 87).

In a study also dealing with grief, Moon (1990) interviewed female and male participants to investigate how each of their lives had changed following the AIDS-related death of a loved one. The interview evoked an emotional catharsis for virtually every participant, thereby facilitating their grieving process. They acknowledged appreciation for being able to talk about their experiences. Kreps (1992), who informally interviewed women to learn about their thoughts and experiences regarding relationships and autonomy, noted that:

Every woman I interviewed, without exception, made a point of thanking me for the opportunity to think about the subject. The woman quoted next is a good example....

"I wanted to let you know that in thinking about these questions that you posed, the questions themselves have acted as a springboard for other sorts of thoughts, and I'm sure that this is going to continue to perk, as my daughter would say, and bear untold other kinds of fruit. So thank you."

It is important to add that I do not suggest that the participants in my study needed to be changed, but it may have been valuable if through our interaction their own process were facilitated.

As a concluding note to this section on the impact of the research on participants, I draw upon Whittaker's (1981) guiding principle for respecting those we invite to be participants in our research. She suggests viewing privacy, time, and knowledge, as forms of property. This notion of property includes ownership not only of one's experience, memory, and attitudes, but also of the understandings and reflections one has about one's self. Whittaker writes:

The implication about privacy is that there exists some inviolable essence of the person, uniquely the property of that person. Others have obligations not to transgress it, dominate it, take advantage of it, and so on (p.442).

It could be said that research gets done by the negotiation of the boundaries of privacy. Ethical guidelines and the accompanying assurances to the people to be researched confer legitimacy on the process of encouraging them to let go their claims on privacy (p. 443).

The persons that sat with me talking about healing are incomparably more important than the research about their healing. Rather than this research being *about* people with HIV/AIDS and their healing, it is aimed to be *for* people with HIV/AIDS who are healing. Thus, consideration of the participants was paramount in acquiring knowledge, through the interviews, and also in interpreting that knowledge. The interpretation is presented in the following chapters.

## The Stories

The researcher's words are the glue that holds the report together. However, the research report must be grounded in the experience, and therefore the voices, of the participants. Their words need to be woven together with [the researcher's] into a well-integrated account. The researcher's words must be as free as possible of judgement and rhetoric.... In this way, the researcher can provide a forum in which the experiences and thoughts of the participants can be expressed (Kirby & McKenna, 1989, p. 156.)

This chapter on the results of the research is divided into two parts. The first part presents the stories of the five participants, in the order in which I came to know them. Themes of the stories are discussed in the second part of the chapter.

### Stories

#### Michel L

In 1981, lumps in his neck and arms led Michel L to suspect HIV infection. When the test for HIV antibodies became available in Vancouver in 1982, he was among the first to test positive. At that time he was already very depressed and was not surprised by the diagnosis. Being HIV+ seemed to be just one more thing, which

*didn't bother me because life was over.... I was really emotionally destroyed from my childhood and also by society's beliefs, as a homosexual, that it wasn't right to be the way I was. That's why emotionally I did not love myself and by not loving myself I attract illness.*

Michel L tried to commit suicide three times and then decided that it must not yet be time for him to die. After three weeks of not answering his telephone, he called a friend, who is a nurse, for help.

Reflecting on that time, he says:

*Sometimes to rebuild a solid home we have to demolish the old one and start from scratch again. That's what happened to me. I was so close to death and I almost did die and I thank God for coming to pick me up—three days [later] I woke up.... What am I doing here? I guess he doesn't want me, it's time to do something. I demolished my old castle.*

Now, almost ten years later, Michel L has recently had another biennial check up and all is well; there is no change in his blood cell count. What got him through? . . . friends believing in him and working on himself. During these ten years, he has explored many different healing avenues—individual and group therapy, workshops, talks and forums. He expresses a passion for trying everything:

*Last night I went to a forum on Chinese medicine. I said, "Michel, if you don't go and check you'll never know if it could be good for you. If you don't like it you just leave it and take something else." You risk nothing, you get nothing.*

The few illnesses Michel L has had have not been thought to be HIV related. In 1986 he had pneumonia, but not PCP, the pneumonia common to persons with AIDS. He views his pneumonia as a response to a visit from his father, who came two days before he became ill, and left a month later, when Michel L then started to get better. He attributes the illness to "lots of unfinished business" with his father, who beat him as a child. Michel L has since found peace with regards to his father. The intense hate he once felt has been replaced with loving him as a human being. He sees his father as not a good father, but "he did the best he knew how." Moving from hate to love involved forgiving his father and also himself for what he did to his father.

Michel L was recovering from a cold at the time of the interview. The previous week, typical for someone who is HIV+, he questioned whether it was "just a cold." However, sickness is not necessarily bad, according to him:

*Sometimes to me a well person ... they need to get a little sickness to make yourself appreciate health, because we tend to as a human being when everything goes smoothly we tend to take it for granted and then it's not good anymore and that's why the house tends to fall apart. And I think that's why sometimes like I've got a cold now, to make me appreciate that I've been HIV for so long and I've been well for so long.*

*Getting sick is an opportunity to grow up.... Disease is not something that we don't have any control over.... There are no 'mistakes'. To me there is everything you can get over, as long as you want to.... [My cold was] just a virus that got anchored into my system, that I've got to get rid of by taking care of myself.*

According to Michel L, taking care of oneself and being cared for are what bring about healing; in other words, loving oneself and being loved.

*In the doctor field they [are] all educated to be curing not caring and my belief is if they would start to care first with a person, they might be able to heal them faster and easier, because every human being needs love and affection, needs to be cared for.*

But he suggests that it is mostly up to each of us to take care of ourselves:

*If you don't take care of yourself and you don't do what's good for you no one else will.*

So taking care of oneself and secondarily, being cared for, will facilitate healing. To Michel L, healing means to be happy again, with no physical problems. He speaks optimistically about "our world" and "global healing." He sees the world as perfect as it is, giving everybody the lessons they need to evolve. He cites evidence of it becoming a happier place—the friendly



relations between the US and Russia, the collapse of the Berlin Wall, and the brevity of the Gulf war. Michel L contributes to global healing:

*During the war we had the 'triangle' we called it which was a universal prayer and you had to connect yourself with two people you really care for and say that prayer everyday.*

He believes that the energy thus created is far more powerful than war and helped therefore to curtail the recent war. The power comes from believing in oneself:

*I'm almost sure that's why nothing is happening to me healthwise because I believe very strongly into myself now. And I believe in the universe, that it sends me here also to help a lot of people and that's why I'm not dying of AIDS.... By my lifestyle and being open about it, showing the society and the medical world that being HIV doesn't mean death.*

Michel L was not always so open about his HIV status. It wasn't until 1986, four years after diagnosis, that he told his friends. Four years after that, in 1990, he felt strong enough to be public about being HIV+. Why the secrecy? In 1982, being HIV+ meant immediate rejection. At that time there was not the help or support that there is now; for instance, AIDS Vancouver.

*If I had told people I believe now that it could've killed me, because I could've been totally overloaded with bad energy, because I wasn't strong enough emotionally to declare myself.*

Michel L has needed to learn how to protect himself, acknowledging the destructiveness of some people's energy. As he has done more and more work on himself, so the effect of negative thoughts and words—for example, a derogatory comment about homosexuality—disturb him less. He believes that he is attracting a better energy towards himself now.

Michel L sees destructive patterns repeating themselves:

*I'm watching my brothers and sisters and I'm watching their children and they're just passing along all the traumas to their kids. All my nephews and nieces are going through exactly the same traumas that all my brothers and sisters and I went through 15 years ago, 20 years ago, ... because my brothers and sisters did not decide to change the pattern.*

Michel L strives to love his nephews and nieces unconditionally, and that means not judging them. This is important because he views the alternative—that is, rejection, by family, friends, society, and work colleagues—as a major hindrance to good health. By contrast, self-esteem, lack of emotional stress, and education—from living, not “book education”—are all associated with good health. Michel L has observed that the people who are dying from AIDS have very low self-esteem. Self-esteem is tied up with feeling comfortable about being oneself; for example, “being masculine in a woman's body.” According to Michel L, society's judgements about right and

wrong are incongruent with "living in our hearts", which is what he aims to do. Society's equation of HIV to death compounds the issue.

What about death? If someone dies it is better for that person, in Michel L's mind. He speaks about us controlling our own lives:

*If you don't look after your car ... like if you don't feed your car ... it won't last very long. Then you'll have to go and change it for another car. It's the same with our bodies. If we don't take care of this body, it's like if you don't like your car, it's enough to make it have accidents, breakdowns. Then you'll get rid of it because you're creating all that energy to get rid of it in your subconscious.*

In any case, Michel L believes that people reincarnate. However, it's not easy for him to watch somebody deteriorating physically and dying of AIDS:

*To make sure that I'm able to deal with the physical destruction I look them in the eye if they allow me to and then I look at the soul and that's when I see what the real person is. It's not the physical.*

And yet Michel L acknowledges that we need to take care of ourselves physically as well as psychologically and spiritually.

Exemplifying how he does take care of himself, Michel L talked about a current intimacy issue that is limiting his relationships with some people:

*There's a blockage, that means the energy stops circulation in my body and there's something wrong and I have to work on it.*

He has asked a friend to guide him in a rebirthing experience to help remove the blockage. That is, he senses a problem and is finding a way to resolve it. Michel L's healing continues. Comparing now with when he became aware of his seropositivity, he experiences far greater happiness:

*It's night and day, black and white, and I feel those two comparisons are still not strong enough ... as much as [Michel] hated himself in 1981, as much as he's loving himself now. It's a wonderful feeling. Before I couldn't spend any time on my own, I was very unhappy and scared and now I love being alone and that means I managed to make peace within myself and I think being HIV did a lot unto this ... it gave me the opportunity to be able to change my life for a better quality, instead of a quantity.*

## Richard

Richard's story is one of searching and struggling. Although he had always been interested in self-awareness, Richard sees his healing journey beginning when he sought help during a severe depression in 1989. He felt unable to get out of the depression, however his attempts to seek counselling were futile:

*I felt like I wasn't connecting with anybody to get to shift because they were trying to deal with self-esteem now and I was trying to get them to help me through my childhood ... so it wasn't working.*

After eight months of depression, Richard's concern about his tiredness led him to seek the care of a doctor. He soon learned that he was HIV+. Richard's fight against a lack of compassion and ignorance he experienced from medical practitioners began at that point, by rejecting the doctor's sentence of AIDS. Of greater impact than the HIV+ diagnosis was learning a few weeks later that his T-4 count was 20 (where 500 or less is considered serious).

*I didn't get more depressed from being HIV+ but when my count was 20 I felt like I was going to die NOW and I didn't want it to control my dying and I wanted to have control of that.*

Richard's depression deepened. Because of an increasing fear of suicide, he tried to check himself into the psychiatric ward of St. Paul's hospital. After an unsuccessful fight over two days to be admitted, Richard was feeling helpless and hopeless:

*As I'm reaching out, which is the first time in my life that I would do that to get help, because I was "strong" before, do it all on my own, [it] wasn't working and I felt like there was no place to go.*

A similar three hour fight at the Royal Columbian Hospital in New Westminster proved more successful. This gave Richard a tremendous sense of relief:

*I finally got in and when I got to my room ... everything I held onto all my life and everything that I was holding onto about HIV—all these people were saying AIDS to me and I had no symptoms except for the blood test ... -and when I got into the room, I had my own private room, it's like it all let go. I didn't have to work, I didn't have to cook, I didn't have to clean or pay rent or anything like that. And at that point now I wanted to die.*

For two weeks Richard hardly ate and was expecting to slowly die. And then he started fighting. He continued to reject the sentence of AIDS:

*They would come in every day and talk to me about AIDS: "You have AIDS, what's that like?" "I don't have AIDS, I'm HIV+." So I had to fight with them on that.*

Another source of conflict was a sign about blood precautions put on his door. The battle of taking down the signs (about five times daily) went on for about three weeks and then the hospital staff agreed to make a small card and place it inside the room.

Richard's major disappointment during this time was the lack of therapy. He strongly believed that he knew what he needed from therapy, however the regular consultations with the psychiatrist were not helpful. They focussed on the effects of the medication and AIDS.

*There was no therapy.... They were trying to talk to me about AIDS. So I was still trying to deal with the rest of my life and come up to HIV and AIDS and they just weren't cooperating! (Richard laughs)*

After three weeks in the hospital, the psychiatrist told Richard that he should be able to leave within the week. Richard protested strongly:

*"No, I don't think so. I think if one thing—one little thing—fell on my lap, on top of everything else, I think that I would just lose it." ... They didn't listen to me then either.*

Richard was discharged. Five days later, after unsuccessfully seeking help from the Mental Health Association and various churches, Richard consumed the remaining medication he had. He had cleverly and carefully determined that the pills would be fatal, but not painful. After taking the pills, he experienced calmness and then felt the urge to talk to somebody, so he called his sister in Toronto, even though he has never been close to his family. Two or three days later Richard woke up in hospital. He argued with them against their suggestion to go back to the psychiatric ward and felt blamed, not heard:

*[The nurse or doctor] said, "If you can't take responsibility for your life, somebody has to." I said, "I did take responsibility for my life, listen to me, listen to me...." She didn't want to listen to me and six burly security guards come bumbling through the emergency ward. So needless to say I went up to the psych ward again.... I felt like I had no rights and it's not like I just decided to kill myself and tried to do it, I tried to get help before that point and it wasn't working ... and rather than them taking that responsibility they just shoved me back into this place, this hellhole.*

Richard faced another battle this time: to get his own private room again, which he did, after sleeping in the "padded" room for a few nights. Richard recalls being disappointed by a lack of compassion from the staff towards the patients and disheartened to see the patients as "zombies" because of their medication. He enjoyed interacting with the patients and encouraging their socializing. He knew he had been appreciated, by how sad they all were when he left the previous time. Feeling truly accepted by the other patients precipitated a major shift for Richard. This acceptance spread to receiving the friendship and love offered by family, friends and work associates.

*They came to give me love and support and I couldn't believe that they loved me and wanted to support me ... because I was weak.... So one day ... I was sitting in a room with all of them and it was just such a powerful experience being aware of the love that they had to bring me. So that was my first step in allowing it to happen—to allow people to come into my life and to know who I am and to let them love me, to believe that I'm worth it.*

Richard used to have a fantasy about being totally loved and cared for in hospital. Numerous short visits for ear infections which began in childhood always left him hurt and disappointed because they would not keep him in the hospital. His more recent experiences have dissolved that fantasy. He has come to realize that the love and care he has searched for needs to come from himself and then through a willingness to accept it from friends.

Once again, therapy was not happening on the ward. As a consequence of refusing to see the psychiatrist because of this, Richard was discharged. He recounts:

*At that point I felt really scared because, although it wasn't really helping me therapy-wise, I had some sense of security and it gave me something to do—it made me fight all the time, so I had some purpose. Anyway ... it was the best thing that could ever have happened.*

Richard made contact with a psychiatrist at St. Paul's, and for the first time felt heard and respected by a medical practitioner:

*He wasn't trying to tell me AIDS, he wasn't trying to tell me anything, he just talked to me about what was right there for me.*

The psychiatrist gave him permission to suicide, but questioned his ability to make that kind of decision when so depressed. This immediately reduced what had previously seemed overwhelming to Richard.

*So when he said that, what felt like this big huge black solid metal ball that was surrounding me and on top of me and underneath me and on the sides, I could see it like two little balls, like one of them could fit in this hand. And one of them was depression and one of them was suicide and I felt like I could juggle them and see which one I wanted to work on first.*

This is where Richard sees his healing actually beginning. He chose to work on the depression and when that was gone, suicide was not an issue any more.

Richard is still committed to his healing. It has been a journey of increasing awareness and acceptance. Fighting when necessary has continued to be a vital part of the process. Richard started coughing and expressed concern about the coughing for two months and finally screamed at his doctor before tests were done to reveal that Richard had MAI (Microbacterium Avium Intracellular). That meant that Richard had AIDS. Despite the arduousness of all the fighting, Richard appreciates that it enabled him to connect more strongly with an inner strength. It may be why he is still alive at the time of this writing:

*If I wasn't a fighter, if I didn't just say—I'm tired of feeling this way because the doctors are not doing what they need to be doing with me—I could be dead.*

Much of what Richard spoke about, beyond the chronological details recorded above, concerns how he is different now and particularly, how differently he perceives things. According to Richard, what helps him in his healing is how he perceives AIDS. Richard views AIDS as similar to natural disasters—for example, earthquakes and volcanoes—and other diseases. He believes that they are all trying to teach people something. Of crucial value to Richard, AIDS has taught him about what is really important to him. Seeing the lessons in disasters,

*I don't feel like I'm a victim. I feel like there's a purpose for this in my life and I have the choice to learn from it or to block those lessons.*

Part of the learning for Richard is coming to know at a deeper level what he first knew only in his mind:

*I did a lot of work before the depression and was involved with metaphysics and knew logically that there's lessons and there's mirrors—what we see out there affecting us is a mirror of something that's going on in here [points to chest].... The HIV, AIDS, suicide, somehow that enabled me to connect what I knew up here to my heart and so it became a way of being rather than a way of thinking.*

For instance,

*I've known for a long time that death is a natural part of the process, but now I experience it as being that.*

Richard does not fear death. Rather, he believes that we die when our souls are ready to die. From the initial struggle of not wanting AIDS to kill him, then wanting to kill himself, Richard says he has been through the process of letting go of control in those situations and is learning to be willing to have whatever happens, happen. At times Richard has fantasized about who he would like to be in his next incarnation, but he ends up trusting that whatever he needs for his soul to evolve in the most natural way will happen.

“Letting go” is a recurrent theme in Richard’s thoughts on healing. Healing includes letting go of past conditioning, of how we were taught to be. For instance, part of Richard’s healing has been letting go of needing to be “strong”:

*Before I would think that I had to be strong. You can't let people know that you're weak and you cry because then they won't feel like you're the person to do the job or to be their friend.... And now I realize I have choices. So when I feel like I have to be strong I sit back and look at it ... and then choosing what I want to be and from that comes allowing myself to be human, allowing myself to cry, allowing myself to tell somebody, "... I just don't feel like a very good human being right now."*

So recognizing that we have choices—in how we behave, whether or not to take medication, and so on—has been important to Richard. He chose to take medication for the MAI, although he says that “healing is not drugs.” Working in a collaborative way *with* the doctor is most beneficial. More and more of his decisions come from an increasing trust in his intuition, the knowledge that comes from within. Richard draws an important distinction between what he hears “out there,” for example, what he reads about nutrition; and what he hears “in here,” which is his own intuitive sense of what he needs. And taking care of one’s basic physical needs is fundamental to healing. According to Richard, basic needs must be taken care of first; otherwise that is where one’s energy and attention go.

Richard has worked at also letting go of trying to change other people’s views. Realizing that the views of others (particularly many PWAs) do not fit his own experience has been a catalyst for Richard’s developing awareness of his own views. Seemingly paradoxical, accepting other people’s differences has paralleled a reduced sense of separateness from people and world happenings. Accordingly, Richard now rebels against what he sees as an importance placed on differences: gender, religion, sexual orientation, HIV+/ HIV-. Not feeling as separate from other people and what goes on in the world is a sign of healing for Richard, as is his acceptance of circumstances that others may often deem “negative” (for example: a gloomy day, death). Acceptance of self, others, and circumstances, are crucial elements of healing, according to Richard.

*Healing is being willing to come to a place where you're OK with yourself—at least for most of the time, I don't know if it's possible all the time—to be with yourself and to be with what's happening out there, outside of you, that is meant to be ... something's going to come from that which is going to be positive.*

Richard’s self-acceptance includes acknowledging his limitations. He recognizes the paradox in that accepting that he has limits and is not perfect is liberating rather than limiting. Liberation is also experienced through cleansing; according to Richard, healing means cleansing yourself—spiritually, emotionally, mentally, and physically. He aims to work gradually toward that, without unnecessarily stressing himself, and using a sense of peace as a yardstick. For instance, Richard smokes. While he views smoking as not ideal, for him to give it up does not feel constructive because,

*It takes me away from peace and then it's really easy for me to get caught up in other areas of stress.... I think that something came before smoking and when that something is transformed then there will be no more need for smoking.... When I get to a certain point the cigarettes will go automatically, it won't be a struggle.*

A recent experience of disrupted peace for Richard serves as a good example of how he deals with issues as they arise: Firstly he recognized that he had lost some peacefulness and then he reflected on it. He pondered options on how to deal with it and talked to supportive people, eventually resolving the issue and finding renewed peace. All the while, he continued his usual activities—various commitments, working out at the gym, and praying for peace. Working out at the gym and a commitment to do so every second day are important to Richard's healing. Making the decision to do so indicated a step in self-acceptance because it involved overcoming self-consciousness about being thin and fear of homophobic reactions. Praying is another important component of his routine. Every morning Richard asks for peace. He has found that asking for peace reduces the possibility of disappointment, because there are then no expectations of particular outcomes.

Reflecting upon a recent incident when

*on top of the brick wall was a bird and it was tweeting as I was passing by and I really felt like it was trying to speak to me...*

*[Richard said] Healing must be—it's not my total experience yet, it must be—getting in touch with the oneness of everything.*

Much of what he said regarding acceptance and lack of separation suggests that Richard was moving towards—and perhaps had glimpses of—that experience of oneness. Moreover, he was more content than when he became aware of his seropositivity.

*I feel like I'm a different person; I experience my person differently now. Every day is like a lifetime; there is no need to fill it with activities.*

Richard died shortly before I was ready to present him with a draft of his and the other participants' stories.

## Jim

(Refer to Appendix F for the transcript of the interview with Jim.)

The landmark of Jim's life was learning that he was HIV+. He views his life in two parts: before HIV and after HIV. Jim found out he was HIV+ soon after the antibody test became



available in Canada. He had recently moved back east to pursue his career as a journalist and a new relationship. He was enjoying life, until, feeling exhausted and drained despite efforts to exercise, he consulted a doctor. Months later, the results of a blood test revealed his seropositivity although his blood counts were normal. Meanwhile, enlarged glands, the exhaustion, and the sudden surge of publicity about AIDS, was very frightening.

*I'm just freaked out and feeling very isolated and just thinking that I'm in an absolute nightmare....*

*On the way to my doctor's office I passed through a cemetery that was on both sides of the road and I'm just thinking, I'm entering into the world of death. Death was right on my doorstep and meanwhile I had to struggle on....*

Jim did struggle on, in a new, high pressure job, a new city, and now living with a person that he did not get along with well. He spoke about the support he got from particular people at this time:

*My lifeline was in a sense the telephone and I spent a lot of time calling, particularly a woman I had met in Toronto, a lesbian who was ... your typically healing oriented person who I could speak with ... and a lot of tears and really in a state of just panic.*

Jim's sister, who had also recently moved to Quebec, proved to be an enormous support for him. He also did some deep work around dying with a bioenergenics counsellor. Confronting his mortality challenged a romantic ideal Jim had held of the "tragic hero" as epitomized by Lawrence of Arabia. Death following a heroic struggle had previously held some appeal, but the stigmatization of AIDS interfered with the possibility that he could die a hero. All in all, confronting his mortality had a major impact on Jim:

*This crisis made me realize that I was actually very ambivalent about living to begin with. In other words, a large part of me really did want to die because life just seemed so much of a struggle; and yet equally as strong was a very powerful will to live. And so I had this tremendous ambivalence and a large part of that will to live was really fear of death, a tremendous fear of death and a sense that a confrontation with mortality, the idea of mortality and it just seemed inconceivable to me. How could I possibly die at this point, it just was mind boggling. So I was in a tremendous state of struggle, internal struggle.*

When the results finally came and confirmed his fears, Jim felt psychically prepared, partly because of a prescient dream the night before. His response to learning of his seropositivity was as follows:

*I went out to the swimming pool and decided that I had to carry on. And a large part of that was I think based on a fear of ... being ashamed, like there was a tremendous amount of shame surrounding the idea of dying by AIDS because of all the negative connotation around*

*homosexuality. So some kind of inner strength propelled me to go and, "damn it all, this is not going to beat me."*

But it was far from easy:

*So I remember at the pool and I used to swim ... a lot and this was sort of my main exercise and I was swimming there and when I reached the end, the lifeguard tapped me on the shoulder and said, "you are going too slowly, you'll have to go in the other lane." And because I'd been in this sort of exhausted state and I was just so embarrassed.... I just had to plod on and work was extremely exhausting. Everyday I'd come back and I'd trudge up these three flights of stairs, weighted down by these heavy coats and the whole climate there and it went on like that for maybe six months; until one day when I was again walking up these stairs I felt a certain kind of return energy and it was just a little bit lighter going up the stairs and it was like, I thought to myself, "oh, maybe there is hope" and ... over the next six months I guess with the arrival of spring and I began to feel that, "well, I'm not necessarily going to die right then and there," so I began to look towards having a life, creating a life there.*

With this return of life, Jim began a new relationship with a woman. He found great comfort in going to the country where his sister and her lover had a house. He found solace in the river and eventually bought his own property in the same area:

*a little chalet on the river that appealed to me greatly and there was something very healing about the river. The river became a symbol for me of healing.... I'd just lie down on these rocks by the river ...*

Jim spent a lot of time alone and walked many introspective miles. He continued to value some friends and the time spent with his sister, which helped to process his grief and fear.

The following winter was again a difficult time for Jim. The relationship had ended and work had become more stressful. He recalls the distress of dealing with medical practitioners at the time:

*It was a horrible experience going to see these doctors because they were as freaked out as I was and they were not very compassionate. They kind of I think regarded me as a, almost a, not human ... an AIDS victim that they could monitor.*

Yet Jim did receive compassion and understanding from a hospital psychiatrist, who

*didn't accept that I was dying of AIDS. He treated me as a client with all of those normal ... psychological issues that needed to be addressed and a lot of it was very spiritual in nature.... He ... largely would just sit and look and nod. Yet for me it was enormously helpful.*

Jim reached a crisis point. He felt like he could not hold it together any longer. He decided to take a month's leave of absence and return to the west coast, which meant exposing his situation to his producer.

*I felt like at this point I don't care ... I gave up on all this effort to try and hold it together.*

An old friend of Jim's took him in and provided a refuge for him to rest and recuperate. Jim recalls his experiences there:

*It was a rambling big house, full of antiques and books. My job was to walk the dogs, work in the garden, do some kind of secretarial work—letters and arranging interviews and travel arrangements and that sort of thing. And I settled into this life, putting Quebec behind me, for a few weeks anyway, and walking the dogs up the mountain. This mountain road ... was a healing experience, there was something about the rushing water again that I found great comfort in and everyday I would go higher and higher so I'd be gone for hours, way, way, way up, miles and miles above [Howe] sound and I was getting in good shape. My energy returned and I was happy.*

In addition to the exercise, some valuable reading, and some deep work looking at life and death with his bioenergetic therapist, and Jim felt again that there was hope. He made the important decision to not return to Quebec, thereby letting go of the life he had tried to set up there. He lived at his friend's place for a year and spent a lot of time working in the garden. Doing hard labour was what gave him the most pleasure:

*We cut down a few big fir trees to let in more light so I spent a lot of time cutting wood and digging beds, hauling rock, using a wheelbarrow. And it was this labour that was so important to me, getting out of my head, away from intellectual pursuits in journalism and feeling in touch with the elements, earth, and metal. And that's all I wanted to do, really, that's all I wanted to do and I hated it when I had to do some kind of correspondence or something.*

Jim had no goals at this time. According to Jim, the biggest impact of being HIV+, which is associated with the societal expectation of it as a death sentence, has been on his ambition:

*When I went back east in 1984, I was ambitious, I felt that I really wanted to succeed in the media world and as a result I did ... have some major successes, did documentaries on CBC radio, the national network, wrote in the Globe & Mail, and really, interviewed cabinet ministers .... Subsequent to my return I gave all that up and only in the last couple of years have I reentered the media world but at a much lower key level, so I'm writing for obscure magazines and I don't really have goals or ambition....*

*[Having lived for 10 years with the continual message that AIDS is fatal] has killed my initiative and I'm not suggesting that that's an entirely a negative thing because it has forced me to be more realistic and grounded in a day to day manner, but nonetheless I haven't made any plans.... I don't think about real estate, I don't think about career, I don't think even about what I'd like to do next year; like I'd like to travel? set goals? I don't set any goals and so it really means an existence that is very much like "here and now." And there's, I think, a down side to that, which is a rootlessness or, I don't know exactly, and yet I think in fact it is more true to my nature and that the rest is kind of an illusion. And I am in a sense a free spirit, kind of a Bohemian and this is my life. But I suspect that over the next few years there will be a shift towards more goal setting, and one of the steps in that progression is the fact that I've started getting tennis coaching; it represents an investment in my future.*

Jim is also taking courses towards finishing a university degree.

Another of the consequences of being HIV+ for Jim, who declares himself to be bisexual, has been a reduced involvement with women. He sees the HIV issue as causing undue stress and

potential heartache in relationships with women, whereas HIV is an assumed possibility in the gay subculture. Regarding interactions with people in general,

*It's important to liberate myself from controlling people, people who want to control and manipulate me .... It's vital for my survival to be conscious of those situations and challenge them. It relates to my relationship with my mother, in particular, in so far as I'm reclaiming myself as an individual.... So I'm very, very sensitive to any interaction ... that is coloured by another individual's madness, alright? I've got my own madness, that I'm working through.*

Jim goes on to say how he has changed in how he responds to other people's "madness":

*My reaction now is largely just to withdraw because previously I would be much more prone to confrontation or challenging that other individual's psychology, but now it's like, wait a minute, it's my self-protection.... so my way of dealing with it was not a confrontational one. It was like holding my strength, holding my place with it and that extends throughout all my dealings in the world. It's the only way I can be in the world ... there's so much madness all around us that I follow my own path to avoid it. So it's something about finding my own strength [and] ... setting my boundaries.*

Speaking of boundaries, one of Jim's challenges has been learning to honour his limits:

*... learning to acknowledge my limits—very difficult issue for me, because of the I think rebellious nature ...—independent-minded and strong willed—that I had to adopt in order to survive my mother that has carried through and has in a sense been detrimental in so far as I sometimes I am not able to know my own limits. So I overextend myself, become exhausted and get sick, repeatedly. Then I'm thrown into crisis again and around and around we go. So one of the lessons that I'm looking at now is like learning to honour my limits. I don't like to think I have any limits and yet you keep running up against them, your humanness, frailties and all that.... I really see it as a lifetime challenge.*

The recurring periods of exhaustion are accompanied by gastrointestinal problems, leading Jim to spells of despair. At times he has wondered about suiciding, thinking that it may become his only option. Doctors have not been able to identify or relieve the gastrointestinal problems which has lead Jim to pursue alternative healing avenues, such as Vipassana Buddhist meditation, different workshops, reading, and healthier eating. He has also drawn upon his self-healing ability.

*I was plagued and plagued and plagued by this problem and every time this would flair up I would go into a healing crisis where I thought, "I'm dying, dying," again. And I would be compelled to go inwards and find some kind of resource, inner resources to pull me through, but only by reaching rock bottom. So there's a sort of paradox there of going through these slow deaths. That is something that I've struggled with now for maybe eight years and I'm still working on it with health consultants and doing cleansing programs.... It gets into an area that modern medicine just doesn't have a clue about ... you really have to become a pioneer in your own health.*

Jim describes an example of his self-healing:

*At the Vipassana retreat ... I was just freaking out because, here I'm doing everything, yet I'm still feeling sick. And I remember during one of the breaks going and lying on one of the bunks in one of these little cabins and I'm just almost shaking with fear and panic, I had a vision that, of the Christ coming to my side of the bed and just sort of glowing in light and putting his hand on my head and saying—I don't know the words but—impressing upon me his love and healing and it was real, it was as real as I can imagine.*

Some of the tools that Jim has and still does rely on for his healing are books, tapes, and music: Books by Tom Harper—For Christ's Sake, Stephen Levine—Healing into Life and Death (and others), Alexander Lowen—Fear of Life (and others), Greenwood and Nunn—Healing and Paradox, writings by Ram Dass, a book entitled—Dynamic Laws of Healing; tapes by Louise Hay; and songs by a reggae group: Toots and the Maytals—including “Spiritual Healing” and “Peace Perfect Peace.” These materials have strongly influenced Jim's views on life and death.

*I began to see death as offering peace after the trials of life. So it began to even take on an attractive quality. And I entertained ideas of reincarnation with a sense that this can't be all there is because why would we go through all these trials and accumulation of insight and wisdom if we die and it's gone, it doesn't make sense. So I've become quite philosophical and prematurely old in a sense and wise in a sense and I know that might sound a little pretentious but nonetheless that's what happens I think, for myself anyway. Some people I think go into more denial.*

Jim has also looked to death as an escape, but came to see the futility in that:

*I recently had the flu ... I got knocked right off my feet and I was very sick and it's hard not to think about AIDS when you're in that state. But it's not as though I think, “oh, I'm dying,” it's like, “oh, I've been through this before and batten down the hatches,” but nonetheless it sort of throws you back into the emotional crisis and all the issues that I'm working on in my therapy resurface ... I was really full of despair, thinking, “I just want to die, this is so much struggle it's just not worth it. I want to die, let's just get on with it.” I was forced to pick up Stephen Levine—I rarely consult now with my healing books ... unless I'm really forced to—and I opened up to this page on ... countering the notion that death is the goal for the liberation into a peaceful existence—the sort of approach that the traditional Christian church advocates—and he is saying that it's all in the here and now and if you just wait and expect it to happen when you die, like there's no guarantee of that. I'm not being very eloquent at trying to express this but it's the idea of returning “home” and what he reminded me of was that the “home” is right here right now in the living and the kingdom within. So I realized, “alright, OK, it's not time to go yet!” So I reemerged from that, so what it, what I learned through all this is that there's this series of little deaths that I keep going through and that I will keep going through over and over again, plunging back into the confusion and despair and that that is just the nature of life and that even though it get's a little easier each time, somehow that I shouldn't look towards some great breakthrough because that's just not our existence, what our existence is on earth.*

Meanwhile, friends of Jim are dying from AIDS and causing him to wonder why some people die and some do not die. This has led him to reject the medical model of HIV with its theory of the inevitability of physical deterioration. Jim has had little to do with other PWAs because of the emphasis he sees that they place on drugs and the disease model.

*My experience has been, "Hey wait a minute, I'm not sick" [that is, with AIDS symptoms]. I keep having to reestablish that and what better evidence is there than your own state of health?*

[Since the initial interview Jim has participated in a PWA workshop on relaxation and stress which he found most valuable. He "broke through stereotypes" he had held about people with HIV/AIDS and experienced a "brotherhood of survivors."]

Jim does not expect to die prematurely from HIV and is busy enjoying himself:

*I think I'm going to live to be an old man.... Yet at the same time I have the sense that this life has been very rich to this point and that if I did die I don't have any regrets. So it's somehow not as important, but what is now important—is for me my passion—is playing tennis. It's my expression of physical vitality and enjoyment of life and fun.... I feel as though I'm through the crisis part of all this and now I'm more interested in enjoying life in the present, whatever duration life might be.*

There has been a shift over time for Jim in becoming less determined about pushing himself to go swimming and to do everything that seemed healthily correct. While he views his earlier determination as valuable in accessing an inner strength, now he is more likely to have a beer and generally enjoy himself more:

*I'm less of a purist, less zealous about my health; for example, I'll smoke two or three cigarettes a day or I'll party, I might smoke pot occasionally, yet I'm in good health. I play tennis a lot.... I think there's a danger when people are confronted by ... a life and death situation that they become over-zealous in their approach to healing; they become purists, ... they adopt a kind of mind frame that is constrictive both in practical life terms but also spiritually. There's a denial of the importance of expression of the ecstatic, dionysian, celebratory aspect of life and through that comes the renewal, in all sorts of traditional cultures.... So to participate in a winter solstice party, a couple of years ago—adopting some sort of pagan rituals with a group of friends, for example—was a very uplifting experience even if it also included an overindulgence in, I don't know what, alcohol, stuff. So that in any case for myself it's really important to have that kind of latitude, that it's as much a part of my healing as taking care of myself. So what I learnt is that indulgence doesn't—I think from our cultural upbringing I had this very black and white perspective of good and bad ideas, notion of what indulgence was—and then I realized that indulgence is alright but overindulgence is where you get into trouble. So it's important for me on occasion to go dancing and be expressive and if that includes some substances that's OK and I'm finding my levels.*

Jim's tempered attitude towards indulgence matches a more relaxed attitude towards understanding the meaning of it all. At times he has desperately tried to comprehend the meaning of HIV, AIDS, and his situation, yet now is more resigned to simply not knowing. Prompted by Louise Hay's suggestion, he speculates that it is predominantly gay men who have been getting AIDS because of internalized oppression and a lack of self-esteem that have come from society's

negative attitude towards homosexuality. In any case, Jim's focus is less on trying to figure it all out and more on what he needs to do right now.

Jim has come to understand that feeling as though he wants to die and give up is a natural part of his experience. He believes in the paradoxical concept that we actually find our salvation in the process of giving up the struggle.

*The major challenge is learning to give up in the face of it, give up the struggle and to be able to fail and somehow rely on a kind of renewal that comes from that. And it just keeps on happening over and over again. So I think that of anything that I've said that's one of the most important messages is that we've got to give into it. It's a very scary thing because if you think you're going to give into it then you're going to die, so when is it right to make that decision: do I need to go out and exercise or do I really need to just go to bed and read a book. And so it's always presenting itself in little ways like that or maybe in bigger ways like ... is it right for me to go on lithium or maybe even AZT, which to me is like poison, but maybe there will come a time, I don't know.*

Reflecting on his journey, Jim says

*It's been very much an inward journey and in some respects I feel as though my youthful altruism has been sacrificed, it's gone by the wayside and I feel self-centred, almost to the point of being selfish.*

Yet, Jim also observes:

*I do feel that I am a much more compassionate person, although very discerning as to where I will employ that. And it's more often than not in a casual kind of circumstance—somebody on the street, an old lady crossing the street—rather than a situation where you'd think it ought to be applied, in other words I don't have time for people who are self-indulgent or, what I mean is wallowing or needy.*

Jim has experienced his journey as humbling, as cause for humour, and providing a profound sense of the hopelessness of it all:

*... humour ... this is something that ties in with the giving up of the struggle and that is being able to embrace the hopelessness of it all. And I mean the ironical business of it all, of our lives ... it is just utterly, utterly hopeless. And rather than that being something to despair about in fact it was something to take comfort in because if you look at the word "hopeless" and you divide it up into "hope" and "less" and you look at what hope means, hope is always something in the future—like I hope this happens, I hope that happens—and most of the time we're disappointed; so if we do away with the hope, or realize that it's hopeless then somehow there's some salvation in it. I don't understand it entirely.... So, my message is that it's hopeless! [said with a broad smile]*

## Michel G

Michel G learnt that he was HIV+ in September of 1986. His boyfriend had died four months earlier. According to Michel G, the relationship was destructive and they were no longer

living together. He knew that Andre was ill, but not that he was dying. It was the closest death Michel G had yet experienced and was shocking:

*It's like being plugged on BC Hydro for about 10 seconds!*

In a stupor, Michel G went to the hospital where Andre had been. The death was confirmed.

Reality did not hit till the following morning:

*It struck me after I slept. When I woke up I was washed up for—I like the expression: “I had the wind knocked out of me”—for about six months. Six months of schizoid ... schizoid in the sense that the world didn't make much sense for me before, but it REALLY didn't make any more sense after this.... All of life seemed to be going in the wrong direction .... nature made sense but the world, man's world [choice of pronoun intentional], was just like: What are they doing? Where are they going? Nothing made sense any more.*

So when Michel G went for an HIV test, four months later, he was in a state of cynicism and apathy:

*I remember actually saying: “Well go right ahead, lay it on me, what more can you do to me, what can be worse than this.” There was something that could be worse than that. That's when the doctor said that I was HIV+. But I was still so washed up by Andre's death that it was like ... sure, anything else going to go wrong? So it was really like apathy, like, go ahead if you are going to destroy me, do it now.... The bomb might have dropped and I would've said, OK, what's next?*

He got no support from his family; in fact he got no reaction from them. By contrast, he

appreciates the response from his friends:

*What they did, which I thank them [for] now when I look back, is didn't overreact and didn't underreact, just said, “Oh you're going to be OK.” Kind of like a grandmother who doesn't really know what the hell's happening or what you're talking about. So the best thing to do is say, “you'll be fine” or “just don't worry about it.”*

Michel G says that a part of him died and for a time he felt confused about whether he was actually alive or dead and what being alive meant. Then he went into what he calls a hyperrealistic phase, which lasted two and a half to three years. He describes this phase:

*I would try to get drunk and it wouldn't work. I could drink 20 beers and it had no effect. It actually excited me more than anything else and I wouldn't lose my awareness, I was trying to sleep or not be so aware, because I was what would seem to an ordinary person, over-aware, hyperrealistic.*

At the same time he was seeking to understand “death,” because

*in those days—that was 86—it was still a death sentence. When the guy said “HIV,” you thought “dead.” You didn't think [that a] Course of Miracles was going to come and knock on my door, it was DEAD. I'll be dead in so many weeks or so many months... But there's a part of me that was saying—that wasn't saying, “no”—but that was saying, “ha ha, there's a joke to this and this can't be; this is not the way the story's going to go.”*



Michel G maintained the belief that he was not going to die and this guided his behaviour. He fluctuated between periods of drinking and partying until he emotionally broke down and periods of strict macrobiotic diet for many months. Prior to being HIV+, he had explored metaphysical and spiritual literature (for example, Buddhist writings) and eaten a macrobiotic diet. He bought his first AIDS book a month after his HIV+ diagnosis. Over the following year he read and researched intensively. The understanding gained from all his reading (that is, not just about AIDS, and pre- as well as post-HIV+ diagnosis) has shifted to a deepened understanding of health and healing through his experiences since being HIV+. This exploration has continued and has included participation in different workshops and healing opportunities. Michel G sees the power of their healing potential as inextricably linked with the belief system surrounding them. The mind frame seems far more important to him than what one actually does:

*I think the angle I was coming from all the time ... for example, change your nutrition, was ... where you're kind of twisted because if you're starting from a point of view that something is WRONG with you ... you automatically get caught up in it.... The guilt loop— where you do something that you think is wrong then it produces guilt which makes you feel bad, so that to get relief you go back to the exact same thing... The possibility is almost always there, we can do it through guilt or we can do it through love. If there's a switch that has to be made it's more than to buy a book and say, OK now what I have to do is this, then I'll live. I tried that. I went to AA thinking, "oh, if I stopped drinking then I won't get sick and I'll get to live longer." That cannot be your goal. If your goal is only to survive, then you're caught in the same thing as before... [H]alf the people are living out of a reaction to the fear of death or a reaction to: I have to make it, I have to survive, I have to have the food, the house, or whatever. So, if illness does teach you anything and if there is a lesson to be learned it's to move out of that first degree of lifestyle, which is a continuous reaction to everything. And also, a lack of trust in the self. So, I'll stop making speeches [!].*

Regarding his own behaviour, Michel G says:

*I usually don't know why I'm doing what I'm doing, but I do it; and to leave me alone, that I know what I'm doing but in fact really don't know what I'm doing.*

In a similar way, he views his healing as happening almost outside of conscious awareness:

*When I start talking about souls and whatever, then I'm getting closer and closer to what it is that has to be worked on, but at the same time the work is being done. It's kind of strange how it's all working together. Even though I haven't made myself a home like I thought I would, even though I didn't do the things that I thought I should've been doing to heal, I'm seeing that my healing has actually happened or it is in process, which doesn't mean that I will be symptom free and that I will live for 100 years, but there is something that has happened.*

What is healing?

*It's almost as if I know what it would be [to be healed], but I'm not there and I don't really want to.*

*Healing is experiencing your life and taking risks, and being responsible for everything that happens to you ... the word is "responsible," it's not being "guilty," which is much more about what we're taught in our society than true "responsibility."*

Michel G became aware of the difference between responsibility and blame in his late teens, the time when he became critical of the world. His criticalness seems to have served to help him define himself:

*I had built my life much more on what I didn't like and did not want to be than on what I wanted to be and what I did like. I was much better at protecting myself from everything I thought was stupid and silly and not right, or even wrong. But when it came to creating my life I never knew what I liked.*

He was confident in his opinions on, for example, interior decorating, or literature,

*but when it came to me I just didn't know.*

Determining his own life—for example, finding a place to live—has felt overwhelmingly difficult for Michel G. He thinks it requires more emotional courage. He has come to know himself better, and in so doing he recognizes a “personality” that has been constructed to fit into society, a personality that is not really “Michel.” Becoming more “Michel” is very much a process.

*And that's what's scary because you're switching from somebody you think you know that you are, to not knowing ... it's a death process.*

For example,

*It's [easy] for me to ACT OUT "the lover" because I've done it before ... but when I go deep inside ... then it's a whole different story.*

For Michel G, that is where alcohol and drugs can come in to play, to numb uncomfortable feelings. Yet he recognizes the importance of those feelings in understanding who we are and what we need.

Overcoming fear is a crucial element in Michel G's healing process:

*If there is anything I think that would definitely screw up or slow down or block healing, [it] is the mind, the belief system, or the unwillingness to change the mind, and fear.*

He has become aware of his own fear partly through rebirthing therapy. He senses resistance coming from fear. Michel G likens the fear to how one might feel just before speaking in front of a group.

*When that moment occurs you can decide to stay with your head or talk from your heart. Now what your heart will say is actually coming from your soul. So that's basically the choice you have, and that's the choice we have for everything in our life. So when I get to that point where I have to choose, there's an amazing fear that comes up and in most of my life I have chosen to escape.*

Fear loomed large in Michel G's childhood:

*... adrenalin ... such a strong shot of it that it blows your mind and you're kind of out of it for a few days. That occurred in my life since I was 5, 4 years old, because of violence. I've even looked at how I became addicted to that because it was the strongest emotion or feeling I've ever had—was fear—so how we recreate that fear to wake us up through relationships, drugs, or accidents, or something.*

He experienced the fear the previous evening during a talk by a woman called Nero, who claims to have reverted back to being HIV-, despite being HIV+ previously:

*The same feeling as with my traumas and as with last night: I thought my stomach was going to blow to pieces, and the adrenalin rush, and the explosion of the head. So this thing has come back in my life, continuously.... I thought I was going to blow up ... it's fear.*

He views the episode that previous night as providing a choice: the choice to run away or, with courage, to face the fear and in so doing, heal.

Michel G says that he no longer “hopes” for healing, rather he recognizes the healing is going to come from his own work. He says that ultimately we have to take care of ourselves and

*hope is for people who very often don't want to be responsible.... You're going to live your life whether you want to or not, so you might as well be responsible for it.*

I understand his comment to mean that we are responsible for our own lives so we might as well acknowledge it.

*There's this very funny saying that Quebecers use ... in French it's “sans sauce” ... the picture is, life is a great struggle, right, and how are you going to get out of it? How are you going to get out of your struggle? But it actually sounds like, how am I going to GET OUT of life? Instead of, how do you HAVE a life? Who tells you what anyway? Who do you rely on?... What's real for one is obviously not real for the other ... there are no more heroes or models .... People who aren't going to be able to become lighter and follow their soul direction aren't going to make it.*

Taking responsibility, according to Michel G, involves engaging in life rather than trying to escape the struggle that is life. An important part of engaging in life for him involves processing experiences on an emotional level;

*otherwise you end up ... blocking yourself out, which down the road doesn't work because you can't block yourself out from everything. You'll end up then getting less and less feeling; or feeling more the pain and needing more relief, which our society is very much based on.*

Michel G has physical symptoms associated with HIV and his T-cell count is very low. But for him, healing has more to do with emotional health than physical health. Without the fear that obstructs his healing journey, Michel G expects that he could fully experience whatever presents

itself, as opposed to suppressing it or escaping from it, through alcohol, for example. Looking back he sees how he has fled from pain in his life, thereby “avoiding” life. Michel G asserts, however, that we are taught to be suppressed and limited.

*You're suppressed all your life, your true natural being. So healing would be to integrate my whole personality, my whole self, so that there would definitely be a stronger me.*

The impact is far-reaching.

*... everybody suppressing. Then we even forget why we're suppressing, so we become so asleep that we're just doing it mechanically. So all you can do, if you want to do any work in that, is to be yourself, that realized self, because when anybody comes in contact with you they'll actually wake up. They know that they're hitting something ... it's obvious, you feel it right away. I know when I walk into a room if I'm in the presence of somebody that's slightly more awake than others.... What I'm talking about is a kind of self-realization that gives you a very high energy that is feelable.*

Self-realization comes through a kind of surrendering,

*a surrendering to a part of you that's actually not more real, but—I don't like to use the word like “true essence”—but basically that's what it is. So that things flow instead of the mind always saying, “that's the way it is, that's the way it's going to be, I'm going to make it this way” and so forth.... It changes the whole mode, it's a switch.*

Michel G referred to an example given at the talk the previous evening:

*Nero was explaining last night about being in a room with ten angry people. You can [run away or fight] or become a victim of their anger; [or] become kind of so liquid and permeable that you just slide through and actually you can light up a whole room of ten angry people ... but until the mind lets go, the friction is amazing.... It's just a switch from how you were doing it ... a different way of seeing things.*

The possibilities of seeing things differently and making changes

*are endless as far as I'm concerned, more now than ever. I felt that before but I didn't understand it, now I KNOW it. I've experienced things that make me really believe that the possibilities of the universe are endless.*

Michel G's faith in possibilities extends to his judgement—or lack of it—of people. He aims to have a broad, accepting perspective on people's behaviour. He gave an example from a workshop where a woman spent the entire time crying and “running around.” While a psychiatric assessment of the woman would likely not be favourable, Michel G has faith in the integrity and worth of this woman and her reality, which will be different from others' reality. He maintains that the more perspectives you have the less vulnerable you are. Vulnerability is connected to the circumstances and beliefs—of self and those around—when one learns of being HIV+ :

*Vulnerability plays a major role in HIV... a lot of people told that they are HIV today live longer than the ones that were told in 82,83,84... [partly due to] outside pressure. We've*

*seen that in biological and sociological research: In a small village, if the whole village except one person believes that this one person is going to die of something or believes in an evil spirit and this one's got it, well the chances that this person goes crazy and does come up with an evil spirit are very high, because you're fighting against what should be your support.*

Michel G is aware of the powerful influence of other people and has sometimes found himself in relationships that have not been healthy for him.

*I've been known to trust people that are crazy, because I was raised with crazy people—crazy in the sense of that you never know what's going to happen.... I've always given a chance to crazy people, in the sense that I always thought that there was still a human being behind that craziness, right? Well I would go along but then end up getting hurt because obviously you never get what you want, or you never get your needs met from crazy people. They're much too busy with their madness.*

Even still, he expresses a relentless hope and faith in himself and others:

*I can't totally discharge bad habits and craziness because I know that there's a way. If I'm still here and I'm talking to you, then there is a part of me that was never crazy and is clear, because I've made it. I've made it this far. So that's the part that I always give to people, that I leave to them, because I always believe—everything I've seen in this lifetime—anything could happen.*

*I have my brother who's taken drugs all his life who's still standing. He's not a happy person, but I do believe that he could—there could be a switch around in his life—and that he could be transformed; not to a better person but to a happier person in his life.*

While he wonders if he would know how to be with a balanced and caring person, Michel

G's optimism extends to relationships:

*If two people in a relationship decide that there is another way to live their relationship, or to experience whatever it is they're having difficulty with, then they will find a way because the possibilities are endless.*

So he finds it difficult to leave a relationship, even when he is aware of its destructiveness to him.

*The hard part is to leave the person, because they're still a person. You can't just open a self-help book or whatever and say, "Well, I'm sorry, you're dysfunctional. I can't be with you" .... It's fine if you're going to live your life like a shopping plaza, and just choose out the good and throw out the bad.*

When Michel G does not have someone to love he finds it very difficult and life seems to lose meaning for him. He feels more confident about his ability to take care of others than himself, having learnt this from his relationship with his mother. Michel G learns from reflecting upon past relationships. He sees similarities between the women and men to whom he has been attracted and his mother and father. As he spoke about some of these previous partners, he voiced compassion and an understanding of why they had the problems that they did.

Michel G says that part of overcoming his own problems lies in becoming more aware of when his response to situations is out of fear. He recognizes his need to trust his feelings yet his mind has usually had to be in control. Now it is important for him to

*be able to let go of that control tower and trust your heart, and move from the heart.*

*When I get that rush signal and I feel like leaving from wherever I am, it's because I'll be talking from the heart and not from the mind.*

The resolution of conflicting internal messages may be critical to health:

*If people can dematerialize then illness is definitely a choice, not on the part of the personality level, but could be a choice of the soul level. Or that it's the perpetual conflict between the two that creates a breakdown in the body, because if it's not flowing then there is a continuous friction, which eventually creates a breakdown where disease enters.*

*... They're all explanations, which is interesting, but when you're in it ... the minute I woke up in the store I got back on my path, because, the street signs only give you the name of the streets, they don't tell me where to go.*

Michel G has chosen not to walk the streets of religious groups, even though he has valued spirituality since the age of at least 17.

*Was it out of fear, or hidden wisdom, I don't know. I know that I've felt separate from a lot of the world.... There's also the positive side of it, where actually those groups are accelerators for you. Meaning that, for example, the Rajneesh was an accelerator for people to process faster. So you would meet your grief, pain, and sorrow quicker in a group like that than—it's easier to hide in the world than to hide in a small group ... if we're doing a "healing circle," well you're going to have trouble hiding.*

Michel G expresses a skepticism towards so-called "spiritual leaders." He reports, for example, that some of the Rajneesh leaders were HIV+ and engaging in frequent unprotected sex. He does, however, participate in a meditation group. This group focuses on the meditation and does not involve personal sharing.

Emotional intimacy with friends, however, is important to Michel G. He has experienced with dissatisfaction some primarily physical relationships with men and speaks of his need for a more "wholesome" relationship, which includes emotional connection. Lately he has been missing the greater warmth and emotionality he experiences with Quebecers and has been wondering about moving back east.

*I know that what you see outside of you is very much a reflection of how you feel and who you are, but I also know that culture does exist and I have been finding it very, very hard to live in Vancouver on a cultural level. Maybe that has been a good thing because it's forced me to look at some things, but I do find it difficult to communicate on an emotional level.*

Despite how much he has already learnt, Michel G still has a sense of "not knowing":

*I've become aware of all these different things; that's all fine and I can sit here and talk to you about it. When I walk out the door, I'm always at zero. I don't know what the next move is going to be.... I'm still functioning from survival mechanism. I've learned about all these other things, but it's not integrated and I don't know how it's going to be integrated.... I still don't have all the information for myself.*

While Michel G's words may suggest an insecurity, perhaps they elucidate the ongoing nature of the healing process:

*There is no such thing as "healed" anyway, because life goes on for a long time. It's an endless journey, so there is no healed.*

*In rebirthing you are told that part of your unconscious mind is part of what your conscious mind doesn't want to know. So it's very possible that my life could be planned otherwise than what I am actually consciously making myself believe is going to be. The idea would be to make it come together.*

## Michel T

[Michel T's story is short and devoid of quotes. The interview lasted about an hour but was unwittingly not recorded. A few months after our interview Michel T was diagnosed with a serious infection. Treatment was to involve considerable discomfort and loss of dignity. He chose to end his life.]

Michel T knew that he was HIV+ years before the antibody test came out that later proved it. He knew when he visited a man in hospital who was close to dying from AIDS. This man's lover and Michel T had been sexual together. It was 1981 and Michel T was visiting San Francisco. He then flew back to his home in Key West, Florida, and immediately declared celibacy, much to the surprise of his lover and friends. He turned his "orgy" room into a studio and began to paint for the first time in his life.

Painting has been healing for Michel T. It has been a powerful source of expression. At other times he has written, in prose or poem. His paintings decked the walls of his apartment where our interview took place. He proudly explained to me the series of paintings he is working on, entitled "Addictions of the '80s." Each painting focuses on an addiction theme: tobacco, alcohol, food, marijuana, and the last one yet to be finished, sex. His paintings are rich in colour and symbolism. Some of his earlier paintings were sold as part of the first AIDS benefit, in New York.

From the moment that he returned to Key West in 1981, Michel T aimed to set an example of awareness and self-responsibility. At the eulogy for his lover who died from AIDS a few years

later, he informed the congregation of the HIV antibody test and advised them to get tested. His own seropositive diagnosis had been confirmed that very day, also his birthday.

Michel T returned to Vancouver to be a part of his father's dying process. Dying is key to his concept of healing. He defined healing as accepting death and being ready to die. He had an acute awareness that we know for sure that we are going to die, but we do not know when that will be. Since his health fluctuated, he was never sure how he would be at any time. Michel T showed complete acceptance of that uncertainty by doing what he could when he could.

And what gets in the way of healing? Fear. Fear sometimes manifests as anger and hate and Michel T worked at letting go of these. Physical exercise in the gym helped to release and express these emotions. Many avenues for self-expression—painting, writing, exercising, and talking—seem important to Michel T's healing. Addictions also interfere with healing, according to Michel T. While choosing not to take drugs, he saw all substances of addiction as being tools that become addictions when power is given over to them. At the same time, Michel T passed no judgement against those that do use substances of addiction or in other ways behave differently from himself. Rather, he expressed compassion and forgiveness towards other people, particularly his father and siblings who have been, even in recent years, abusive towards him. At the same time he was aware of what felt constructive or destructive, having been sensitive to the psychic energy of those around him.

Michel T expressed great appreciation of his friends. AIDS Vancouver and the PWA Society have also provided valuable support. Furthermore, he also recognized opportunities for healing presented by those who are more difficult to get along with. Michel T seems to be a friend to many. I have the image of him gently approaching people and offering friendship and then allowing them the space to respond as they wish. In response to the question of how we, including counsellors, can foster other people's healing, Michel T replied, "Being there; being there and responding from the heart."

Michel T's favourite quote came from Gandhi and is something like, "Be a person of your time." Michel T identified with Gandhi's words; as a person with AIDS, he saw himself as a person of his time.



## Themes

From the above stories, I identified various themes that I perceived to capture the essential features of each story and to enable comparing stories. These themes, discussed in turn below, are: circumstances around the HIV+ diagnosis and its impact; the journeys; acceptance and letting go; healing; beliefs, death and illness; self-responsibility; people; and reflections on the journey so far.

### Circumstances Around the HIV+ Diagnosis and its Impact

Michel L and Michel T “knew” they were HIV infected back in 1981, before the antibody test was available in Canada. Jim learnt in 1985, Michel G in 1986, and Richard in 1989. The impact of learning about their HIV+ status varied among the five. Michel L, Richard, and Michel G, already severely depressed, were not immediately shocked by the new information. The impact was greater for Richard a few weeks later when he learned of his extremely low T-4 cell count. Death then seemed to loom near, as it did with Jim, although Jim’s emotional reality at the time of diagnosis had been an optimism about life. The impact on him was traumatic: “I just freaked out and feeling very isolated and just thinking that I’m in an absolute nightmare.... Death was right on my doorstep.” He was surprised to realize some ambivalence about living in the first place; “life just seemed so much of a struggle.” The struggle of living felt overwhelming for both Michel L and Richard, who attempted suicide shortly after learning of being HIV+. Michel T took a proactive approach after the diagnosis by declaring celibacy, turning his “orgy” room into a painting studio, committing himself to setting an example of awareness and responsibility, and educating people he knew about HIV.

Richard, Jim, and Michel G all consciously rejected (not without struggle) the societal expectation that HIV was a death sentence and they each expressed a will to live. Richard said, “I do not want [HIV] to control my dying.” For Jim and Michel G, death was inconceivable. According to Michel G, “When the guy said ‘HIV’ you thought ‘dead’ .... But there’s a part of me that was saying ... ‘this is not the way the story’s going to go.’”

### The Journeys

Learning about being HIV+ may have precipitated major changes in the participants’ lives.

Michel L and Richard seemed to hit rock bottom shortly after their HIV+ diagnosis and have since then been rebuilding their lives. They each consciously reached out for help. Michel L maintains that "sometimes to rebuild a solid home we have to demolish the old one and start from scratch again. That's what happened to me." Michel L's journey has been one of exploration and developing self-awareness. In fact, evolving self-awareness characterizes the journeys of all five participants. For Richard the initial reaching out was futile, only leading to further frustration and a sense of hopelessness. However, fighting for what he has needed has enabled him to contact an inner strength. Richard sees his healing actually beginning when he connected with a particular psychiatrist shortly after he attempted suicide. Searching and struggling describe his early journey and echo in Jim's story.

Jim dragged his feet for the first few months after learning of being HIV+, toiling to maintain his work commitments. He found comfort and sustenance in quiet places away from the city and especially by rivers. By the time his energy returned Jim had quit work and was in good physical condition. Doing hard labour was what gave him the most pleasure during this period, freeing him from intellectual pursuits and enabling him to be more in touch with the earth. Jim has since resumed working as a journalist, but less intensively than previously. He describes recurring periods of exhaustion, going through many "slow deaths" over the years, each time becoming more self-aware, particularly regarding his limitations. During these episodes Jim was compelled to turn inwards and, like Richard, connect with inner resources.

All the participants have had periods of not being employed, which seemed to be fruitful in allowing them to devote time and energy to themselves and their needs. Michel T's journey has involved reaching out to people, both in receiving help from empathic people and in sharing his knowledge and experience. Similarly, Michel L and Richard have been highly active in contributing to educational and counselling programs of the PWA Society and AIDS Vancouver. Michel G talked about becoming more involved in these organizations. His own healing journey seems to be experienced as very much happening, but rather chaotic! Since an initial state of confusion and his "hyperrealistic phase" he has had periods of "partying" that have led to emotional breakdown and also periods of health conscious living. Like the other participants,

Michel G's reading and exploration has enhanced self-awareness, particularly regarding societal and familial conditioning. He realizes that: "I've become aware of all these different things," and yet, "I still don't have all the information for myself." The process of evolving self-awareness seems to incorporate acceptance, which is a recurring theme across the stories.

### Acceptance and Letting Go

All five participants spoke of acceptance and/or letting go, two concepts that seem to be intertwined. Michel L has found peace with regards to his father by accepting his father's imperfections and forgiving him for not being a better father. Michel T also expressed forgiveness towards his abusive father. Acceptance of other people's differences was noted as valuable by Michel T and Richard. Interestingly, Richard's developed acceptance of other people's differences has paralleled a reduced sense of separateness from people. There seems to be a parallel between acceptance of others and acceptance of self. That self-acceptance is fundamental to healing and a sense of well-being was expressed by Michel L, Richard, Jim, and Michel G. Michel L reflected that "before I couldn't spend any time on my own, I was very unhappy and scared and now I love being alone and that means I managed to make peace within myself." Additionally, their stories suggest that self-acceptance is an ongoing process. Michel G described self-realization and subsequent self-acceptance as happening through peeling away what has been superimposed by conditioning and a kind of "surrendering to ... [one's] true essence."

Part of self-acceptance for Richard and Jim was acknowledging their limitations. From the initial struggle of not wanting AIDS to kill him, then wanting to kill himself, Richard said he had been through the process of letting go of control in those situations and was learning to be willing to have whatever happens, happen. Every morning he asked for peace. He had found that asking for peace reduced the possibility of disappointment, because there were then no expectations of a particular outcome. Jim similarly spoke about letting go. He finds salvation in embracing "the hopelessness of it all"—that is, hoping less—which reduces expectations and therefore disappointment. Of all that Jim said, to him the most important message is to give up the struggle, to "embrace the hopelessness of it all," and be able to fail.

## Healing

Aside from the opening question to participants regarding circumstances around learning about being HIV+, the only question asked of all the participants was about their thoughts on what healing is. To Michel L, healing means to be happy, with no physical problems. Taking care of oneself and secondarily, being cared for, will facilitate healing. He attributes his healing to friends believing in him and working on himself. Richard also defines healing as being more than physical. Healing to him means cleansing yourself—spiritually, emotionally, mentally, and physically. He aims to work gradually toward that, without unnecessarily stressing himself, and using a sense of peace as a yardstick. He holds the idea that healing is “getting in touch with the oneness of everything.”

A sense of oneness is integral to Michel G’s concept of healing. He spoke about the endless nature of healing and that it is “to integrate my whole personality, my whole self, so that there would definitely be a stronger me.” Healing is also “experiencing your life and taking risks, and being responsible for everything that happens to you” and this for him necessitates processing experiences on an emotional level. For Michel G, healing has more to do with emotional health than physical health. Without the fear that obstructs his healing journey, he expects that he could fully experience whatever presents itself, as opposed to suppressing it or escaping from it, through alcohol, for example. Looking back he sees how he has fled from pain in his life, thereby “avoiding” life. By contrast to Michel G’s focus on living, dying is key to T’s concept of healing. He defines healing as accepting death and being ready to die.

What gets in the way of healing? Michel G and Michel T mentioned fear as an obstacle. Michel G also thinks that beliefs and an unwillingness to change the mind block healing. Michel L has observed that the people who are dying quickly from AIDS (that is, not healing) have low self-esteem. Furthermore, rejection—by family, friends, society, and work colleagues—may hinder good health and healing. The destructiveness of heterosexism was discussed by Michel L, Richard, and Jim. For example, Michel L said, “I was really emotionally destroyed from my childhood and also by society’s beliefs, as a homosexual, that it wasn’t right to be the way I was.” In addition, Jim spoke of the “tremendous amount of shame surrounding the idea of dying by

AIDS because of all the negative connotation around homosexuality." Stress as a hindrance to healing was mentioned by Michel L and Richard.

The participants' thoughts on healing converge in an understanding that healing is multi-dimensional. Perhaps this explains or is explained by the broad range of healing pursuits that they have experienced. All five participants have explored various healing avenues and found activities that they find healing for them. These include: individual therapy, group therapy, bioenergenics, rebirthing therapy, workshops, talks, changes in diet (macrobiotics, vegetarianism), gym exercise, walking, meditation, praying, painting, writing, talking, music, meditative tapes, and books. No single activity was found valuable to all five people, yet some form of physical exercise was important for most of them. I would characterize all the above activities as vehicles of self-expression and/or self-awareness. The power of potentially healing activities may well be, as Michel G asserts, related to the beliefs held about them.

### **Beliefs, Death, and Illness**

Four of the participants put forward beliefs about illness and AIDS. They professed the powerful influence of beliefs generally. For example, Michel G attributes the longer survival rates today of people with HIV, compared to the early '80s, to the acknowledgement now that death is not necessarily inevitable from HIV infection.

What else about death? All of the participants spoke about it. Michel G expressed a lack of fear of death; Jim expressed a fear of death. Jim's views on death shifted away from the idea of death as an escape from life towards a belief, also held by Michel L and Richard, in reincarnation. Jim sees life itself as a series of little deaths, possibly similar to how others experience "letting go." Richard's conviction about death is that it is a natural part of the process and that we die when our souls are ready to die. As mentioned previously, Michel T's understanding of healing revolves around accepting death.

Michel L attributes illness to not loving self and unresolved personal business (e.g., the pneumonia he had during a visit from his father). Accordingly, he asserts that illness can be overcome by taking care of oneself. While this view focuses on personal responsibility, I expect Michel L would agree with Jim's sociological thought: that it is predominantly gay men who are

getting AIDS because of the internalized oppression and lack of self-esteem resulting from society's attitude of heterosexism. Michel L does not view illness as necessarily bad. He says that "getting sick is an opportunity to grow up." Both he and Richard view illness as natural and offering valuable opportunities for growth. Richard sees AIDS as one of many natural disasters (e.g., earthquakes, etc.) that provides lessons for us. Michel L and Michel G concur in their belief that illness itself is at some level a "choice." Michel G wonders if illness is soul-directed or a consequence of conflict between one's personality and soul.

Michel L, Richard, Jim, and Michel G all spoke about having learned from illness. The learning relates to self-awareness. Michel G and Richard spoke about intellectual knowledge, partly gained from reading, shifting to a deepened understanding through their experiences. Richard describes the result as "a way of being rather than knowing." Illness has encouraged Michel G to become more aware of his reactions that were previously unconscious. Illness has also stirred him to trust more in himself. He and Richard spoke of coming to respond more from "the heart" as opposed to the mind.

Notwithstanding the power of beliefs, Michel G and Jim both expressed the view that an intellectual understanding has limited value. Perhaps an example of that is the anxiety felt when one contracts a cold (as two of the participants did around the time of their interviews). It raises concerns about whether the illness is AIDS-related. Jim's challenge when he becomes exhausted and ill is to acknowledge his limits, an issue familiar to Richard. Illness has taught Richard what is important to him. He believes that illness provides valuable lessons and we "have the choice to learn from it or to block those lessons." Illness has challenged Michel L to take care of himself.

### **Self-Responsibility**

All participants gave substantial reference to self-responsibility. Michel T specifically set out to be an example of self-responsibility. Part of Michel G's definition of healing is "being responsible for everything that happens to you." He believes that healing is going to come from his own work and that ultimately we have to take care of ourselves. He spoke of the necessity of following one's own "soul direction," since "there are no more heroes or models." Similarly,

Michel L views taking care of self as the prime mover for healing: "If you don't take care of yourself and you don't do what's good for you no one else will."

Richard also spoke about taking care of one's physical needs as being fundamental to healing. An aspect of self-responsibility that Richard often mentioned is choice; for example, choice in whether or not to take medication. More and more of his decisions come from an increasing trust in his intuition, the knowledge that comes from within. Jim is also aware of needing to constantly make decisions about what best to do for his own healing. Jim's sentiment that one has to "become a pioneer in your own health" suggests an internal force driving decisions. He has turned inward to find his own strength and has set stronger boundaries. However, in Richard's story, responsibility for self is intertwined with interacting with others. Richard knew early on what he needed, which included help from others. Many times he seemed to try and tell people what he needed but did not feel heard. He came to realize that the love and care he had searched for needed to come from himself and then through a willingness to accept it from friends. Becoming more responsible for self has paralleled Richard's letting go of trying to change other people's views. Jim has also become more discriminating regarding whom he chooses to confront; that is, "choosing his battles." Michel G has become more aware of having alternatives to choose from when it comes to responding to others.

A final comment which seems to fit in a discussion about self-responsibility is the concept of projection expressed by both Richard and Michel G. They contend that what is perceived to be going on in the world external to self is a reflection of what is going on internally. For example, Richard says that "what we see out there affecting us is a mirror of something that's going on in here" [points to chest].

## People

All participants talked about the impact of people on their well-being. Michel L, for example, attributed his bout of pneumonia to a visit from his father, who had beaten him as a child and with whom he had "unfinished business." Michel L spoke about needing to protect himself, and Jim about liberating himself, both acknowledging the destructiveness of some people. Michel T is aware of who feels constructive and destructive, being sensitive to the psychic energy of those

around him. Similarly, Michel G has come to recognize the high positive energy that emanates from someone more aware and self-realized than others.

Realizing that the views of others do not fit his own experience has been a catalyst for Richard's developing awareness of his own views. Michel T and Michel G also mentioned that they have learned from difficult people. Michel G has come to know himself through being aware of what he did not like about others and also gained self-awareness through reflecting on past relationships. In particular, Richard gained strength from fighting against the staff in the psychiatric ward. Besides Richard, Michel L and Jim spoke about unpleasant experiences with medical practitioners. Michel L, who views being cared for as vital to healing, was critical of health practitioners because of their emphasis on curing rather than caring. Richard and Jim were both severely distressed by the lack of compassion, as well as ignorance, that they experienced from medical practitioners. It was not helpful for them when their health practitioners focused on their being HIV+. Yet they both also found compassion and understanding in particular psychiatrists.

Michel L, Richard, Jim and Michel G spoke of the destructiveness of people's belief that HIV meant death. Michel G drew an analogy: "In a small village, if the whole village except one person believes that this one person is going to die of something or believes in an evil spirit and this one's got it, well the chances that this person goes crazy and does come up with an evil spirit are very high, because you're fighting against what should be your support." Michel L was wary about being public about his HIV status. He did not feel strong enough to combat the negativity and rejection he expected from people until years later. The destructiveness of heterosexist attitudes and behaviours has previously been mentioned.

On a more positive note, every participant expressed appreciation for friends and particular people who were accepting and supportive. Michel T also found valuable support in AIDS Vancouver and the PWA society. Feeling truly accepted by other patients in the psychiatric ward precipitated a major shift for Richard. This acceptance spread to receiving the friendship and love offered by his family, friends, and work associates.

## **Reflections On the Journey So Far**



Michel L and Richard expressed how much happier they were now than at the time of the HIV diagnosis. Michel L says:

*As much as [Michel] hated himself in 1981, as much as he's loving himself now. It's a wonderful feeling. Before I couldn't spend any time on my own, I was very unhappy and scared and now I love being alone and that means I managed to make peace within myself and I think being HIV did a lot unto this ... it gave me the opportunity to be able to change my life for a better quality, instead of a quantity.*

They both perceived profound differences in themselves. In Richard's words:

*I feel like I'm a different person; I experience my person differently now. Every day is like a lifetime; there is no need to fill it with activities.*

Jim perceives himself as much more compassionate now, yet discerning as to where he will employ that. Reflecting on his journey, he says

*It's been very much an inward journey and in some respects I feel as though my youthful altruism has been sacrificed, it's gone by the wayside and I feel self-centred,.... I feel as though I'm through the crisis part of all this and now I'm more interested in enjoying life in the present, whatever duration life might be.*

There has been a shift over time for Jim in becoming less determined about pushing himself to go swimming and to do everything that seemed healthily correct. While he views his earlier determination as valuable in accessing an inner strength, now he is more likely to have a beer and generally enjoy himself more. He believes that an overzealous approach may in fact be constrictive and there is value in a Dionysian and celebratory enjoyment of life. Richard's example of not unnecessarily stressing himself—that is, by not forcing himself to refrain from smoking—seems consistent with Jim's sentiment. Jim's tempered attitude towards behaviours matches a more relaxed attitude towards understanding the meaning of it all. Somewhat related to Jim's recognition that there will be constant challenges regarding decisions about behaviour, Michel G humbly acknowledges his lack of understanding or “not knowing,” despite how much he has learnt:

*I've become aware of all these different things; that's all fine and I can sit here and talk to you about it. When I walk out the door, I'm always at zero. I don't know what the next move is going to be.... I'm still functioning from survival mechanism. I've learned about all these other things, but it's not integrated and I don't know how it's going to be integrated.... I still don't have all the information for myself.*

Some of the sentiments expressed by the participants suggested that what might at one point in time appear to be disastrous may well turn out to be perceived positively down the road. For example, Richard's fighting with medical personnel, which he experienced as onerous and unjust,

enabled him to connect more strongly with an inner strength. Moreover, both Michel L and Richard expressed appreciation for being HIV+, because it precipitated self-reflection and healing.

Only Jim spoke about the future, in connection with his journey so far:

*[Having lived for 10 years with the continual message that AIDS is fatal] has killed my initiative and I'm not suggesting that that's an entirely a negative thing because it has forced me to be more realistic and grounded in a day to day manner.... I am in a sense a free spirit, kind of a Bohemian and this is my life. But I suspect that over the next few years there will be a shift towards more goal setting, and one of the steps in that progression is the fact that I've started getting tennis coaching; it represents an investment in my future.*

The participants' journeys continue. Michel T and Richard have died. Jim talks about his tennis. Michel L speaks about a current intimacy issue that his working on, to help remove the energy blockage. Michel G does not know what the next move will be.

## Implications for counsellors

When we engage in research we involve ourselves in a process in which we construct meaning. Because the social world is multifaceted (i.e. the same situation or experience is able to give us many different kinds of knowledge) ... [w]hat knowledge we are able to observe and reveal is directly related to our vantage point, to where we stand in the world.... [W]hat we see and how we go about constructing meaning is a matter of interpretation (Kirby & McKenna, 1989, p. 25).

The stories of Michel L, Richard, Jim, Michel G, and Michel T are rich with implications for counsellors and these are the main foci of this concluding chapter. Firstly, I discuss the explicit references made by participants regarding how counsellors can enhance their clients' healing. Secondly, I draw implications for counsellors from within the stories, mindful of the literature discussed in previous chapters and reflecting on my own understanding of healing and HIV/AIDS. A more honest title to this chapter might be: "How *I* will approach counselling people with HIV/AIDS in light of the participants' stories." Yet the suggestions I document below may well be informative for other counsellors who wish to enhance their clients' healing. I conclude the thesis with some personal reflections on the research process.

Richard's initial attempts to seek counselling were futile: the psychiatrists he came into contact with wanted to discuss issues other than those Richard wanted to discuss. Soon after attempting suicide, Richard saw a psychiatrist at St. Paul's and for the first time felt heard and respected by a medical practitioner: "He wasn't trying to tell me 'AIDS,' he wasn't trying to tell me anything, he just talked to me about what was right there for me." This psychiatrist was accepting and identified what was going on, which had the impact of immediately reducing what had previously seemed overwhelming to Richard.

The following insights into how counsellors can facilitate the healing of people with HIV/AIDS come from Richard's experiences as both a client and counsellor:

- Be willing to help without expectations of an end result.
- For the moment, discard books and technical knowledge.
- Humanness is needed: be compassionate.
- See the person as a person; and not as different or other because of being HIV+ or having AIDS.
- Understand and convey that HIV/AIDS is not a death sentence.

- Listen to what the clients say; do not rely on what you think their problems are.
- Allow your emotions and express them; e.g., sadness if a client is dying.
- Be educated about AIDS.
- Re suicide: validate their right to do what they want with their lives and clear a path for them.
- Validate their feelings.

Richard's suggestions are consistent with my own understanding of effective counselling. Two statements, however, that may be particularly controversial are the one regarding HIV/AIDS as a death sentence and the one on suicide. These issues are discussed later in the chapter.

As did Richard, Jim found a particular psychiatrist helpful. The psychiatrist largely just sat and looked and nodded, and conveyed understanding and compassion. What made a difference to Jim was that, instead of being treated as a terminal AIDS case, "he treated me as a client with all those normal ... psychological issues that needed to be addressed." At times a minimally directive approach has been valuable for Jim and at other times a more confrontational approach has been useful. Both Jim and Richard spoke about the empowerment that comes from being truly listened to. Similarly, Michel T's answer to how counsellors can foster other people's healing is "being there"; being there and responding from the heart. While the participants have their own understanding of healing, for this thesis I have conceived of healing as enhancing the subjective experience of one's quality of life.

From statements in the stories of the participants I have drawn the following comments and suggestions for counsellors, organized according to the themes discussed in the previous chapter.

### **Circumstances Around the HIV+ Diagnosis and its Impact**

The variation in the participants' responses to learning of being HIV+ suggests that there is no typical, predictable response, except that it is likely traumatic and likely to precipitate an intense evaluation of one's life and the meaning of life generally. The high intensity of psychosocial impact has been well documented (e.g., Federal Centre for AIDS, 1992; Dilley et al., 1985; Callen, 1990; Kendall et al, 1989; Nelson & Jarratt, 1987). Counsellors' understanding of the trauma associated with a HIV+ diagnosis and subsequent soul searching will assist their empathy which I believe, along with other counsellors (e.g., Nelson and Jarratt, 1987), to be a crucial component of

effective counselling. Bear in mind, however, the caution of Bor, Miller, Scher, and Salt (1991) against making any assumptions about the impact of an HIV diagnosis.

According to Jim, the biggest impact of being HIV+ was on his ambition and goal setting. The challenge of rethinking life goals has been identified as a key counselling issue by Hoffman (1991) and of dealing with the possibility of a curtailed lifespan by Siegel and Krauss (1991).

### **The Journeys**

Evolving self-awareness characterizes the journeys of all five participants; for example, Michel G's experience of "becoming more Michel." Enhancing self-awareness may well be a desirable pursuit for clients in therapy. Part of self-awareness is being attuned to the impact of various situations and activities. Given the likelihood of experiencing HIV seropositivity as traumatic, it may be helpful to encourage clients to pursue situations and activities that are nurturing and provide sustenance; or more simply, to encourage them to do the things they like to do. For Jim, "there was something very healing about the river.... I'd just lie down on these rocks by the river..."; Michel T's passion was to paint.

Since two of the five participants spoke about their suicide attempts and another seriously questioned whether he wanted to live, the issues around suicide seem to be necessary for counsellors to be aware of, to know their own views on, and to address in therapy (refer to Chapter 4 for a short discussion on this issue).

Sharing their experiences and knowledge has been important for most of the participants. (That is why they participated in this research!) If clients indicate such a desire, informing them of the possibilities of volunteer work at AIDS Vancouver and the PWA Society may be helpful. Talking and writing about traumatic experiences have been found to enhance immune system functioning according to Pennebaker, Kiecolt-Glaser, and Glaser (1988). Focussing on the HIV or AIDS may not be helpful, however, unless directed by the client. Bor et al. (1991) hold the view that HIV/AIDS may not necessarily be the main problem nor the enduring problem. Templeton (1990) has observed that many of the issues that confront people with HIV/AIDS are not new to them, but the resolution of those issues tends to become more compelling.

Richard asserted that one's basic physical needs must be taken care of first; otherwise that is where one's energy and attention go. Counsellors may need to give attention to their clients' basic needs or at least ascertain that basic needs are being taken care of. It implies that, for instance, it will not be effective to focus on childhood trauma when a client is in need of food or a roof. Poverty is a very real problem for many people with HIV/AIDS (McKillop, 1990) who have not been employed for long enough to have had the opportunity to accumulate wealth.

### Acceptance and Letting Go

Acceptance—of self, circumstances, and reality as perceived—and letting go—of attachment to wanting things to be other than they are—seem crucial as companions to self-awareness in the healing process. Letting go is a grieving process, with the incumbent feelings of anger and depression. Processing the grief will require the counsellor to be patient and respectful of the probable pain and time involved. The content and timing of issues to be dealt with seem entirely personal. I surmise that respect of the client's pace in developing self-awareness will allow for a naturally evolving acceptance. Offering insights to clients too forcefully may even hinder healing by either creating defensiveness necessary for the clients' protection or by overwhelming clients with more than they can handle. Moreover, consistent with Miller (1991), prematurely suggesting to clients that they accept, and perhaps forgive, may repress as yet unresolved aspects of an issue, thereby interfering with its complete resolution.

Since self-acceptance is so crucial to a person's well-being, it would seem also crucial for counsellors to be accepting of their clients, despite apparent differences between them. I believe that the greater the counsellor's own self-acceptance and general acceptance of others, the greater their ability to foster self-acceptance with their clients. The message is that counsellors need to do their own personal work. The beneficial effects on their clients of counsellors' self-awareness is recognized by many (e.g., McKusick, 1988; Nelson & Jarratt, 1987; Pohl, 1988; Price, Omizo, & Hammett, 1986; Templeton, 1990a; Werth, 1992; Ybarra, 1991; Nelson & Jarratt, 1987; Getzel, 1991).

### Healing

The multidimensional nature of healing as understood by the participants suggests a holistic approach to healing. A holistic approach—embracing physical, emotional, intellectual, and spiritual dimensions— is consistent with the sentiments expressed by Houston (1987), Achterberg (1987), and the thirty-seven physicians, psychologists, nurses, metaphysical healers and shamans who were asked about healing by Carlson and Shield (1989). A medical practitioner with a sole focus on the person's physical being is inadequate. Blum (1985) reports that the potential for patients' physical health improvement is greater when the health provider's perception extends beyond the focus on physical symptoms and disorders and includes attention to the patients' psychological and emotional needs.

Similarly, counsellors need to acknowledge that their expertise and ability to facilitate healing with their clients is limited. Counsellors may help their clients by encouraging them to consult with various specialists in order to provide for all aspects of their being. For example, a person may benefit from seeing all of the following people: a counsellor for emotional and psychological issues, a massage therapist or bodyworker, a medical practitioner, a naturopath for alternatives to mainstream medicine, a spiritual guide, and an exercise specialist. Complementary therapies (to Western medicine) characteristically take into account the whole person as the context of illness being treated (Strawn, 1989).

Complementary therapies also typically require a relatively active participation on the part of the consumer (Strawn, 1988). The variety of healing avenues explored by each of the five people and the variation amongst their choices is consistent with Callen's investigation of long-term survivors of AIDS and Kendall et al.'s interviews with people "doing well" with AIDS. These results all support the maxim: "to each their own." Counsellors may serve their clients well by supporting and encouraging them to explore various healing possibilities. The effectiveness of various therapies have been reported (e.g., Reuben, 1986), yet many have not been subjected to rigorous evaluation. Perhaps the value of these activities can best be measured by each individual's experience of them. If Pert (1990) is correct, then believing in the possibility of healing—and believing that one is doing something to bring it about—often has beneficial effects. While none of

the participants talked of group counselling in their stories, its documented value (refer to Chapter 4) signifies that counsellors and clients bear it in mind as a possibility.

Given the prevalence of heterosexist attitudes and responses (Herek & Glunt, 1988; Dowell et al., 1991; Kelly et al., 1987; Triplet & Sugarman, 1987; Toughill, 1990) and their destructiveness (Kelly, 1989; Canadian AIDS Society, 1989; Dilley et al., 1985; Rosse, 1985; Federal Centre for AIDS, 1992; Douglas et al., 1985; Gecchi, 1984) it is imperative that counsellors who chose to work with gay, lesbian and bisexual clients attend to the resolution of their own heterosexism in order than they can honour these clients. Furthermore, a knowledge and understanding of the issues that are particular to gay, lesbian, and bisexual people may be necessary (Templeton, 1990a; Price, Omizo, & Hammett, 1986).

Confronting fear and other uncomfortable feelings is integral to Michel G's understanding of healing. His desire to process experiences on an emotional level fits well the counselling domain. Richard also spoke of working towards being more in touch with his feelings. The study by Temoshok, Sagebiel, & Sweet (cited by Solomon, Temoshok, O'Leary, & Zich, 1987) demonstrates the physical health benefits of emotional expression— measures of more emotional expression correlated with enhanced immune system functioning. Pennebaker, Kiecolt-Glaser, and Glaser (1988) suggest that inhibiting one's thoughts, feelings, and behaviours is stressful and that actively confronting upsetting experiences may reduce the stressful effects of inhibition and allow for the understanding and assimilation of the experiences. Counsellors can encourage and support their clients' exploration of suppressed and repressed feelings, thereby, like other healing avenues, facilitating self-expression and self-awareness.

Jim's experience of his healing as involving a "series of little deaths" is consistent with Mehl's (1988) assertion that healing always involves a death and transformation of some part of the person. In my experience, personally and as a counsellor, healing is intense and powerful, it has a deep impact on on us, and it takes time, energy, and courage.

### **Beliefs, Death, and Illness**

The Federal Centre for AIDS (1992) reports that people's ability to cope depends in part on their belief systems. Presuming the powerful influence of beliefs as also suggested by the



participants, counsellors may assist clients by encouraging the conscious expression of their beliefs and by facilitating an understanding about how the beliefs manifest as emotions and behaviours.

Michel G spoke earnestly about the obstacle of holding a view that there is something "wrong" with one. Counsellors may assist clients who hold such views to alleviate guilt and become self-accepting, the importance of which has been mentioned earlier. Alleviating guilt and enhancing self-acceptance may be done in some instances by attributing cause to an understandable or necessary response, such as recognizing that a particular behaviour may have been adaptive, life-enhancing, and in some cases even life-saving, at some point in their life; for example, being unduly submissive because of a domineering parent.

The belief broadly held in our society and reinforced in the media that HIV inevitably leads to AIDS and premature death (Callen, 1990; Nicholson, 1991; Kinsella, 1989) will likely need to be addressed at some point in counselling. (For the discussion on the impact this belief may have on people with HIV/AIDS refer to Chapter 2). Richard suggests that a counsellor "understand and convey that HIV/AIDS is not a death sentence"; however, counsellors may indeed expect that their clients will die because of HIV/AIDS. On the basis of extensive research and pilot interviews, Solomon et al. (1987) have predicted that one factor contributing to longevity in persons with AIDS is "acceptance of the reality of the diagnosis of AIDS in conjunction with refusal to perceive the condition as a death sentence, or at least an imminent one." *What is the reality of the diagnosis of AIDS? Perhaps there is an alternative perspective: that many people have in fact died of AIDS, but it does not mean that everyone with AIDS will die from it; indeed they may die from causes unrelated to AIDS. Yet a person with AIDS does have a compromised immune system and it is imperative not to disregard or minimize this fact.*

The essentialness of hope and of the protective mechanism of denial were discussed in Chapter 4 (e.g., Hoffman, 1991; Callen, 1990; Macks, 1989; Templeton, 1990a). Constructive denial allows for much needed cognitive and emotional breaks from HIV/AIDS, and it cushions the impact and intensity of emotional reactions (Macks, 1989), thereby allowing people with HIV/AIDS to deal with their realities in manageable steps (Templeton, 1990a). Counsellors need to respect the value of denial and not to force awareness on their clients. Planning when to give

information and assessing how that information is being used may help counsellors to be sensitive to their clients' readiness for new knowledge (Price, Omizo, & Hammett, 1986). Whether or not a counsellor expects that a person—or people with HIV/AIDS generally—will die because of their conditions, people are living until they die and must be treated accordingly; a dying person is still living. We all will die eventually. Rinken (1993) writes about the taboo of death, offering a reason why non-HIV-infected people might find it easier to think of HIV as a death sentence and possibly thus treat an HIV-infected person differentially from a non-HIV-infected person:

People are generally not ready to acknowledge themselves as mortal: death is generally not taken into account for the way in which individuals conduct their daily lives, especially when young.... Now, diagnosis as [HIV] positive is likely to impose the lucid awareness of being mortal on individuals who are as ill-prepared to handle this thought as is their social environment. The latter may react by imposing social death on the infected: the equation of a life-threatening condition with imminent death is an easy way of exorcising one's own fears (p. 118).

Rinken raises the challenge: "How can the thought of death be applied as a means in order to shape one's conduct of life in a meaningful way?" (p. 118).

Contrary to the general societal attitude that illness is bad, counsellors may help clients find valuable knowledge through their illnesses, by focusing on this more positive approach. Dafter (1990) speaks of many different cultures in which sickness and suffering are considered to be a normal part of life that force constructive reevaluation. The danger of deadening the body's messages and thus opportunities for growth, through the use of painkilling drugs for example, is asserted by Owen (1987), Cousins (1979), and Mehl (1988).

The limited value of an intellectual understanding, as suggested by Michel G and Jim, implies that a purely cognitive counselling approach will necessarily be limited in effectiveness. Jim might suggest that counsellors and clients focus more on what needs to be done at any point in time than on trying to understand the meaning of it all.

### **Self-Responsibility**

The importance of self-responsibility to the clients implies that it be worthy of counsellors' attention. If counsellors are to facilitate self-responsibility in their clients it is essential that they interact with clients in ways that are consistent with self-responsibility, that tell clients implicitly and explicitly that they are in charge of their own lives. For example, they might offer clients

suggestions rather than directives. Kendall et al. (1989) advocate encouraging as much autonomy and freedom of choice as possible with clients, by allowing for an environment that is respectful of self-judgement and autonomy. Moreover, counsellors' effectiveness in this regard will depend on how well they model self-responsibility.

Kendall et al. (1989) also talk about the importance of persons with HIV/AIDS knowing all the options open to them. If clients do not see all the options available, counsellors might make apparent the choices they indeed have. Discussing various options with broad-minded counsellors may help clients explore the possibilities and come to their own conclusions. The challenge for people with HIV/AIDS to take control of their health and to make decisions regarding their treatment has been identified (e.g., Siegel and Krauss, 1991). The self-care aspect of self-responsibility, seen as essential particularly by Michel L, could be encouraged by counsellors being especially supportive of their clients' ideas and efforts in this regard. Jim spoke of having to "become a pioneer in your own health."

Self-responsibility and taking care of oneself depends on being aware of what one needs. This is a particular area of self-awareness that may be prompted through counselling. Richard said that more and more of his decisions come from an increasing trust in his intuition, the knowledge that comes from within. There is support for the value of intuitive knowledge (e.g., Noble, 1991; Brooke Medicine Eagle, 1988; Mehl, 1988; Achterberg, 1988; Reuben, 1986) particularly amongst mental health professionals and support seems to be growing in the health care field generally. Each of the 25 long-term survivors that Callen (1990) interviewed expressed the sentiment that persons with AIDS have to follow their own instincts and trust their own judgements.

If the projection idea of Richard and Michel G is true—that what is perceived to be going on in the world external to self is a reflection of what is going on internally—then counsellors may use whatever clients say about the external world as information about their clients' personal states and perhaps encourage them to "own" whatever they are projecting and thereby take a step towards resolving issues of concern.

While the value of assuming some sense of self-responsibility has been oft mentioned (e.g., Cousins, 1979; Strawn, 1989; Achterberg, 1989), the inherent danger of oversimplifying healing

by overemphasizing self-responsibility has been voiced by Sontag (1977) and Dafter (1990). It is not constructive to blame people for the illness they have, yet encouraging self-responsibility with regards to how they *respond* to the illness may be helpful. Further, Strawn (1989) suggests differentiating between “responsibility for participation” versus “responsibility for outcome”—the client is responsible for participating in and applying the therapies, not making them work.

## People

The powerful impact of other people on one’s well-being evidences the potential constructiveness or destructiveness of the counsellor. The impact may be particularly powerful because of the intimate nature of the counsellor-client relationship. Because of the social stigma associated with HIV and thus that infected individuals are often denied the comfort and support society gives to those who are seriously ill (Federal Centre for AIDS, 1992), support from a counsellor may be particularly valuable.

The acknowledged appreciation for supportive relationships by the participants relates to counselling objectives framed by Kelly (1989) and Hoffman (1991) regarding increasing/maintaining support in the client’s day-to-day social environment. It may be valuable for counsellors to check out with clients their social support network. Furthermore, exploring clients’ perceptions of their present and past relationships, including those with parents, will likely be a fruitful source of self-awareness. Perhaps discussing disappointments and expectations—for example, of medical practitioners—may help minimize further disappointment in the future.

The sexual transmissibility of HIV exacerbates the distress of the condition (Federal Centre for AIDS, 1992). To whom people with HIV/AIDS disclose their condition (Siegel & Krauss, 1991), plus when and how, may well be an important topic for counselling. [A counsellor may feel in a contentious situation if an HIV+ client discusses having unsafe sex and not informing a sex partner of seropositivity.] Templeton (1990b) has observed that disclosure to family and friends about HIV status and (if applicable) gay lifestyle have been important in her clients’ “steps toward wholeness.”

## Reflections On the Journey So Far

Jim's and Richard's attitude of not unduly stressing themselves by having to be perfectly health conscious in their behaviours would seem to ask counsellors to be accepting of their clients' choices in what might seem not to be in their best health interests, thereby respecting that their clients know best what they need. The participants seemed to feel good about themselves when they reflected upon where they had come on their journey so far, on how they were happier now, and how much they had learnt. I suggest that giving some attention to clients' achievements may well enhance their self-esteem.

## Conclusion

The stories of Michel L, Richard, Jim, Michel G, and Michel T affirm that some people experience an enhanced quality of life following an HIV/AIDS diagnosis, thereby adding to the self-reports (e.g., Callen, 1990; Larkin, 1991; Mehl, 1990; Melton & Garcia, 1988; Mignone, 1988; Nungesser, 1986), further anecdotal evidence (e.g., Bamforth, 1987; Callen, 1990; Goldner, 1988; Matousek, 1993; Nichols, 1986; Owen, 1987; Pohl, 1988; Salisbury, 1987; Schultz, 1988; Serinus, 1986; Walker, 1991) and the few academic research reports on this theme (Kendall et al., 1989; Pachuta, 1990; Solomon, Temoshok, O'Leary, & Zich, 1987). The negative psychosocial consequences reported in the literature are not to be ignored, but the picture they paint is incomplete. With the exception of the issue of childbearing potential, all the psychosocial consequences mentioned in Chapter 2—depression, anxiety, suicidal ideations, fear of death and dying, guilt associated with lifestyle and possible infection of others, frustration, anger, isolation and relationship disruption, preoccupation with symptoms, grief around loss of health, body image, sexuality, and perceived loss of control and a sense of helplessness—came up in the participants' stories.

The uniqueness of individual clients must be recognized in order to do justice to each client, given the differences observed in individuals' responses to HIV/AIDS (e.g., England, 1986; Kelly, 1989; Price, Omizo, & Hammett, 1986; Getzel, 1991), plus other factors discussed in Chapter 4 including attributional style (Brickman et al., 1982), culture (England, 1986; Hansen & Resick, 1990), and sex-role stereotyping (Broverman et al., 1970). It may be tempting for counsellors to hold expectations in order to feel some control over their interactions with clients,

yet this will not necessarily serve their clients' best interests. At the same time, being aware of how various people do deal with having HIV/AIDS may enhance counsellors' empathic abilities. Because hope is so essential for people with HIV/AIDS, it is of paramount importance that, whether or not counsellors expect that their clients will die from HIV/AIDS, counsellors treat their clients as living people. People are living until they die and it is essential to their well-being that they be treated accordingly.

Common to the journeys of the five participants is evolving self-awareness and a greater trust in their intuition, particularly with regards to knowing what they need for themselves. Our society devalues intuition in favour of knowledge that comes from external authorities. Counsellors can address this imbalance by encouraging clients to explore their intuitive knowledge and by showing faith in their clients for knowing best what they need for their own healing. Notwithstanding, counsellors can also offer information at their disposal. What is important is to offer such information as "possibilities" rather than "facts" and allow clients to come to their own conclusions. By so doing, counsellors will foster their clients' self-responsibility. In summary, I conclude that it is imperative for counsellors to care for their clients, to honour them for being who they are, and to support them in their own ways of caring for themselves. To this end counsellors need to care for themselves and be aware of their own beliefs, expectations and assumptions, all of which could interfere with honouring their clients.

There is a strong thread of similarity among the participants in this research. They see themselves as being on healing journeys and are committed to their healing. Not everybody with HIV/AIDS shares this orientation, or even agrees about the "honey in the rock" (Matousek, 1993). Grant and Anna (1988) caution counsellors against focussing on intense psychotherapy with their HIV/AIDS clients because this may not be what their clients want. I present the findings and implications of this research as a small plot in the challenging field of counselling people with HIV/AIDS. To the extent that counsellors accurately recognize similarities between any of their clients and the five men whose stories are the focus of this research, then perhaps the insights expressed herein may be applied to the benefit of those clients.

This research punctuated the participants' journeys at a point in time. While Michel T and Richard have died, the journeys of healing for Michel L, Jim, and Michel G continue. It is impossible, of course, to know just how their lives will evolve. Furthermore,

not only is it impossible to know what the future holds for them, it is impossible to know what their memories of the past will be when they bring them out again in the future, in some new and changed context (Bateson, 1989, p. 34).

The lack of predictability arising from this research illustrates the nature of people's lives. More importantly, this research has aimed to be for the participants and "storytelling is fundamental to the human search for meaning" (Bateson, 1989, p. 34). In addition, telling the participants' stories and some of my own story has facilitated my search for meaning, especially through reflecting on the research process.

### **Postscript: Personal Reflections on the Research Process**

Everytime we do research we stir up our own unconscious material, .... It seems to us that the researcher must *actively* explore the strivings of his or her own unconscious while engaged in research, and that it is essential that she or he is practised and competent in a discipline for doing this .... We are simply repeating the ancient injunction "know thyself" which has been repeated (and repeatedly ignored) through the ages. We cannot study human processes except as aware human beings, and for this we require a "way" to self-knowledge, a process of self-inquiry, which is systematic and which is powerful enough to reach into unconscious processes, since that is where the disturbances are likely to lie (Reason & Rowan, 1981, pp.244, 246).

Thus, doing research, if desired, can facilitate the researcher's own awareness and self-knowledge. This has been my experience.

I knew from the beginning that I wanted to explore healing. The method of doing so emerged along the way, rather like Kirby & McKenna (1989) describe: "Researching is like embarking on a voyage of discovery. As the voyage takes place, the researcher maps or charts the process of exploration" (p. 43). It has been an enormous struggle, yet each progressive step affirmed for me the rightness of the choices I had made.

The process for me has been: to come to more fully know what is important to me and how I view the world, to express it in writing, and ... down the path ... come to value it and affirm my personal truth. At times, the way seemed blocked by anxiety and self-doubt. During the many breaks I took I assimilated what I had written so far and gathered strength to continue. A fear which I recently came to realize was of being prohibited from expressing what is important to me,

which would have the destructive impact of inhibiting my spirit, thereby contributing to the sense I have often felt of being invalidated and silenced. At times I tried to minimize the intensity of my anxiety by telling myself: "It's only a master's thesis," but it has been much more than that for me. I have expanded the boundaries of my self-confidence, self-knowledge and knowledge of others.

Talking with each of the five participants was scary, fascinating, intimate, informative, and satisfying. I felt like I was plunging openly into unknown encounters and they were offering me the privilege of hearing their deeply personal experiences. As I was writing about Richard's struggle, I reflected upon my own struggle in doing this thesis. At times I felt like I was rebelling against the status quo—including the mainstream positivist approach to social science research and the narrow view of the Western biomedical model—which did not fit my understanding and what I wanted to do. Yet, like Richard, I became more in touch with what is important to me and more confident in my own truth. At times I have been propelled by outrage at an inequitable system that devalues how I make sense of the world.

I wish that I had kept a journal, documenting my shifting perceptions throughout the study. I find that I quickly forget old perceptions once they have been superseded and therefore am less able to report here all that I have learnt during the research process. Perhaps one of the most significant shifts in perception, and one that I do remember, concerns the issue of "HIV as a death sentence." During the earlier phases of the study, from my reading and interviews with the participants, it seemed to me to be vitally important for people with HIV/AIDS to believe that death was not an inevitable consequence of their conditions. Did this mean that counsellors needed to also believe this, or at least not tell clients if they believed otherwise, for the benefit of their clients? ... Yet so many people *have* died from HIV/AIDS? (as Dr. Suzanne deCastell kept reminding me!) ... ??? Months later, following many conversations and personal angst it dawned on me that whether people would, or were expected to, die from their conditions was infinitely less important than that they be treated as living, and regard themselves as living, until they die.

There were other bright lights along the way. Joy Moon's thesis defence gave me the inspiring awareness that I *could* do a qualitative study involving interviews. I sensed and appreciated each participants' support of me and this project; Jim, in particular, offered many



helpful insights. Dr. Celia Haig-Brown's qualitative methodology course focusing on ethnography gave me the method and encouragement I needed. Halfway through analyzing the results I came across the book by Sandra Kirby and Kate McKenna (1989), entitled Experience research social change: Methods from the margins. In it I read about what I was in fact doing. It was so validating to see in print a philosophy of doing research that I identified with and numerous sentiments that spoke of my experience, such as: "One of the characteristics of living in the margins is the frequent necessity to perform a kind of doublethink/doublespeak in order to translate our experience into acceptable and understandable terms for the status quo" (p. 33).

With a sense of accomplishment—personal and professional—I can also now appreciate Kirby and McKenna's assertion that "the research process is an enabling one... as [people] become creators of knowledge, they become more confident in their ability to 'intervene in reality' in a meaningful way" (p. 167). I am appreciative of having had this opportunity to devote attention to the most important quest in my life—healing—and by so doing develop my sense of personal power.

## **Appendix A**

**Notice in the PWA Society newsletter  
and AIDS Vancouver Volunteers' Newsletter**

### **ARE YOU ON A HEALING JOURNEY?**

I want to hear stories of healing in process, and to give expression to your experiences through my thesis (for my master's degree in counselling psychology at SFU).

If you would consider meeting to talk about healing for about an hour, please call me at:

**294-3883**

**Janet Beggs**

## Appendix B

### Information sheet and consent form

#### Information for participants

The purpose of this research is to facilitate the healing of those with AIDS and HIV infection. I want to learn about your healing journey. By increasing our understanding of healing and AIDS/HIV infection we hope to improve counselling services.

Your voluntary involvement will be an interview lasting approximately one hour and the audiotaping of the session. You are invited to meet a second time to discuss the collective findings. The information you give will be treated confidentially and used by the research team only. Your identity need not be known by anyone other than the researcher conducting the interview (Janet Beggs). If you wish, your real identity will be preserved. At the completion of this study in 1991, the tapes will be given to you or erased. There will be a written thesis on the study, available for public viewing. You will be given a copy. Any questions you have will be answered by Janet Beggs.

oooooooooooooooooooooooo

I, \_\_\_\_\_ agree to participate in the healing and AIDS research conducted by Janet Beggs under the supervision of Dr. Suzanne De Castell from Simon Fraser University. I have read the above description of the study and I understand the purpose of this research and that anonymity is guaranteed, if I choose it. If at any point I wish to discontinue the study my decision will be respected. Complaints may be addressed to the Associate Dean of Education, Dr. Robin Barrow (291-3395).

My involvement in this study is a contribution to a greater understanding of healing and AIDS/HIV infection and the improvement of counselling services.

Participant's signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix C

### Interview Questions

We are here to talk about your healing journey. Perhaps we could begin by you telling me when you became aware that you were HIV positive and how that impacted on you at the time?

What's happened since then?

#### SPECIFIC QUESTIONS ON HEALING:

How do you understand healing?

What words or images come to mind when you think of healing?

What promotes healing?

How can you foster your own healing?

How can others facilitate your healing?

- friends/health care workers/ counsellors/ . . .

What else helps?

What hinders healing?

How can you hamper your healing?

How can others inhibit your healing?

- friends/health care workers/ counsellors/ . . .

What else gets in the way?

What else is important for me to know in order to understand healing in the context of your healing journey?

## Appendix D

### Subject Profiles

(profiles constructed from the interviews; material in square brackets added December, 1993)

#### Michel L

Michel L is a gay man in his 30s. He was raised in Quebec and now lives in his own home in East Vancouver, BC. He works for himself as a housing renovator and is active as a volunteer with AIDS Vancouver and the PWA Society.

#### Richard

Richard is a gay man in his late 20s or 30s. He lives in Burnaby, BC. He is on disability allowance and thus not employed. He does much volunteer work, however, with AIDS Vancouver and the PWA Society. [Richard died many months after our interview, in the palliative care unit at St. Paul's Hospital.]

#### Jim

Jim is a bisexual man in his 30s. He rents an apartment in Vancouver's West End and works as a freelance journalist. [When I spoke with Jim about the first draft of the findings, he was working with an organization located on Granville Island that coordinates community festivals, in addition to freelance work]

#### Michel G

Michel G is a gay man in his 20s or 30s and comes from Quebec. He is temporarily staying at an apartment in Vancouver and has no employment.

#### Michel T

Michel T is a gay man in his 20s or 30s, from Quebec. He is on disability allowance and lives in a housing complex for people with HIV/AIDS in downtown Vancouver. [Not long after our interview, Michel T took his own life after being diagnosed with a serious opportunistic infection.]

## Appendix E

### Consent form for inclusion of interview transcript

23 Dec, 93

Dear

Season's greetings to you!

I successfully defended my thesis last Friday, and when I have made the minor revisions required of it I will give you a copy. I am writing to you now to request permission to include the transcript of our interview in an appendix to the thesis. My committee thought that some transcripts would be a useful inclusion.

What it means is that, since the thesis will be publicly accessible through being in the SFU library, anyone has access to the material and can make of it what they will, now or at any time in the future. As you know, your first name has been used throughout the thesis. Your last name does not appear anywhere.

If you would rather not have the transcript included, that is absolutely fine. I'd appreciate you telephoning me and letting me know that, so that I don't wait unnecessarily for your permission (I'm expected to hand in the finished thesis by Jan 4th!). If you are completely comfortable with the transcript being included in the thesis, please sign your name below and mail this back to me in the envelope provided. You also have the option of editing out any sections of the transcript that you would rather not make public.

I will not include the transcript without your signed permission.

Again, thanks.

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I, \_\_\_\_\_, hereby give Janet Beggs permission to include the transcript of our interview in an appendix to the thesis of which I was a participant, under the condition that sections of the transcript, as indicated, are left out.

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix F

### Transcript of the interview with Jim

In the following transcript, lines in italics are mine (the interviewer) and those in plain text are Jim's. Jim edited the transcript—specifically, by adding or changing punctuation, deleting some repetitive words, and providing words/phrases of clarification, enclosed in square brackets.

*We are to talk about your healing journey and perhaps we could begin by you telling me when you became aware of being HIV+ and how that impacted on you at the time.*

1985 was a long time ago, seems like another life, many lives ago and that year stands out for me as a ... I guess some kind of a landmark year dividing the before and after, before HIV and after HIV. Leading up to it of course were I guess three years, three years approximately, two-three years of the initial publicity surrounding AIDS and the fear that went with that and it was as though there was this growing dread that was filtering through the media and yet personally I wanted, I think like a lot of men in my situation, wanted to just not acknowledge it, and ignore it, and by the time 1984 came around there was enough information out there to know that, that something really serious was happening and yet the idea of safe sex was something I didn't really want to face up to and it, it's sort of strange because there was I guess a double standard in a sense because.... I should point out to you that I'm bisexual and in my relations, my sexual relations with women, it really wouldn't be an issue to use a condom and yet somehow in the gay subculture it was at that time just sort of not done, and to bring it up it would be really awkward and inhibiting and I remember my doctor probably around 1983, my doctor, at the time when I was in for a consultation about something he, he opened up his wallet and pulled out condoms and he said, "I keep these in my wallet and you should too" and I was thinking, "alright, yeah" and not listening to the advice and I had been in a long term relationship—well, long term in the context of my life, about three years and I think it ended at about 1983. So I was back out into the sexual milieu and that year I remember particularly being very disillusioned by the quality of the contact that I'd had, that it just seemed really bankrupt and not emotionally satisfying—not even sexually satisfying either—and that summer I was living in Kitsilano and sharing a house or an apartment with a woman friend of mine and she had a friend visiting from Toronto, a woman, and after she'd been there a week all of a sudden we fell in love and had this passionate affair and it was quite extraordinary for me because it had been some time since I had been involved with a woman and I really was swept off my feet and I felt that well, this was the real thing and it was very exciting. She went back to Toronto and it leading up to that time [when we met] I had planned to move back east to pursue my career as a journalist and I was planning to go to Montreal but after this encounter I decided, well partly on her invitation, to go to Toronto and in a way it was like making a new start in that it was I think a kind of decision a lot of young people make or maybe when they are around thirty deciding that they have to go somewhere different or try something new. So I headed off in September with two suitcases and she picked me up at the airport and still not knowing that I was HIV+ until sometime later, nonetheless as I say living in this climate of increasing fear and she didn't express any concern about it and we weren't using condoms or birth control, she was older and not—for some reason

which I never really quite understood—she was not fertile I guess is the the way to describe it. In any case, eventually that affair turned out to be somewhat of a disaster after I lived with her for about five or six months and that's a story all on its own that I won't go into great detail about but essentially we were both bisexual and her path was leading her increasingly to the company of women and she was doing her PhD in I think feminist poetics—again it's a bit of a mystery to me, and her whole life was focused around that and I felt like somewhat of an intruder into this [world] and I didn't belong and my inherent bisexuality was really put to the test in a sense—we'd get on the streetcar together and there would be attractive young men, single young men who would, would be eyeing me up and I'm sort of in this "clutch your girlfriend" mentally, and during that period as well I had work in Montreal for CBC radio and I was back and forth on the train and so we had this actually one separation over the Christmas period and I had an affair with this guy in in Montreal but I promised myself that I would be faithful to her, I would go back and resume [our relationship. Meanwhile I guess for whatever reason she felt that this was really not going to work out and had reached some decision, she had an affair. It was all really complex and dramatic and crazy and so ultimately we parted. I lived in Toronto apart from her in a co-op house and that whole year I had in Toronto was one of a lot of excitement, a lot of romantic involvements—in a very sexual state—having an affair with a French Canadian guy and then having an affair with a young Italian woman and by the end of that year, that next summer, the crisis really began. I remember going to the swimming pool with this Italian young woman and feeling that my energy was ... something was wrong physically and I felt exhausted and drained and, despite my efforts to exercise and all that, something really serious was wrong and I went to a doctor and he, I, I went for blood tests and—this was very early on [in HIV testing]—and they had to send the samples off to Ottawa and it it would take two months or something for the results to come back. Meanwhile I got a phone call from a producer from Quebec City wanting to know if I was interested in in a job there and I decided that I had to take it because my career, it it was important for my career and it was fulltime work and I was up to that point struggling as a freelancer and this, it was time, I had to get serious. So off I went in really in a state of panic, underlying panic, afraid of what these results would be and also feeling physically not well and I think my glands under my arms had, what do you call it ... they'd

*enlarged*

enlarged, and I think that in retrospect it was really, my physical state was, was ... it was the anxiety that made me think I was having symptoms but they were, like they were, some things were manifesting, not the classic symptoms of night sweats and all that, but the glands and the exhaustion. Anyway, I arrived in Quebec City, I stayed with a guy who was gay there through a contact I had known. He was freaked out that I was freaked out and really unnerved by this sort of [scenario of] AIDS moving closer and closer and I had to start work right away, [and] the very first day that I went into the office at CBC radio and the newspapers were full of stories about the first case of AIDS in Quebec City and everyone was talking about it, the reporters and producers, and I'm just freaked out and feeling very isolated and just thinking that I'm in, that I'm in an absolute nightmare. I went, shortly after I arrived there, I went, found a doctor and went to see him and and told him what was going on and he phoned Toronto and was trying to find out where, where the results from these



tests were at and at one point, (cough) pardon me, I've just had a cold, at one point after doing an exam, a physical exam he said, he looked at me with a real air of serious concern, he said, "well, it's fatal" and he said "if it's not that [AIDS] it could be Hodgkin's disease." I'm just astounded by this and I remember actually leaving, leaving his office, everything took on a surreal quality and I'm on my way back into the part of town where I lived, the bus, or a taxi, I can't remember which one, passed through a cemetery that was on both sides of the road, and I'm just thinking I'm entering into the world of death. Death was right on my doorstep and meanwhile I had to struggle on ... just a moment/

*not yet ... so you were passing through the cemetery*

and I just thought I'm dying; I was preoccupied with the idea that I'm dying and meanwhile I had to try and cope with this new job, high pressured situation—I was, I was a broadcaster/reporter on a daily current affairs show and what made it enormously difficult was that even though we were the English CBC station most of my research and legwork I had to conduct in French, and my French was at best marginal, and it was an enormous struggle professionally to carry out my work and at the same time I'm going through this crisis that was of enormous proportion *and in a new city*

and a new city, and living with a person that I really didn't get along with, and who was, who was freaked out, not in a real direct way but eventually he asked me to leave and I wasn't ready to leave but I found this little apartment in a 3 storey walk-up in a really dingy place, and while I was living at his place my lifeline was, in a sense, the telephone and I spend a lot of time calling, particularly a woman I had met in Toronto, a lesbian who was from Buffalo and she was kind of your typically healing-oriented person who I could speak with and I was on the phone and a lot of tears and really in a state of just panic. So one of my first decisions was to find some kind of counsellor there in Quebec City and I had been involved in bioenergetics counselling here in Vancouver before I left and I'd pursued that in Toronto and I felt that that was the path that I needed to pursue, and it was very difficult trying to find somebody and finally I did succeed and tracked down this guy at this sort of institute, and he was younger than me—28 or something —and it, I just felt, "oh he's too young, how can he understand." Nevertheless, I went to see him and really did some very deep work about the whole idea of dying. I just remember waiting for the bus in this landscape of Quebec in winter, hideously cold, thinking why am I here and yet the idea of going back, I couldn't imagine going back to Vancouver in this state, like being defeated and dying. The idea of telling my parents was just beyond me, and so I had to kind of soldier on in a sense. Fortunately my sister, one of my sisters, she'd moved to Montreal and was seeing a French Canadian guy and ultimately they moved to Quebec City. He had a house in the country about an hour's drive away from Quebec City and ultimately they moved to the city. She proved to be enormous support for me and we'd been close growing up and this relationship continued and I remember one day meeting her at a cafe, having an emotional exchange, and I was talking about how I felt to be going thought this and I remember telling her that one of the ideas that was in my mind was that the people who are dying of AIDS were like the chosen people in some way, that I had a certain amount of, let me put it this way, I was, I realized, this crisis made me realize that I was actually very ambivalent about living to begin with. In other words, a large part of me really did *want* to die because life just seemed so much of a struggle—and yet

equally as strong was a very powerful will to live—and so I had this tremendous ambivalence and a large part of that will to live was really fear of death, a tremendous fear of death and a sense a confrontation with mortality, the idea of mortality, and it just seemed inconceivable to me, how could I possibly die at this point, it just was mind boggling. So I was in a tremendous state of struggle, internal struggle, and eventually the results came, my, the doctor I'd seen told me and I he was he was very pessimistic and I left feeling devastated. I'd actually had a dream the night before that, in which I learned that the results had been positive so in a sense I was psychically prepared. The next evening I went out to the swimming pool and decided that I had to carry on, and a large part of that was I think based on a fear of, like a sort of a fear of being ashamed, like there was a tremendous amount of shame surrounding the idea of dying by AIDS because of all the negative connotation around homosexuality, so some king of inner strength propelled me to go, and damn it all, I'm ... this is not going to beat me, this sort of idea, so I remember at the pool and I used to swim, swim like, I'd swim a lot and this was sort of my main, my main exercise and I, I was swimming there and when I reached the end, the lifeguard tapped me on the shoulder and said, "you are going too slowly, you'll have to go in the other lane," and because I'd been in this sort of exhausted state and I was just so embarrassed that it was, I, like I realized that I really was starting, I just had to plod on and work, work was extremely exhausting, everyday I'd come back and I trudge up these three flights of stairs, weighted down by these heavy coats and the whole climate there and it went on like that for maybe 6 months until one day when I was again walking up these stairs I felt a certain kind of return energy and it was just a little bit lighter going up the stairs and it was like, I thought to myself, oh maybe there is hope and it was only, well it was the beginning of a return of energy and over the next 6 months I guess with the arrival of spring and I began to feel that, well, I'm not necessarily going to die right then and there, so I began to look towards having a life, creating a life there, and I found great comfort in going to the country where my sister and her lover had this house and after one visit there I saw a little bit of property, a little chalet on the river, that appealed to me greatly and there was something very healing about the river. The river became a symbol for me of healing and I purchased this place. I remember that first time I saw it. It was a sunny day early, like in the spring and it was the return of the sun and I'd just lie down on these rocks by the river and for maybe an hour and just felt a great, well, solace by, from this place. So I eventually bought this little chalet and started to renovate it and I was, at that time felt as though [Quebec] was my new home and that I would live there and that the west coast was 3,000 miles away and that it was irrelevant to my life and that I had to make a go of it here

*Can I interrupt... I have this sense of you at that time spending a lot of time alone*

A lot of time, very introspective, long walks. Fortunately I did have a social life of sorts, primarily with French Canadian friends and another, actually another important contact was a gay couple who lived in this little village, St. Adelphe. They were friends of Pierre's, my sister's man, and they—in particular Mario—(his lover was Salvadorian) they had a log house and they were, in Quebec they often use the term "granola" to describe people who would adopt the countercultural ways and it seems that it was a much stronger influence than elsewhere in North America, it's retained, they retained a lot of the ideals and that, at least the lifestyle, a lot of smoking hash, that's just part of it ... Anyway I found great comfort, particularly

from Mario. I don't know if I ever spilled out exactly what my situation was, but I think he knew, he had another friend one time that I was visiting who it turned out was HIV+ and we were like the walking wounded, I remember, none of this was really acknowledged but just being there in this, in this lovely setting in the forest in this cabin and eating vegetables from their garden. It was a very healing experience. So the land for me became very important and being in the country and being with people who were sympathetic in one way or another and really looking back on my sister was ?? me. She had, she'd also been involved with the bioenergetic therapy and co-counselling as well so we knew how to do peer counselling in an effective way so that I could discharge my grief and fear which seemed bottomless—there was no end to the grief and fear. Time went by and I was invited out to a party in a village south of Quebec City and I knew I had to go. It was a Saturday night and I felt even though it felt kinda crazy, like it's better to stay home and rest and all of this, but I felt I had to go and I went and I met a woman there about my age and there was a strong attraction and they call it a "nuit blanche" which is an expression for doing an all-nighter and we found ourselves out in this cow pasture as dawn was arising, standing back to back because it was the only way we could really contact, and having this energy go, share between us, and that was the beginning of another affair and my first affair since the diagnosis and I felt that, well I'm alive, I'm still sexual, life goes on, so we started seeing each other and had very powerful connection. She lived in Montreal and we would commute on weekends and see each other and it felt like this was "it." That she had been through a lot of trauma in her life and disappointment in relationships, etc. and we both felt a certain kind of maturity in looking at our relationship. I didn't tell her about my status initially. I was of course careful to use condoms in sexual intercourse, and this was really difficult because she was like, really didn't like that idea at all and just thought it was really weird and so that the kind of cultural or social stuff around that I described from my initial reaction to using safe sex, she had that. I'm trying to be responsible and like she, "well, why do you want to do that." It's like, "oh Christ, here we go" so nonetheless I insisted. It wasn't until I guess a month or two after we met that we were out in the country, we were down at the chalet and I told her my situation and she was really very ignorant about the whole... (phone)/

#### *Ignorant about HIV*

Totally, and her initial reaction was that our love would prevail and that she would stand by me and I was naturally relieved and felt that, oh, life was not so bad if this was an indication, so it would proceed with that understanding and through that fall we saw each other a few times every other week. We had actually, I had a week off and we went and stayed there [in the country] together and something, some weirdness in the chemistry happened, and I think that this gets into the area of my personal psychology and her background and I think that despite the first powerful attraction we both had, it was as though it was ill-fated because of our background and our experiences in relationships. So by the time Christmas came around it was falling apart and this was terribly distressing to me, and she, I remember in Montreal one time I'd gone down for the weekend that despite what she had said that summer, earlier that year, she felt that the whole question of HIV was just too much for her and this was just very distressing for me and really set off a crisis. At the same time I was under an extraordinary amount of stress at my job and I was at odds with my producer, two of my producers, despite the fact that I felt that I was

doing a really good job and had got good feedback from people. I was a bit of a maverick and I wasn't really a team player and I can from this point look back and see I didn't play the game right. So, I had never mentioned anything about my health situation [to them] so I was, they were threatening not to renew my contract unless I complied with a whole list of totally unreasonable demands: I wasn't allowed to do anymore environmental stories, on and on it went. I had to phone the union in Toronto and they told the producer to back off. Finally I signed and it was as though—they were cutting back on my time off—and it was though they were closing in and constraining me. This relationship had broken up, it was the middle of winter, and I really felt that I was falling apart, life was falling apart, I was falling apart. I went to see my doctor. At this point I had other doctors at the hospital where they were doing an AIDS monitoring kind of team they had set up and they were, that was a horrible experience going to see these doctors because they were like, they were as freaked out as I was and they were not very compassionate, they kind of I think regarded me as a, almost a, not human, like as though, here was one of their ... an AIDS victim that they could monitor

*A data point*

Yeah ... (phone) pardon me/

I can't remember where I was at ...

*The doctors and you feeling like you were another AIDS victim.*

Exactly. Fortunately, however, I was referred to a psychiatrist who worked at the hospital and I went to see this fellow, Dr. Gagnon, and he was an extraordinarily kind man. I guess he was in his 30s or 40s, early 40s, and he just possessed a quality of great compassion and understanding, wisdom. So I'd have these appointments and I'd have to sort of sneak away from the office, take a taxi out to the hospital and see him and on a couple of occasions I'd just break down in tears and just say I can't cope, I can't cope, and he questioned me about my family background, my parents and, in other words he didn't except that I was dying of AIDS. He treated me as a client with all of those normal, well normal

*Yes, normal!*

Normal psychological issues that needed to be addressed and a lot of it was very spiritual in nature and in a way it was quite formal. He sat behind a desk and had the Kleenex box and I was over here in a chair and he had his jacket and tie on and largely would just sit and look and nod. Yet for me it was enormously helpful and I talked about going back home and he acknowledged that it was very important for me to further investigate the, my relationship with my parents. I guess 2 or 3 months went by seeing him and finally I reached the point where I couldn't carry on and I said, "look, I want to take a leave of absence and I want you to sign the papers," and he was a little reluctant to do it but he did finally and I took it in to show my producer and—I think it did mention HIV related—well even at that point though it wasn't even known as HIV, it was HTLV-3 or something, and you've got to try and put it into the context of 1985 (or this was '86) and it was at really the height of the hysteria. Every other day in the Globe & Mail the, one of the lead articles was something about AIDS, so

*Something derogatory or negative*

Yeah, or alarmist, so it was a big step for me to show [the papers to] my producer and yet I felt like at this point I don't care, I really, I gave up on all this effort to try and hold it together. So I took a month's leave of absence and I flew out back to

Vancouver. Fortunately, I had a place to stay at a little town near Squamish on Howe Sound with an old friend of mine who was actually a fairly well-known media personality who was living there in a big old house there and he said, "Look, you come and stay here, I'll look after you." I was very grateful that I had a place to go because I couldn't cope with the idea of my parents, it was just beyond contemplating. So I went there, I remember arriving and I just had got a terrible cold and I was just looking grim. He picked me up and I think he was really shocked and he took me and I just went to bed, I just was like flat out, but I found, I finally found a refuge, got back on my feet, got over this cold and had a nice room of my own. It was a rambling big house, full of antiques and books and Laurier went and worked in town everyday at a TV station and I was, my job was to walk the dogs, work in the garden, do some kind of secretarial work, letters and arranging interviews and travel arrangements and that sort of thing, and I settled into this life, putting Quebec behind me, for a few weeks anyway, and walking the dogs up the mountain, this mountain road I found a lot of, it was a healing experience, there was something about the rushing water—again—that I found great comfort in, and everyday I would go higher and higher so I'd be gone for hours, way, way, way up, miles and miles above the Sound and I was getting in good shape, my energy returned and I was happy. I remember reading, I was inspired by some of the books that I read at the house, in particular there was one called "For Christ's sake" by—are you familiar with it?

*M m h u m m*

Tom Harper and he put into , he put Christian belief into a whole different perspective for me and he talked about Christ in a very inspiring way and he talked about the "living waters" and I thought this is what it is, the living waters, all these rushing creeks that were cascading down the mountains and I felt that again there was hope. The end of my leave came around and I wasn't ready to go back. During that time I had started to see my therapist who I'd been seeing originally before I left Vancouver

*Bioenergetic*

Bioenergetic therapist, and I was doing very deep work, very deep work, really looking at life and death, this ambivalence, very power-, very strong, ambivalence—do I want to live, do I want to die? I was driving to see him for an appointment and I had a car accident and it was 2 or 3 days before I was set to go back to Quebec, and this just threw everything into, it just upset the whole plan. With his insight I saw it as sort of a sign that ... I wasn't ready to go back. So I phoned [my producer] and said, "look, I need another month." So I took another month. By the end of that month I just knew that it was over. I phoned and resigned. It was a very strange feeling hanging up the phone realizing that whole life that I had tried to set up was no more and here I was kind of as an appendage of somebody else, but I got over that and I lived there for a year and I spent a lot of time working in the garden. It was a big property huge trees, and a big overgrown garden with rockeries and for me doing hard labour was what I got the most pleasure out of. We cut down a few big fir trees to let in more light so I spent a lot of time cutting wood and digging beds, hauling rock, using a wheelbarrow, and it was this labour that was so important to me, getting out of my head, away from intellectual pursuits in journalism and feeling in touch with the elements, earth, and metal and that's all I wanted to do, really, that's all I wanted to do and I hated it when I had to do some kind of

correspondence or something . During this time I would go into the city and I would be involved with, I was doing a lot of different kind of healing pursuits. I went on a Vipassana Buddhist meditation 10 days in silence, and different workshops, reading, hanging out at Banyen Books, Woodlands, vegetarian eating. There is an important element to this whole story that I need to talk about and it has to do with an aspect of my health. Throughout this whole period and going back several years I have reoccurring periods of exhaustion but accompanied by gastrointestinal problems that , despite visits to various doctors and specialists, I could never get an accurate diagnosis on it. I felt, despite the return of my health, I would be periodically, I would go through these setbacks where I would just be in misery with a whole host of ..?... symptoms—headaches, just awful, awful times, yet the doctors would say that it's not related to AIDS, your blood counts are all normal and we don't know what it is. So that lead me to pursue alternative health, healing avenues and I went to see naturopaths and they diagnosed the candida problem, if you're familiar with that?

*m m h u m m*

and yet this is something that's very hard to get a handle on and I went on things like, special diets, what a pain in the ass, especially living under somebody else's roof who particularly liked gourmet cooking, (he was very respectful of what I was trying to do) and if I had to look at another rye crisp I'd just throw it out the window, but I pursued it. I was plagued and plagued and plagued by this problem and every time this would flair up I would go into crisis and I would go into like healing crisis where I thought, I'm dying, dying, again and I would be compelled to go inwards and find some kind of resource, inner resources to pull me through, but only by reaching rock bottom. So there's a sort of paradox there of going through these slow deaths. That, it's something that I've struggled with now for maybe 8 years and I'm still working on it with help consultants and doing cleansing programs and even just as recently as last weekend, on Sunday I just had a terrible day, the flare up of these symptoms and it's like, maybe I'm just in denial and I really have AIDS and that, but being, in the absence of these symptoms I know that's not true and I know that I'm gradually making progress with it from my most recent consultation, the candida levels are down. But it gets into an area that modern medicine just doesn't have a clue about, you know what it's like. You really have to become a pioneer in your own health. So during this period I really went inward, exploring my own healing, for example, at the Vipassana retreat these symptoms were arising and I , I think it was the third day or something, I was just freaking out because, here I'm doing everything, yet I'm still feeling sick and I remember during one of the breaks going and lying on one of the bunks in one of these little cabins and I'm just almost shaking with fear and panic, I had a vision that, of the Christ coming to my side of the bed and just sort of glowing in light and putting his hand on my head and saying—I don't know the words but—impressing upon me his love and healing and it was real, it was as real as I can imagine and I remember at one point telling one of the leaders that this had happened and I was a little confused because this was a Buddhist retreat and he was very diplomatic [saying] "well people have all sorts of experiences, just let them come on, just accept them for what there is." So I guess all of that was about 4 years ago now and I'm just trying to bring it up where I am now. Well a couple of the tools that I relied on and still do for inspiration include Stephen Levine's books, "Healing into Life and

Death," my copy is really well thumbed through and also Louise Hay's, her tapes, which I just listen to regularly just as a matter of course, thousands of times I would have listened to them, and it's as though I guess looking at the progression, first it would have been Louise Hay's, and that bolstered my will to live, and it seemed as though it was necessary for me to kind of access this inner strength and determination, you know push myself to go swimming , push ...(?)... and I'd go and visit my parents at the summer place in Lake Cowichan on the island and I do these laps across the bay with this great dedication and now I don't care, I have a beer and it's like I don't know ...(?)... that sort of shift over time more, so that I'm more in a place of enjoying life but nonetheless that was important, the determination. Then progressing into more of the Buddhist philosophy expressed by people like Ram Dass and Stephen Levine, life is like, that death is let's say not as horrific as we might imagine. So I became more philosophical and one of the doctors, Eric Jeffries, who takes quite a Jungian perspective on healing and illness, he said to me during one visit , "look, death sits on everybody's shoulder, it can happen at any time" and I'm thinking, I don't want to hear this, he pressed this point on me, so over time the fear of death has gone and now I see it more as in a sense returning home, I see it in, I see it as—there's a couple of songs by this reggae singer, Toots and the Maytals. One is called "Peace, Perfect Peace" and the other is "Spiritual Healing" and again that tape was a real standby for me during these times, for inspiration and I began to see death as offering peace after the trials of life. So it began to even take on an *attractive* quality and I entertained ideas of reincarnation with (?) a sense that this can't be all there is because why would we go through all this trials and accumulation of insight and wisdom if we die and it's gone, it doesn't make sense. So I've become quite philosophical and prematurely old in a sense and wise in a sense and I know that kind of might sound a little pretentious but nonetheless that's what happens I think, for myself anyway. Some people I think go into more denial. Meanwhile, during this whole period of course friends are dying and dealing with that and wondering why do some people die and why do some people not die and questioning the whole medical model of what HIV is; it's like, wait a minute ... I was talking about that [to you] over the phone. So I don't even buy it as a real thing because I don't have any hard data to indicate otherwise. So I don't like being identified as a PWA, I don't see that. I think I'm going to live to be an old man and in fact at one point earlier on during the whole crisis stage visited a psychic healer and this man was extraordinary. He was able to tell me things about myself that I didn't really want to acknowledge but were true. He said "you've got a lot of learning in this life and that you're going to live to old age" and I do have sense of that. Yet at the same time I have the sense that this life has been very rich to this point and that if I did die I don't have any regrets so much. So it's somehow not as important, but what is now important is for me my passion is playing tennis, it's my expression of physical vitality and enjoyment of life and fun and a place, it's a new social venue, away from bars or my other friendships and that. So I guess I'm approaching life, I'm through the crisis and even though issues come up, I'm able to deal with them better and /

I was saying that I feel as though I'm through the crisis part of all this and now I'm more interested in enjoying life in the present, whatever duration life might be. I'm less of a purist, less zealous about my health, e.g., I'll smoke 2 or 3 cigarettes a day or I'll party, I might smoke pot occasionally, yet I'm in good health. I play tennis a lot

and it's a sense of like I think that there's a danger of falling into an over-zealous approach/

so I was saying that I think there's a danger when people are confronted by life and death a life and death situation that they become over-zealous in their approach to healing, they become purists, a kind of mind frame, they adopt a kind of mind frame that is constrictive both in practical life terms but also spiritually. There's a denial of the importance of expression, of the ecstatic Dionysian, celebratory aspect of life and through that comes the renewal in all sorts of traditional cultures that pattern is repeated over and over again. So to participate in a winter solstice party, a couple of years ago, adopting some sort of pagan rituals with a group of friends, e.g., was a very uplifting experience even if it also included an overindulgence in, I don't know what, alcohol, stuff. So that in any case for myself it's really important to have that kind of latitude that it's as much a part of my healing as taking care of myself. So what I learnt is that indulgence doesn't ... I think from our cultural upbringing I had this very black and white perspective of good and bad ideas, notion of what indulgence was and then I realized that indulgence is alright but *overindulgence* is where you get into trouble. So it's important for me on occasion to go dancing and be expressive and if that includes some substances that's OK and I'm finding my levels. Well I recently had the flu for the first time in about five years because I made a point of getting a flu shot every year and I forgot last fall and boom, I got knocked right off my feet and I was very sick and it's hard not to think about AIDS when you're in that state but it's not as though I think, oh, I'm dying, it's like, oh, I've been through this before and like batten down the hatches, but nonetheless it sort of throws you back into the emotional crisis and all the issues that I'm working on in my therapy resurface—the conflict with my mother and all that stuff—and I began, I was really full of despair, thinking, I just want to die, this is so much struggle it's just not worth it, I want to die, let's just get on with it. I was forced to pick up Stephen Levine, I rarely consult now with my healing books until I'm, unless I'm really forced to and I think, oh, God. So I started looking at it and I opened up to this page on the idea of well, I'm trying to summarize it in my mind here, countering, basically he's countering the notion that death is the goal for the liberation into a peace, peaceful existence, the sort of approach that the traditional Christian church advocates, and he is saying that it's all in the "here and now" and if you just wait and expect it to happen when you die, like there's no guarantee of [attaining] that [peace]. I'm not being very eloquent at trying to express this, but it's the idea of returning home and what he reminded me of was that the home is right here right now in the living and the kingdom within. So I realized alright, OK, it's not time to go yet. So I reemerged from that, so what it, what I learned through all this is that there's this series of little deaths that I keep going through and that I will keep going through over and over again, plunging back into the confusion and despair and that that is just the nature of life, and that even though it gets a little easier each time somehow that I shouldn't look towards some great breakthrough because that's just not our existence—what our existence is on earth. So another example of how I've kind of modified my approach to healing: Recently I approached my doctor here about my idea of going on lithium. In previous times that really would have been an anathema to me, if that's the right word, the idea of some kind of chemical, pharmaceutical approach was contrary to everything I believed in about healing and holistic approach and even the therapeutic



counselling approach, but one of my sisters, another sister, has been on various pharmaceutical drugs for about 10 years and in and out of mental institutions and going through a series of mental, emotional problems, attempted suicide. She's kept it together, kept her family together and most recently been on lithium and I talked to her about it and at one point I would have tried to confront, or not confront her, but talk her, try and encourage her to look at another approach, but in my own way being quite zealous and single-minded about it and so anyway, to illustrate the shift, here I am, asking for her advice on this and she's saying it's the best thing she's done, it's given her stability, it's not a heavy drug, it's a, basically a salt compound and

*that occurs in our brain*

it's a biochemical thing. So I said, what the heck because, after all the work I've done I still would experience periods of terrible anxiety, terrible debilitating anxiety that would destroy me and it might not be really apparent to people around me but inside it's like, oh my God, like I just physically feel that my energy is so enervated that I just want to jump out of my skin. So for the last 3 weeks now I've been on that and it's just like, such a relief, I just can't tell you. My therapist has been supportive of it, my doctor said, look, we'll try it and it has just had an extraordinary affect at eliminating the anxiety but not masking it over with other, oh well not masking it, like many anti-depressant might

*not deadening you*

not deadening me at all and I feel happier. I feel more of a sense that, I'm more aware of my breathing and just being in the moment. So I'm more pragmatic and willing to look at what I need to do now and that the whole idea of healing, if you set too difficult an agenda you're setting yourself up for disappointment. I think you have to kind of look at well, where are you right now, what do you need to do now, what's important. So I guess in a way that brings this discussion up to date from 1984 to 1992. Maybe, I don't know if you have any questions you want to put towards me...

*You've spoken very much in a way of moderation in a sense of like you seem to get a stronger sense all the time of what you need to do for you right now, and do that. So in your day to day life right now you've mentioned some things that either explicitly or implicitly seem related to your well-being, like your tennis and the lithium makes a difference, and having fun, etc., and from other things you've said your book is important to you too. Is there anything that you haven't said that is important to your healing right now?*

On a psychological level, it's very important that I—let me try to formulate this—it's important to liberate myself from controlling people, people who want to control and manipulate me and situations, work situations. It's vital for my survival to be conscious of those situations and challenge them. It relates to my relationship with my mother, in particular, in so far as I'm reclaiming myself as an individual. So, e.g., recently I've been through a difficult period with my roommate. When I was sick with the flu, it was as though he wanted to impose his agenda on my illness, like, "it's just a 24 hour flu, you'll be better tomorrow" and then he's coming in, "how are you today, better, any better?" like not, and I said, "are you asking me or telling me?" and then I confronted him on it and he confessed that it's related to his distress around being sick, so it was very difficult for me, being ill, to live with somebody who has a lot of denial and is functioning from that place of

denial, so that all interaction is coloured by this, this fact. So I'm very, very sensitive to any interaction that has, that is coloured by another individual's madness, alright? I've got my own madness, that I'm working through, but if people are mindfucking with me, I'm very sensitive to it and so my reaction is largely just to withdraw because previously I would be much more prone to confrontation or challenging that other individual's psychology, but now it's like, wait a minute, it's my self-protection. So my behaviour during that illness, e.g., I think I must have been very difficult to live with, but the reason for that is that I was living with somebody who was not empathetic to begin with, and he was like really invasive and immature and in denial. So my bottom line was like, "look, if you don't like it, move out," so my way of dealing with it was on not a confrontational one. It was like holding my strength, holding my place with it and that extends throughout all my dealings in the world. It's the only way I can be in the world, like I won't tolerate, that's why I find it really difficult to imagine returning into the workplace—it's madness, like there's so much madness all around us that I, that I follow my own path to avoid it. So it's something about finding my own strength *and being sure of your boundaries*

Really, setting my boundaries. That makes me think of another issue, which is learning to acknowledge my limits, a very difficult issue for me, because of the I think rebellious nature that I've had to adopt in being able to stay alive, very sort of independent-minded and strong willed that I had to adopt in order to survive my mother that has carried through and has in a sense been detrimental in so far as I sometimes I am not able to know my own limits so I overextend myself, become exhausted and get sick, repeatedly, than I'm thrown into crisis again and around and around we go. So one of the lessons that I'm looking at now is like learning to honour my limits. I don't like to think I have any limits, and yet you keep running up against them, your humanness, frailties and all that. So that's ... I really see it as a lifetime challenge, that I'm only just beginning and yeah, well I think that I've sort of addressed the question. Just to help complete the picture, these days I haven't been involved with women, mainly because they just make you cry—no that's what somebody said once—mainly because of the complications that surround the whole HIV question. In other words it's too traumatic imagining going through the kind of heartache I went through [in Quebec] resulting from the HIV issue, whereas at least in the gay subculture it's a given, that that's a possibility and at least I can get contact. Occasionally I'll meet a woman where there's some attraction happening but it's, it's just one of these things in life that you have to, ... it's the circumstances, so it's bigger than me. I can't change it or fix it or, it's not as though it's out of the question, but I have to proceed on what's apparent and maybe in the long scheme of things it's more my destiny to have contact with men, I don't know, but I can't figure it out. See another, I was reading, I think in Bradshaw recently, that certain people have a tendency to try desperately to figure out what's happening in their relations and in their life and they're almost driven mad by this need to figure out and he says it stems from childhood experiences in which the individual grew up in a family with a lot of madness, so the child is trying to figure out like what's going to happen, what's going to come down next, what kind of craziness is going to come their way, so they are trying to second guess all the time, so I know that I really fit into that and have so desperately tried to understand, tried to figure out, what is going on, what is the meaning of this, what am I going to do, so that finally at this

point I'm more resigned to the fact that well, I can't figure it out. I don't know what AIDS really is, whether it is in fact a modern plague or if it is some mysterious metaphysical phenomenon which I am somehow immune to or whatever, I don't know. It's like, I can't figure it out, what do I need to do now, what is important to do right now. One of the things I should add, though, is that I think the biggest impact on my life, aside from all of the circumstances I've described, I think the biggest impact has been on my ambition. When I went back east in 1984, I was ambitious, I felt that I really wanted to succeed in the media world and as a result I did make some, have some major successes, did documentaries on CBC radio—the national network—wrote articles in the *Globe & Mail*, and really, interviewed cabinet ministers like Jacques Parizeau in Quebec. Subsequent to my return I gave all that up and only in the last couple of years have I reentered the media world but I'm much low key level, so I'm writing for obscure magazines and I don't really have goals or ambition and I was reading an article in [the Gay newspaper] *Angles* recently that posed a question: what impact, let me try and rephrase it, imagine what it's like to have lived for 10 years say—about that period of time—having had the continual message that AIDS is fatal? And it really struck me and I reread it and I thought, I thought really, just imagine it, and I realized that how it's affected me—it really has killed my initiative and I'm not suggesting that that's an entirely a negative thing because it has forced me to be more realistic and grounded in a day to day manner, but nonetheless I haven't made any plans, I haven't... I don't think about real estate, I don't think about career, I don't think even about like what I'd like to do next year, like I'd like to travel? set goals? I don't set any goals and so it really means an existence that is very much like "here and now" and there's, I think, a down side to that, which is a rootlessness or, I don't know exactly, and yet I think in fact it is more true to my nature and that the rest is kind of an illusion and I am in sense a free spirit, kind of a Bohemian and this is my life, but I suspect that over the next few years there will be a shift towards more goal setting, and one of the steps in that progression is the fact that I've started getting tennis coaching; it represents an investment in my future. I decided, look I don't want to continue playing at the level I'm at, it's like frustrating and why don't I improve. So what it does is that I can look ahead to this summer, this season coming up, and get immediate results, like I've just started over the last few weeks and playing even yesterday, for example, my game has improved and it's like, it's tangible. So similarly I'm thinking I'd like to finish my degree so I might go back next year and do another course, do a couple of courses. That's the extent of it, but like I say, it's not an entirely negative process but it's just something that I would say is a factor

*Re changing your attention to right here and now*

Yeah, but there's a danger in too much introspection. I realized that, my God, I must have been hard to live with during some of this time, like terribly introspective and feeling doomed. So anyway

*Pretty natural, given the general societal approach*

Yeah/ (bathroom break)

*We're moving into the afternoon here*

Yeah, I've got somebody coming at 1.

*I think you've given a really full picture. It's an inspiring story to listen to because I hear your trust in yourself and your honouring yourself and watching yourself and*

*your process and thinking about what to do that is for your betterment but not in a sense of the exclusion of the betterment of other people, etc.*

Well, it's been very much an inward journey and in some respects I feel as though my youthful altruism has been sacrificed, it's gone by the wayside and I feel self-centred, almost to the point of selfish, the expression "I'm alright Jack," comes to mind. So, for example, that means that I have been reluctant to get involve in any of the PWA activities. I've felt that I want to avoid it. I feel that a lot of—this is my judgement—but I feel that a lot of guys in particular become professional PWAs and they're really attached to it and I'm nor really at home in the homosexual subculture and I just find going into that office—I get a monthly kind of funds for extra health, I pay my therapy with it and I'm really grateful—but that's as far as I want to go with it and so I don't feel an affinity with the whole PWA movement, I feel like a heretic in that regard

*It seems to me that you draw more on your own resources*

Occasionally I'll be inspired by something that I see written but it really scares because I think to some extent individuals buy into it and when you read the little PWA magazine there's so much emphasis on this drug or that drug and it seems as though it's buying into the whole disease model. My experience has been, hey wait a minute, I'm not sick, I keep having to reestablish that and that what better evidence is there than your own state of health, so why even think that? I see the whole thing as an enormous challenge for people at this point in history. Louis Hay, for example, asks why are gay men getting this and she suggests that it has to do with the internalized oppression and lack of self-esteem and I think there's really something there about it, because growing up with all the negative social attitudes and self-loathing, just think what that does to you, think what that does to your well-being, and it becomes really clear to me and I do respect what the ACTUP guys, people do although I feel detached from that in a sense I felt that my radical days were, when I was in my early 20s I was doing demos and this and that, and I now feel that I'm not, I don't feel that I belong ...

*Something I've learned from Ram Dass is the idea of what we do is by who we are and it doesn't, a person delivering mail can make a big difference to the world just in their mere presence*

Yeah, I'm definitely leaning in that direction and I do feel that I am a much more compassionate person although very discerning as to where I will employ that, and it's more often than not in a casual kind of circumstance—somebody on the street, an old lady crossing the street, or—rather than a situation where you'd think it ought to be applied. In other words I don't have time for people who are like self-indulgent or, what I mean is wallowing or needy.

*It's like you don't have a need to be a caretaker, so you need someone to be dependent for that to happen, but if there's situations in which your compassion makes a difference, in your wisdom,*

Yeah, it arises naturally. So, what do you think?

*Wonderful! I have just one question: you have said an enormous amount and part of the joy in listening to you is the language that you use and your articulation, but the one question that I wondered about was that when you have had those episodes of gastrointestinal problems and it seems to be a time of further introspection, etc., and probably not a very nice space for a while, is there something that, across all those, in particular that you learn from it?*

It's a good question. The expression "learning the hard way" comes to mind. A dear friend of mine in Victoria, an older woman, she phoned me up while I was in the midst of sweating it out with the flu and she was really giving me support to, that this is the process, this is how I process ...(?)... that "hang in there" basically was her message, and I just felt like "what the fuck for" and what she was saying was that it's, the perfect thing to do is to feel like you want to die and give up. OK, this is an important part of my experience that I don't think I've directly expressed so far is that I think that we find our salvation in the process of giving up the struggle and it's a paradoxical concept. Alexander Lowen discusses it in his writing, in particular the one book, "Fear of Life"

*I've read that*

So you're familiar with that, the idea that we give up this struggle and this has been so hard for me because it has been such a struggle to stay alive as a little boy in the face of, I would have to say, a very cruel and twisted upbringing on the part of my mother, which has been reconfirmed to me through my sisters, I have 3 sisters—one of whom is a therapeutic counsellor, we've all finally put this into focus, we grew up under the influence of a woman who was like just not prepared to have children, not equipped to have children and as a result we were subjected to really wicked cruelty. So my struggle to stay alive in the face of that has been such that I've carried that through my life and that's what's been so, the major challenge is like learning to give up in the face of it, give up the struggle and to be able to fail and somehow rely on a kind of renewal that comes from that and it just keeps on happening over and over again. So I think that of anything that I've said, one of the most important messages is that we've got to give into it. It's a very scary thing because if you think you're going to give into it then you're going to die, so when is it right to make that decision: do I need to go out and exercise or do I really need to just go to bed and read a book? So it's always presenting itself in little ways like that or maybe in bigger ways like, gee do I need to, is it right for me to go on lithium or maybe even AZT—which to me is like poison—but maybe there will come a time, I don't know.

*I know I have the experience of the despair and of reaching a peak and I think, dying must be better than this and then all of a sudden there's this light*

Yeah, and to honestly hold that idea that dying will be better, it's our salvation and through all this I got to say the ego takes a little bit of a pummelling and I think as young people we are very egocentric thinking, well, "I'll go out there and show those bastards, and do this and that." And so I've come to be a lot more sort of humble, but also seeing it, having a sense of humour, much better sense of humour about all these things.

*How old are you*

36. Humour, well the hope, this is something that ties in with the giving up of the struggle and that is being able to embrace the hopelessness of it all and I mean the ironical business of it all, of our lives,

*of changing our mothers*

of changing our mothers, the ozone, and it was quite extraordinary, I mentioned this woman in Victoria who's been an inspiration for me, she's battled with leukemia on and off and she's a Reiki master and very much a healing, spiritual woman. I kind of see her as my surrogate mother figure although she wouldn't like to hear that and an older male friend of mine who's been an inspiration for me,

he's more the dionesian side—have a glass of wine, smoke a joint -that's his way of beating and we all arrived at a profound acknowledgement of the hopelessness through our own experiences and we were having dinner out at a restaurant on Robson St recently—I guess sometime last fall—and we were sharing this and we were laughing away having reached this similar conclusion—that it is just utterly, utterly, hopeless, and rather than that being something to despair about in fact it was something to take comfort in because if you look at the word "hopeless" and you divide it up into "hope" and "less" and you look at what hope means, like hope is like always something in the future, like I hope this happens, I hope that happens, and most of the time we're disappointed, so if we do away with the hope, or realize that it's hopeless, then somehow there's somehow some salvation in it. I don't understand it entirely but

*In a way we hope less and are more accepting of what is*

Yeah, so, my message is that it's hopeless

*and you say that with a smile*

Yeah and in(?) needing to give up the struggle and if some people die, that's their karma, I can't understand it, but I suspect that some people think they are really giving up when they are not, I don't know, and they're somehow choosing death, I don't know, it's really an assumption to try and figure out why some people die, it's ... I don't do that anymore

*It's easier just to try and figure out ourselves or at least come to know ourselves*

Yeah so, there you go, if you want to follow anything up, by all means

*Thankyou*

By all means, I'd be happy to clarify chronology or anything like that

*OK, thankyou*

Yeah , it's a little, I don't often toot my own horn like this. I'm usually doing the interviews and I'm thinking that there's something inauthentic about it, like, "who do you think you are?" so I'm just telling that, I'm hearing this going on ...

*And that's what I feel when I ask you a question because I think that you give so much richness in..*

Yeah, but it's like, like ultimately it doesn't really mean anything anyway, sort of, it's like, OK that's great, but now what, it's like "so what?"

*Now what, now you've got to call your tennis partner*

Yeah, sort of simple truths, I guess, is what it boils down to

*I know when I've read Ram Dass and Stephen Levine, etc. , present simple truths in such a way, I mean it is it's like coming home, it's YEAH, but it's nice to hear it too and I think it's valuable to have done(?) it*

I'll show you if you like, there was just this one passage...

Well this idea of coming home he says:

"Death is not God, coming home is not something we can only do later but something available to us right now in each moment we are open to. To the degree we appreciate the light now we will stay with the light then. Death is not God any more than a magic trick is the magician and just as a magician might show you after performing a trick how it was done, so too after death might we gain insight into the trick itself. As the death trick loses its mysteriousness, it tunes us deeper to an edgeless entry into the mystery itself. God is not somewhere or something separate, but is the suchness in each moment, the underlying reality. Like birth or illness or old age, death is just another event along the way. In fact like birth or illness or old

age, death has a universal quality, it is nothing special. It is as common as God, inherent in every moment" and he quotes Kabir (I guess a poet from somewhere): "If you don't break your ropes while you are alive do you think ghosts will do it after? The idea that the soul will join with the ecstatic just because the body is rotten, that is all fantasy. What is found now is found then. If you find nothing now, you will simply end up with an empty apartment in the city of death. If you make love with the divine now, in the next life you will have the face of satisfied desire" and then Levine goes on: "If we do not examine the grief of our homesickness for God now, we will always be looking elsewhere for our healing. Death is not going home, our home is the heart, our real nature. God is just this much, the vast spaciousness of our inherent nature, luminous and whole, the heart of the moment." And I read this little passage when I was sick thinking I just want to die and then I thought, Oh, I can't do that, there's no, that's not a way out, I'll die when it's time

*You can't even (Then together!:) You can't even die!*

And that I think is behind the cultural prohibition against suicide. I think that's where it stems from, it's that well, "Go ahead and do it but it won't get you anywhere." This book also was earlier on ("Dynamic Laws of Healing")—it's almost more evangelical, charismatic maybe—but it was very inspiring during the depths to go through these affirmations, "No, no, no, it is not so" and I think that at each point during the crisis there's something that is more suitable than other things, so that that has a validity at a certain point

*1966 [date of publication]*

Yeah, and it's very much a kind of Christian evangelical approach. Considering my upbringing which was very much in the agnostic tradition, returning to this is like really

*Sacrilege*

Sacrilege, but stranger things have happened. Anyway, I just pointed out that to you as one of my inspirations

*And I think we can read these things and then years later read them and get different things from them*

Definitely. Great, well I'd better just make a shift before my student comes!/  
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