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Finding a Way to Live:
Complementary therapy use among people living with HIV/AIDS

by

Andrea Lyn Mulkins

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

Centre for Health Promotion Studies

Edmonton, Alberta

Spring, 2001

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Always to You
Beautiful One
From Whom
I have come.

And to whom
I shall happily
Return.

UNIVERSITY OF ALBERTA

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Finding a Way to Live: Complementary therapy use among people living with HIV/AIDS submitted by Andrea Lyn Mulkins in partial fulfillment of the requirements for the degree of Master of Science.

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ABSTRACT

As a devastating disease with a poor long-term prognosis and often with minimal response to a limited number of conventional medical treatments, HIV/AIDS is exemplary of the kind of health crisis that promotes a wide range of treatment responses. There is growing literature on the use of complementary health care services and HIV/AIDS but little on the actual experience and process of using complementary therapies for AIDS related symptoms. In the absence of careful study, assumptions about the motivations for those who are attracted to complementary therapies abound.

In light of these findings, this study intended to examine the social psychological aspects of complementary therapies in HIV/AIDS health care and identify the process that individuals incorporate them into this care. However, in addition to identifying this process, it was discovered that complementary therapy use is an integral part of how people living with HIV find wellness within their illness. This was discovered by using a grounded approach in sampling, data collection and analysis with 21 homosexual, Caucasian, adult males at various AIDS service organizations. These men experienced a three phase process whereby the HIV served as a precondition for a profound self-transformation; a commitment to and rediscovery of the meaning of life. Complementary therapies, referred to as 'tools' by the participants, were an integral part of this process and the meaning and purpose for their use shifted accordingly. These tools helped to facilitate personal growth and self discovery already initiated by the diagnosis of HIV.

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I am most grateful to the men who agreed to participate in this study. Although this research was focused on how people living with HIV/AIDS used various tools to find a new way to live, they have taught me more than I could have possibly imagined about my own life and how to live it. It was a dream to have been able to share their incredible stories with them and I offer a very special thanks for their invaluable generosity and trust.

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CHAPTER 1

Introduction

Increasingly, researchers are recognizing the need to understand people's beliefs about health, illness and healing in order to explain the health care decisions they make in the face of illness (Bury, 1997). Of interest, is how people deal with their illness to achieve a maximal level of health within the context of their illness. Since the beginning of the AIDS epidemic in 1981 and up to January 2001, a total of 44, 427 positive HIV tests and 16,628 AIDS cases have been reported to the Laboratory Centre for Disease Control, Health Canada from all provinces and territories. There were 9, 645 HIV and 2,755 AIDS cases in British Columbia. The total number of HIV/AIDS related deaths in the past fifteen years is 1,975 in the province and 11,661 in Canada. HIV/AIDS infection raises the threat of major negative life events and chronic medical conditions. Predominant is the prospect of premature death, which is often preceded by periods of physical disability and pain. As a devastating disease with a poor long-term prognosis, and often with minimal response to a limited number of conventional medical treatments, HIV/AIDS is exemplary of the kind of health crisis that promotes the widest possible range of treatment responses.

The health care industry is currently embroiled in a time of change and turmoil. Cost containment, evidence-based medicine, patient satisfaction and positive outcomes are buzz words in the industry (Pawluch, Cain & Gillett, 1994). Canada's National Forum on Health (1997) has outlined promotion and prevention as a primary focus in the future of health care. The basis of interest in health promotion and enhancement can be traced to a number of disparate forces. Emphasis is starting to be placed on a holistic paradigm, positive health, improved quality of life, personal empowerment, grass roots initiatives, self-care and the acknowledgement that health issues and treatments are highly individualized (Lowenberg, 1989).

Despite the advances of conventional medicine, treatments that complement conventional medical care continue to flourish in developed nations and to be used by a significant (and perhaps growing) number of people to deal with their health problems (Singh, Squier, Sivek, Nguyen, Wagener & Yu, 1996). There is increasing evidence that the use of acupuncture, homeopathy, naturopathy, massage, stress reduction, herbal nutrition and meditation techniques, self help groups and spiritual healing is more prevalent than once thought and that in recent years these therapies have been growing in popularity (Eisenberg, Kessler, Foster, Norlock, Calkins & Delbanco, 1993;Yates, Beadles, Najmen, Thomson, Williams, Kenny, Roberts, Mason & Schlect, 1993; Eisenberg, Davis, Ettner, Appel, Wilkey, Rompay & Kessler, 1998).

In this era of health care reform, this behavior raises important questions about minimizing impact on health care costs by taking health and disease management into one's own hands. Among the factors driving heath care delivery reform is rising medical care costs. It has been suggested by advocates of complementary therapy use that some therapies may have a large role in disease prevention and cost containment (Pelletier, Marie, Krasner & Haskell, 1997). In addition, quality care and the holistic nature of complementary therapies have been thought to attribute to increased satisfaction with a person's medical care, which may also lead to decreased unnecessary physician visits. However, such inquiry is beyond the scope of this research.

Purpose of Research

The purpose of this study is to examine the social psychological aspects of complementary therapy (CT) use in HIV/AIDS health care and to identify what happens in a person's illness management process when individuals incorporate CT use into HIV/AIDS care. There is growing literature on the use of complementary health care services and HIV/AIDS but little on the actual experience and process of using CT for AIDS-related symptoms.

In the absence of careful study, assumptions about the motivations of those who are attracted to complementary therapies abound. Is it because they wish to put themselves in the best possible position to "fight AIDS"? Is it to prevent an opportunistic infection (for example, to boost the immune system)? Do CT's help to manage the symptoms that are not being treated by the physician (for example, mitigating the side-effects of prescription pharmaceuticals)? Do CT's provide a sense of hope or control because people are actively participating in their health care decisions? Or do CT's help people move ahead from their current state so they can gain new quality of their life and health despite their illness?

Of course, these questions are not mutually exclusive and the rationale for using complementary therapies may change over time and change from one of these questions to another. Individuals use complementary therapies for a variety of reasons. Do people attach a broad range of meanings to them and fit them into their disease management process in different ways? Of interest to this study is the timing, pacing, changing perceptions and rationale in the use of complementary therapies. Is the use of CT a process of informal testing or are the complementary therapies used regardless of the perceived effect, even if no difference is evident? Is their use influenced by cost? Are they taken as a result of pressure from family and significant others? These are the questions of interest although, it may not be possible to address all of these questions in this study.

Clearly, use of complementary therapies is an important part of individual's managing HIV/AIDS, yet little is known of the process by which complementary therapies are integrated as treatments for their perceived benefits. What is the role of CT in the lives of people living with HIV/AIDS?

CHAPTER 2

Literature Review

Definition of Key Terms

Before proceeding further, it is important to define terms that will be commonly used throughout the body of this thesis, including the terms complementary therapies and persons living with HIV/AIDS.

Various key terms are used to refer to non-biomedical approaches to healing throughout our society. "Complementary therapies" (CT) is defined as diagnosis, treatment and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frameworks of medicine (Ernst, 1993). The popular term "alternative" will not be used because of its emphasis on the differences between conventional and unconventional approaches. "Alternative" also tends to suggest an attitude of dismissiveness and rejection to other healing modalities (Ernst, 1993). The term "complementary" appears to be more inclusive and not as dismissive of less accepted and established therapies.

When recruiting for the study sample, for purposes of not biasing or excluding any potential participants, complementary therapies are described as "anything not normally given or prescribed by their doctor" (Eisenberg et al., 1993).

Understanding HIV/AIDS

Acquired immunodeficiency syndrome (AIDS) was first recognized in 1981 and has since become a major worldwide epidemic. AIDS is caused by the human immunodeficiency virus (HIV). By leading to the destruction and functional impairment of cells in the immune system, notably CD4+ T cells, HIV progressively destroys the body's ability to fight infections and certain cancers. The U.S Centers for Disease Control and Prevention currently defines AIDS in an adult or adolescent, age 13 years or older as the presence of one of twenty five conditions indicative of severe immuno-suppression associated with HIV infection, such as Pneumocystis carinii pneumonia (PCP), or HIV infection in an individual with a CD4+ T cell count less than 200/cells per cubic millimeter of blood.

HIV is spread by sexual contact with an infected person, by sharing needles and/or syringes with someone who is infected, being stuck with a needle containing HIV infected blood or less commonly through transfusions of infected blood or blood clotting factors. Babies born to HIV infected women may become infected before or during birth or through breast-feeding after birth.

The database of the Community AIDS Treatment Information Exchange presents a five-stage description of HIV disease (Canadian Hemophilia Society, 1998). The first stage is primary (or acute) HIV infection and refers to the time immediately following infection. After infection, many people experience a brief period of illness that may involve symptoms of fever, sore throat, fatigue, headache and other flu like symptoms. Stage two is referred to as seroconversion. This stage emerges one to three months after infection. Following stage two, many persons live through a period in which they may have a few symptoms. This third stage is called asymptomatic infection. This phase usually lasts anywhere from seven to ten years. While symptoms may not be evident, weakening of the immune system can be noted through laboratory tests for CD4 cell counts. As CD4 counts decline, resistance to infectious diseases lessens and individuals may begin to manifest what are called "opportunistic infections". These are illnesses that break through, or infections that overcome the person's weakened immune system. The emergence of these symptoms begins a fourth stage known as symptomatic HIV infection. The continued deterioration of the immune system, with the presence of infections or malignancies which demonstrate severe immune or neurologic dysfunction can lead to the fifth and final stage, which is a diagnosis of AIDS.

Although advances in the management of HIV have demonstrated efficacy in slowing or controlling disease progression, living with HIV infection as a chronic illness presents several challenges for infected individuals (Sowell, Phillips, & Grier, 1998). A major concern for persons living with HIV is in maintaining a sense of emotional wellbeing and quality of life in the face of various disease-related stressors. This is often complicated further with the addition of unresolved conflicts, concerns about life choices, low self esteem, alienation, public discrimination and condemnation, helplessness, depression, anxiety, anger or grief (Gloersen, Kendall, Gray, McConnell, Turner & Lewkowicz, 1993; McCain & Gramling, 1992).

However, despite these significant challenges, a number of studies have found that people living with HIV have had life transforming experiences that they attribute to living with HIV. A new attitude towards life, increased connectedness with others, a sense of wellbeing and hope for longer life were found to be some of these views that were fostered in HIV positive individuals after transcending their initial response to HIV (Salisbury, 1986; Reed, 1991; Gloersen et al., 1993, Schwartzenberg, 1994; Coward & Lewis, 1993; Barroso, 1997; Relf, 1997).

This movement toward self-actualization has been noted to involve an introspective process of searching for authenticity of self and the meaning of having HIV through self-reflection, self-acceptance and ultimately self-love. Barroso, (1997); Coward, (1990); Solomon et al., (1987) suggest that a significant number of people living with HIV have experienced these transformations as a result of becoming aware of and better addressing their spiritual needs. Research that has focused on activities which help people living with HIV to adjust to their illness and find meaning in their lives has highlighted the importance of spiritual beliefs and activities in response to HIV infection. (Katz, 1996; Sowell et al., 1998; Coward & Reed, 1996; Haase et al., 1992; Reed, 1992). There have been a number of studies which have examined the process by which people living with HIV find meaning in their illness and eventually transcend it (Relf, 1997; Gloersen et al., 1993; Coward, 1990); however, there is an obvious gap in the knowledge of what is instrumental in facilitating this transformation.

As AIDS is a relatively new epidemic and the majority of studies on complementary therapies have been conducted as of late; the amount of research done on this topic is minimal when compared to other aspects of HIV/AIDS or even CT use among people with cancer. Previous work has examined a number of different factors contributing to the use of complementary therapies. These studies fall into the broad categories of extent of complementary therapy use, the decision to use and the attraction to complementary therapies.

Extent of Complementary Therapy Use Among People Living with HIV/AIDS

There is evidence to suggest that the number of people turning to complementary forms of health care is growing. A 1990 survey reported that 34 percent of adult Americans used one or more "unconventional" therapies (Eisenberg et al., 1993). It was estimated that Americans made 425 million visits to complementary care providers in 1990. This figure exceeded the number of visits to allopathic primary care physicians during the same time frame. A follow up survey (Eisenberg et al., 1998) found that by 1997, the proportion had increased to 42%.

Health care decision strategies of people living with HIV/AIDS often include the use of complementary health care practices. There have been a number of studies in the past decade attempting to measure CT use among people living with HIV/AIDS.

A review of the prevalence of complementary therapy use among people living with HIV/AIDS in Western developed countries indicates that use ranges from 39 to 81% (Anderson, O'Connor, MacGregor & Schwartz,1993; Barton, Davies, Schroeder, Arthur & Gazzard,1994; Dwyer, Salvato-Schille, Coulston, Casey, Cooper & Selles, 1995; Eisenberg et al., 1998; Ontario Ministry of Health, 1995; Ostrow, 1997; Robinson, Millson, Leeb & Luby, 1998; Stine, 1993). Rates of prevalence greatly vary from study to study. For example, two studies by Ostrow (1997) and Anderson et al., (1993) respectively found that 39% and 40% of their samples used complementary therapies in contrast to the 74% and 81% in the respective studies of Robinson et al., (1998) and HIV Ontario Observational Database (1995). However, Ernst (1997) found that complementary therapy use does not appear to be any more popular among people living with HIV/AIDS than the general population. 24% of participants in a Dutch study reported using complementary therapies before receiving an HIV positive diagnosis and 27% after being diagnosed as HIV positive (Wolffers & De Moree, 1994). This datum does not support the hypothesis that the use of complementary therapies among people living with HIV/AIDS is growing.

Even though there is a growing body of research about the prevalence of complementary therapy use among people living with HIV/AIDS, there are large gaps in the knowledge we are receiving. Eisenberg et al's., (1993; 1998) two studies are the only two longitudinal studies using the same national base, resulting in a greater level of confidence than the rest of the studies. Recent studies have shown that people living with HIV/AIDS often use multiple complementary therapies. Examinations of complementary therapy use over a period of time have indicated that major changes take place over time with regards to whether or not people with HIV/AIDS use complementary therapies and in the number and types of therapies they use (Boon, Brown, Gavin, Kennard & Stewart, 1999; Pawluch et al., 1994; 1998). As AIDS is such a complex disease with a variety of symptoms, different therapies are often used for different health complaints.

Decision to Use Complementary Therapies

How people who have HIV/AIDS decide to use complementary therapies has been a subject of several studies but no formal theory has been developed. Unfortunately, without a clear conceptualization of a decision making process among people living with HIV/AIDS and the various factors that play a role in one's decision, our understanding of the way that people choose complementary therapies will remain limited. Pawluch et al., (1994) and Sharma (1992) have both found that when health problems do not respond well to conventional medical care, or for which few conventional treatment options exist, people are frequently motivated to develop purposive self-care routines and to explore a range of potential treatment. Many view conventional medicine as either an institution with which they felt uncomfortable or an institution that was unresponsive to their unique needs. A sense of marginalization appeared to be a major impetus in a person's decision to explore various other treatments (Pawluch et al., 1998).

Sharma (1992) found that it was important for people living with a serious illness to take responsibility and engage in an active search for potential answers to their health problems. The more serious the health threat is and the fewer treatment options available, the greater is the number of additional therapeutic measures likely to be used (Singh, Squier, Sivek & Nguyen, 1996). Abrams (1997) like Sharma (1992) points out that the general disillusionment with and lack of confidence in anti-retroviral treatments that arrived in the early 1990s was a contributing factor that has led to the rising popularity of complementary therapies. However, this is difficult to confirm as there is limited research on people's dissatisfaction and satisfaction of conventional medical care and treatments and their treatment expectations. Taking control of one's health by seeking out different treatments is a common strategy employed by a number of the participants in Pawluch et al. (1998) study. One way in which people give themselves a sense of control is through making decisions about treatment (Montbriand & Laing, 1991; O'Connor Wicker & Germino, 1990). Options may include choosing among types of treatment, physicians or complementary forms of therapy. Eidinger and Schapira (1994) propose that the choice of complementary therapies require one's active participation in the treatment. They further suggest that active participation has a "beneficial effect on the patient" (p. 2740). Several authors describe the use of complementary therapies as a way to increase feelings of control (Abrams, Dilley, Maxey & Volberding, 1986; Truant, 1999).

A number of studies have assessed determinants of complementary therapy use in people living with HIV/AIDS (Cohen, Mayer, Eisenberg, & Orav, 1990; Greenblatt, Hollander, MacMaster & Henke, 1991; Singh et al., 1996). Questions have been raised about the relationship with the stage and severity of one's illness and use of complementary therapies. A study by Cohen et al., (1990) found that individuals with lower CD4+ counts were more likely to use complementary therapies which has led to a hypothesis that people with more advanced disease would use complementary therapies to a greater degree and they would generally perceive these therapies to be more efficacious. Findings by Greenblatt et al., (1991) confirmed Cohen et al., (1990) hypothesis as they found that advanced stage HIV was associated with an increase in the use of complementary therapies. However, Singh et al., (1996) found that patients with early HIV infection were as likely to try complementary therapies as patients with more advanced disease. Disease related factors, such as the stage of the infection and disease duration appear to have an influence over use.

This wide variation in use is partly due to differences in definition, methodology and the complementary therapies that were included in each study. Some of the studies have asked more specific questions than others. The definition of complementary therapies generated by users of the therapies themselves and personal interview strategies will likely yield higher number of users (Montbriand, 1995). A broad range of factors potentially associated with this range in prevalence of use vary according to demographics, prognosis, stage of illness, social and religious beliefs, duration of study, what the participants were using complementary therapies for, sample size, geographic location and the participants' willingness to speak about their complementary therapy use.

In addition to taking charge of one's illness and seeking out the best possible treatment option, there are other factors that have been thought to play into the way people understand and decide to use complementary therapies. Contrary to the above findings, considerable variation in specific approaches people are using towards complementary therapies has been discovered (Pawluch et al., 1998). People are using complementary therapies for a variety of reasons and bring all different issues to their search for health care options. They are also found to be connected to a range of social factors including one's understanding of their HIV infection, their sexual identity, ethnocultural background and gender.

All of this literature suggests that there is no simple explanation for the decision to use complementary therapies. The apparent popularity of these therapies among persons with HIV/AIDS appear to be a complex phenomena. How are these likely to be influenced by one's social context? An understanding of why people use complementary therapies must include an understanding of who these users are and their social background, experience and circumstances in this study.

Attraction of People Living with HIV/AIDS to Complementary Therapies

Conventional and complementary therapies tend to be contrasted as having different underlying models of care. Although one cannot generalize across all types of complementary therapies, in extreme form, complementary health care is dubbed as having a common philosophy and an underlying set of beliefs, sometimes referred to as an alternative treatment ideology (Pawluch et al., 1994; McGuire, 1988, Goldstein, 1992). This ideology includes a focus on health enhancement and wellbeing instead of on disease. Instead of making a diagnosis based on a patient's symptoms, focus is shifted to evaluating the nature of the physical, emotional and spiritual imbalance.

Complementary therapies are generally less invasive and aggressive than conventional treatments and therapists tend to work with, rather than against the symptoms in an attempt to strengthen constructive forces. In general, patients are encouraged to take an active role in their illness management instead of passive acceptance of prescribed treatments. This nature of care often results in an individualized healing process where the patient is very involved.

These two are both diverse yet the overlap in the practices is huge. These elements of complementary therapies are not unlike the basic elements of the patient-centered approach to patient care which is often promoted in conventional medicine. Patient-centered care has been introduced to conventional medicine because in the past, the conventional approach did not pay much attention to the person living with the disease nor the role that complementary therapies may have in the process of finding wellness within the context of one's illness.

From this we see that HIV/AIDS can be likened to that of a rollercoaster. It is a ferocious disease where the course of it is so up and down. The characteristics of this illness aside from this unpredictability is that treatment options, while somewhat efficacious in suppressing symptoms over a short period of time, produce unpleasant symptoms that demand care and treatment. This illness is approached as a disease that is chronic in nature and yet is a major threat to life with a poor prognosis. It affects not only the physical body, but is equally damaging to the mind and the spirit of the person afflicted.

CHAPTER 3

Methods and Procedures

Methodological Approach

In this study, the researcher used a grounded theory (Glaser & Strauss, 1967) approach throughout the investigation. Grounded theory is a research method developed from the symbolic interactionist view of human behavior and aims to generate theoretical constructs which explain the action in the social context under study (Chenitz & Swanson, 1986). Grounded theory best answers questions that focus on the experiences of participants, documenting the responses through an event. It is more concerned with how participants feel and respond to experiences, rather than, as with ethnography, with how they perceive the world (Morse, in press).

As little systematic investigation of this population has been done, it is imperative that the research be approached without preconceived hypotheses or theoretical framework. Grounded theory is based on the assumption that individuals sharing common circumstances also share a specific social psychological issue which is resolved by social psychological processes (Hutchinson, 1986). The purpose of grounded theory is to discover these social processes involved in the subject being studied. It seeks to unravel the elements of an experience and to challenge the theoretical concepts as they emerge in the data by looking for alternative cases. The theory is generated as the research progresses to explain how those concepts fit together, causing the researcher to follow leads and develop ideas during the research to ensure that the theory is grounded in the data (Strauss & Corbin, 1990).

Grounded theory was selected because of the nature of the research question and the gaps in knowledge concerning the experience of people using complementary therapies. The following discussion will provide an overview of grounded theory and will address sample selection, data collection and analysis, reliability and validity issues and ethical considerations specific to conducting research in the area under study. The characteristics of grounded theory data are that data are continuous over time, experiential and contain adequate variation (Morse, in press). Grounded theory is less concerned with a particular context than ethnography, and places less of an importance on cultural perspectives and world views.

Sample Criteria and Selection

The method of sampling the researcher has selected is known as theoretical sampling (Glaser, 1978). Theoretical sampling is a process where the researcher collected, coded and analyzed the data and decided which data was collected next that would best develop the theory as it emerged. Data collection was influenced by the outcomes of the ongoing data analysis. The researcher used purposeful sampling at the onset of the study to find participants. It was in this stage where data collection began, concentrating on the social processes that appeared to be the most interesting and predominant with these initial interviews. After the preliminary data collection and analyses, the sampling became more selective as the preliminary hypotheses which described the phenomenon emerged from the data and promoted the data collection further (Glaser, 1978).

The sampling criteria was minimally restrictive to achieve a diverse representation of people using complementary therapies. The criteria included gay, Caucasian males, 18 years and older, who had been experiencing symptoms of stage four HIV infection, who had identified themselves as using complementary therapies to specifically address their HIV related health issues. Participants who were at a stage four symptomatic level of infection were selected because at that stage people living with the disease tend to be experiencing early symptoms characterized by non-life threatening infections and chronic or intermittent symptoms.

The sample was fairly narrow in scope for a number of reasons. Gay males were studied because while the rate of infection among heterosexuals is on the rise, gay men still make up the majority of persons infected with HIV/AIDS in Canada (Pawluch et al., 1998). More practically, given the small number of interviews the researcher was able to undertake due to practical limitations, the researcher did not want to cast too wide of a net in terms of the background characteristics of the sample and limit the possibilities for an in depth analysis.

Caucasian men were selected as participants for the same reason of limiting the ethnocultural background; to provide the researcher with data with the most breadth and depth. There has been little research with people who are in the latter stages of HIV illness; most studies have had participants who were seropositive but who may or may not have been symptomatic. The complementary strategies for these people who have had to deal with physical and psychological symptoms have been very different than for those who were seropositive but asymptomatic. It was anticipated that participants were more likely to be treating these AIDS related symptoms with complementary therapies instead of using complementary therapies for various other non-AIDS related health concerns.

As this was not an efficacy study but one that examined the basic social psychological process of using complementary therapies, restrictions were not placed on the types of therapies participants indicated they had used. It was very important that the researcher documented all of the participant's complementary therapy strategies and not limit them to a few categories.

As the study progressed, the researcher became more selective in sampling in an attempt to further diversify and to achieve convergence of the data within emerging categories. It was important to initially interview those who had been using complementary therapies for their HIV/AIDS management for 2 or more years so as to get an idea of the processes which were occurring. It was also valuable to later interview those people who were just starting to use complementary therapies for their HIV/AIDS management.

A sample size of approximately 30 participants was anticipated but was dependent on the quality of the data and amount of variation that occurred within the phenomenon. Recruitment of participants was terminated when convergence of data within categories became apparent. There was no need for the researcher to select participants based on age, gender, religious affiliations, mode of HIV transmission but the data were noted and any significant differences recorded. Demographic data from each participant was recorded to examine the sample's characteristics (see Appendix A). Sampling on theoretical grounds continued until all of the major variables that evolved from the data were explored and the categories that pertained to them were saturated.

The researcher approached a broad range of AIDS community organizations to obtain assistance in informant recruitment such as Friends for Life, British Columbia Persons With AIDS, and CAM Integrated Healing Center. Contact individuals were provided with a letter describing the study, its purpose, how data was to be collected, measures that were taken to ensure confidentiality and the voluntary nature of the study (see Appendix B). These individuals were asked to provide participants meeting the criteria for inclusion in the study with a similar letter and a return form (see Appendix C). Potential participants were invited to contact the researcher by telephone to learn more about the study.

In addition, participants were recruited by word of mouth and through posters that were placed in areas frequented by the targeted population. The posters provided a brief description of the study and invited those interested to contact the researcher by telephone to learn more about the study (see Appendix D).

Twenty-one gay men participated in this study which was conducted in Vancouver, British Columbia. Eleven men responded to a solicitation through several AIDS service organizations, and the remaining 10 by snowball sampling. Participants ranged in age from 22 years to 59 years. Education ranged from high school completion to some post-secondary or trade school preparation. The average annual income level ranged from $12, 500 to $25,000 and most participants lived on some form of disability insurance or social assistance. Sixteen of the men indicated a religious affiliation ranging from Buddhism to just 'spiritual'. The amount of time since diagnosis ranged from two months to 14 years. The men were in various stages of the disease process and many at the time of the interview, were experiencing HIV related symptoms. Many had previously experienced serious acute illnesses related to the HIV infection.

Data Collection

All of the interviews were conducted by the researcher, following informed consent procedures. Participants were given the choice as to whether they preferred face to face or telephone interviews. Participants were interviewed on an individual basis. These were open and interactive interviews and were conducted in a private, quiet, comfortable room at an

HIV/AIDS community organization in Vancouver. Multiple, tape-recorded interviews were held with each participant, and data analysis continued throughout the data collection.

Interviews began with broad, open-ended questions that invited participants to describe in their own words, what they did to make themselves feel better (see Appendix E). Unstructured interviews were designed with the intent to allow the informants to tell their story freely and without the researcher imposing any preconceived ideas. Occasional probes were used to clarify or encourage more detail. As the data collection progressed and theoretical explanation of emerging categories became appropriate, participants were asked increasingly specific questions. Follow up interviews were required to focus on the development of hypotheses about stages in HIV/AIDS management process. Interviews ran between one to two hours in length.

Reflective field notes and subjective accounts of thoughts and perceptions experienced by the researcher when reflecting upon the interview were made following each interview with their purpose being to supplement data collection. Field notes were not taken throughout the interview.

Data Analysis

Data analysis proceeded concurrently throughout the interviewing period and continued until a conceptually dense substantive theory was derived from the data (Strauss et al., 1990). All interviews and field notes were transcribed verbatim by the researcher. Transcribed data was coded and as categories emerged, theoretical codes were generated. The researcher was looking for processes. As the data was received, the investigator applied a system of open coding. The data was examined line by line and identified the process in the data. Initially, data was coded to capture and label the substance and was compared with other data assigned to categories according to obvious fit. Codes which clustered were developed into categories. The researcher used the constant comparison method of analysis throughout where comparisons were made continuously. For example, the first two interviews were compared for similarities and differences in the lives of those involved.

Category characteristics were developed and linkages between categories were determined. Descriptions of typical events and patterns of behavior were conceptualized and summarized. It was then that hypotheses concerning these categories, their linkages and existing literature were formulated and tested in subsequent interviews. Further data collection and analysis produced other categories; some were later recorded and some were combined with others. The data was analyzed for patterns of relationships between two or more categories. These patterns of relationships formed the initial hypothesis to be tested (Corbin, 1986).

As the main concepts became apparent, they were compared with data to determine under what conditions they were likely to occur and if they are indeed central to the emerging theory. The conceptual framework, developed from these data, was tested by collecting data which suggests or fails to support the framework hypotheses. Data were then collected to develop the sub-category. Through theoretical sampling, already discovered categories were expanded, dimensionalized and limited. This process is called saturation of the categories. Data were collected until the researcher was satisfied that no new information was being received. Through constant comparison, the core variable for this study emerged. Two major analytic processes dominated this phase: memo writing and theoretical coding. It was through these processes that the emerging theory was finally integrated. The researcher compared concepts with more highly developed concepts to discover their relationship and once again related concepts were compared with data for validation. Incidents or participants not fitting within the schema are considered "negative cases" and were purposefully sorted out and were interviewed to increase the variability or understanding of the scope of the category.

Process analysis serves as a central analytic approach to the development of a substantive theory. The ultimate goal of analyzing data for process is to account for change in the social phenomenon being studied over time (Fagerhaugh, 1986). Diagramming processes, stages and turning points is part of the procedure for understanding the BSP. A basic social process (BSP) is a type of core category that has two or more stages and "gives the feeling of process, change and movement over time" (Glaser, 1978, p. 97). The basic social process is fundamental and occurs over time and remains intact even when conditions vary it considerably.

The determination of whether a process is central to the social phenomenon under study is based on two major criteria (Fagerhaugh, 1986). The initial criterion is if the core process discovered in the data can account for a large part of the variation in behaviors, be it varied in types or degrees. The second criterion is if the parts of the process are logically integrated. The theory in this study was explained by a core category, one which processed the problem addressed, explained as much variation in the behavior as possible and used the fewest number of concepts possible. The core variable which described most of the process became the basis for the emerging theory.

Memos were recorded by the researcher throughout the analysis and served to capture the analytic thought processes as they occurred. Memos were written records of the analytical process associated with the codes and their relationships (Glaser, 1978). Writing memos involved recording ideas in an effort to capture the initially elusive and shifting connections. Memos documented the researchers thinking process. Through writing memos, the conditions, causes and consequences of the BSP and its stages became clear. The memos were used to document the thought processes associated with coding, guiding subsequent data collection and were critical for theory development and demonstrated integration of the theory. These memos were reviewed often and were eventually coded theoretically. At this stage the researcher returned to the library to seek information in the literature so links to established theory were identified.

The final phase of the analysis occurred when the theory was written. The sorting process which followed memo writing, put the "fractured data" (Glaser, 1978, p. 116) into a coherent theory and aided in forming the outline for the write up of the theory. Coded data, categories, and memos were reviewed during this phase to assure consistency within the theory and for accurate grounding of the theory in the data. According to Glaser and Strauss (1967), a theory should be logical, clear, have density, be parsimonious, have scope, fit the situation being researched and be able to predict and explain the data under study.

Reliability and Validity

Validity and reliability were critical issues in evaluating research findings. Morse et al., (1995) define validity as the degree to which the research findings represent reality. Validity and reliability were established through the use of certain procedures for data collection and analysis.

According to Morse (1986), in grounded theory, validity is established by ensuring the appropriateness of the sample and reliability by ensuring the adequacy of the data. Participants were purposely selected according to the theoretical needs of the study, their willingness to participate in the study and their ability to describe their thoughts and feelings. To ensure that the data was rich, the sample should represent the phenomenon under study rather than the population in general (Morse et al., 1995). Participants from various community AIDS organizations were purposefully selected. This helped the study meet the criteria of adequacy. Interviewing and sampling continued until data was saturated or became repetitious. As Morse (1986) has pointed out, grounded theory does not attempt to quantify attributes and therefore generalizability acquires slightly different meaning. The generalizability in grounded theory is referred to as "theoretical generalizability"; and the theory that was developed is applicable to others who experience the same conditions or illnesses.

Conducting unstructured and individual interviews aided in preventing threats to validity of the study such as altering the truth and social desirability (Brink, 1991; Morse, 1986). Follow-up interviews were useful reliability checks to ensure the data was consistent. Findings were clarified and verified with informants. In addition, the constant comparative process acted as a set of checks and balances for reliability and validity. As previously mentioned, throughout the duration of the data collection process, the researcher was seeking negative cases that would refute the emergent categories. As each interview was tape recorded and transcribed by the researcher verbatim, transcripts were checked for accuracy with the taped version.

Qualitative research is often criticized because of the issue of interviewer bias (Morse et al., 1995). The concept of "bracketing", or consciously identifying researcher's' theoretical biases and placing them aside is a technique used in the study to remove the interviewer bias which

Lincoln and Guba (1985) refer to as neutrality or objectivity in the manner in which the question is framed. Issues of accuracy are also a concern because of inconsistent interview techniques. All interviews were checked for gaps to identify any areas that had been omitted. Following the transcription, the interviews were checked by the researcher to ensure that the interview had been transcribed correctly and had included notations for all pauses and exclamations, and otherwise had indicated as much of the informant's expressions as possible.

Findings were clarified and verified with participants, thereby strengthening reliability and validity. The researcher presented the emerging theory to participants and asked them for a response. The researcher avoided asking leading questions (forcing verification). The researcher in addition turned to related literature for verification. It was important that the findings were identified in the work of other researchers when investigating similar topics (Morse et al., 1995). The constant comparative method was used to decide whether or not interpretations were acceptable or superficial, simplistic, one-sided or distorted.

At onset of the study, I identified personal preconceptions in relation to the subject area to prevent myself from losing objectivity. I kept a journal and used introspection and discussion to facilitate an awareness of changes and to maintain objectivity.

Ethical Considerations

Participants were recruited using a variety of techniques, including written information sheets distributed through the previously mentioned local AIDS organizations, providing a phone number through which potential subjects contacted the investigator for information regarding participation. In addition, informants were recruited by word of mouth and through advertisements in the local AIDS organizations. Contact individuals were provided with a letter describing the study, the purpose, how data was to be collected, measures taken to ensure confidentiality and the voluntary nature of the study.

When potential participants first contacted the researcher, any questions concerning the study were answered. The participants were informed that all interviews were to be tape-recorded and arrangements were made to meet for an interview. It was made clear to the participants that additional interviews and follow-up meetings may be necessary.

At the beginning of each interview, an explanation of the study was provided and consent to participate in the study and to record the interview was obtained. The participants were informed that they were not required to participate in the study, they could stop the interview at any time or refuse to answer any questions. It was made clear that their choice to or not to participate was to have no bearing on them. The participants were assured of anonymity and although some information they provided may be published, their names would not be associated with the publication. They were given a copy of the informed consent form that included a statement of their rights as a subject and the names and phone numbers of a contact person if they had any questions. Interviews were conducted with as much privacy as possible. As participants were given the choice of having a face-to-face interview or a telephone interview, steps were followed to receive consent over the telephone (see Appendix F).

Demographic data was obtained from each participant. This consisted of age, sexual orientation, level and type of education, marital status, number of children and present occupation. Information was used to describe the sample. Permission was obtained from all institutions in which recruitment notices were put up. A debriefing will occur following all interviews (see Appendix G).

The tapes were kept in a locked office and all identifying information was removed from the tapes during the transcription process. All transcripts were coded, and the informed consent forms were stored separately from the data.

There were no direct benefits to participants who participated in this research; however, many participants reported that participating in the interviews had been an enormously rewarding experience. They stated it was a privilege to be asked an opinion and to be listened to seriously. The real benefits of the study were in the further understanding of what complementary therapies are perceived to offer people living with AIDS. Summaries of the research results will be provided to all participants and copies of the research reports and reprints of articles will be supplied to the host institutions.

CHAPTER 4

Results

The participants have found a level of health within the context of their illness that often surpasses the level of wellbeing they were experiencing before they became sero-positive. As represented by Figure 1, Finding a way to live weaves its' way throughout the process that these men have gone through to get to a place in their wellbeing where they not only feel healthy but also secure and confident. It applies to those at various stages along the HIV illness continuum. Many of the participants indicated that they achieved this level of wellness because of the work that they have done on their own, without the help of medical professionals and every part of this process has contributed to the point at which they are at now. Many acknowledged conventional therapies having provided the even ground to be able to focus on themselves without having to worry too much about a physical breakdown but in the end, they were the makers of their own healing. This healing came from within, on their own terms, through the process of searching for tools and the resulting path of self-discovery:

> *I did it myself, I created it, I worked at it, I applied it. It would be easy to say my friend did it for me. It is hard to take the creative act of life and say, 'wow, I am really enjoying what I am doing with it- look what I am creating'. I think that is just the start. Yeah, it was me, I can say confidently; I was the making of my own healing.*

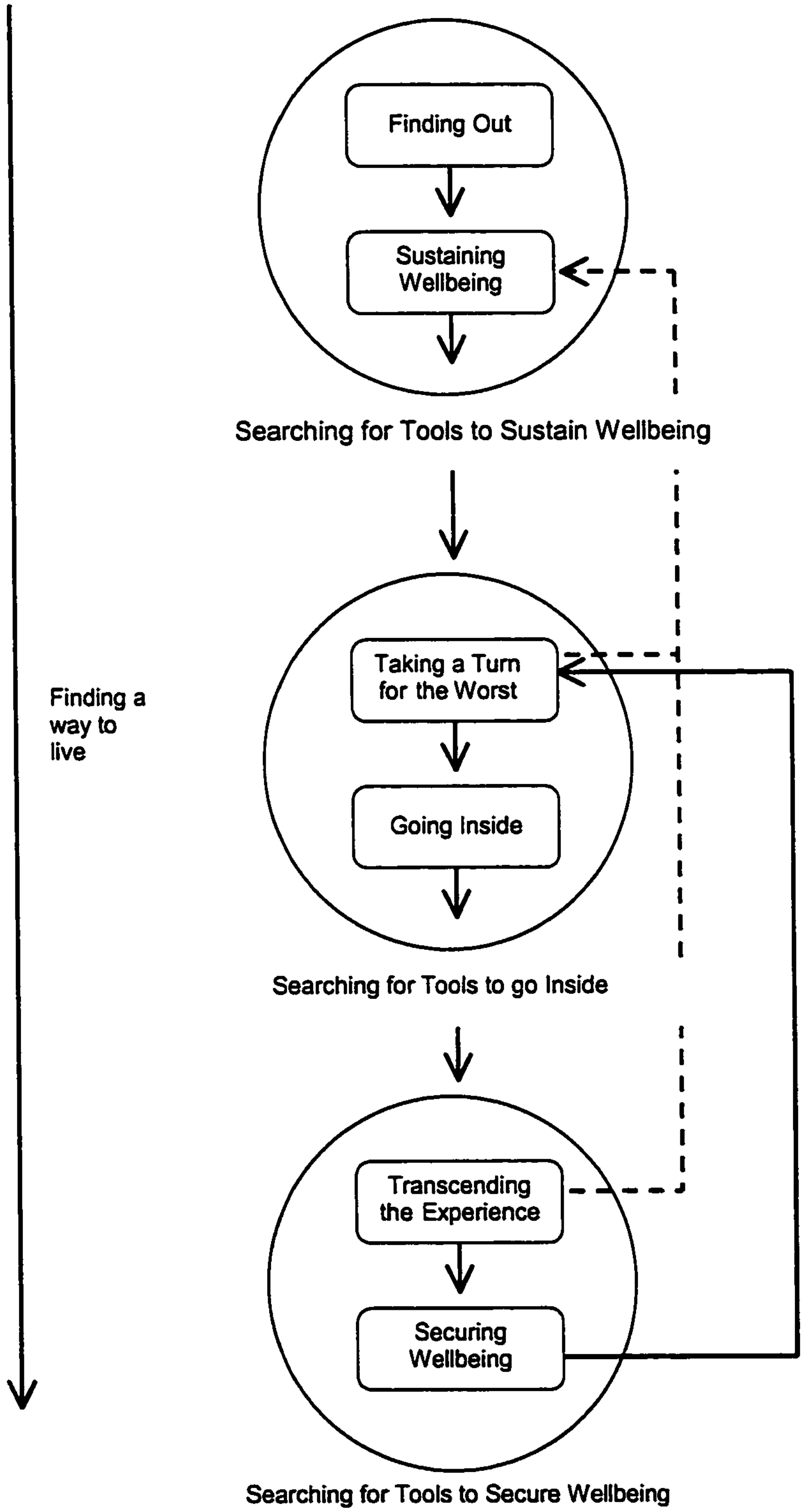

Figure 1. The process of Finding a Way to Live

The tools with which people used to cope or to find a way to sustain, transcend and secure their HIV were continually changing alongside their continuum of healing (Table 1). It is important to note that the tools used to facilitate Sustaining Wellbeing and Going Inside were often continued in the latter stages on an as needed basis. The tools that were utilized to sustain wellbeing were more tangible and reactive in nature whereas when certain tools were no longer appropriate in sustaining wellbeing, they became more introspective, addressing things on more of an emotional and spiritual plane. The tools were the vehicles for personal growth, inner reflection and self-discovery. At this time, participants spoke of such tools as meditation, developing relationships with a higher power, prayer, journaling, a general acceptance and forgiveness.

Table 1: Tools utilized along the HIV/AIDS illness trajectory

Tools to Help Sustaining Wellbeing	Tools to Help Going Inside	Tools to Help Securing Wellbeing
1. Using herbs & supplements (garlic, milk thistle, essential fatty acids, spirulina, DHEA)	1. Mediation	1. Being self aware
2. Using various types of massage	2. Praying	2. Living in the moment
3. Exercising (resistance training)	3. Journaling	3. Finding a balance
4. Paying attention to diet	4. Accepting	4. Listening to one's intuitive voice
5. Practicing yoga	5. Forgiving	5. Sharing one's experience of living with HIV/AIDS with others
6. Quitting Work		
7. Keeping Busy		
8. Seeking the advice of others		
Tools for sustaining and going inside are continued throughout the process --→		

Finding Out

The reaction was shaped by the uncertainty surrounding the progression of the disease and feelings that accompanied it. The means in which an individual responds to this diagnosis and the behaviors that precede it are influenced by a number of factors. Decisions on what to do next were predominantly shaped by the participants' personality and coping mechanisms they have learned throughout life and the circumstances surrounding their diagnosis.

Although for most men, the diagnosis represented a threat to survival and changes in health, lifestyle, social relationships and life goals, the notion of not yet having a cure for HIV accompanied with having to manage their illness over an unknown period of time caused great distress. One respondent recalled his feelings surrounding the uncertain nature of the HIV as:

> *You know, I was normal physically but I had heard all of these horror stories of being fine one day and waking up the next and um, being blind and full of infections. It was like walking on broken glass, you know? I didn't feel confident in myself, I knew that my health could swing at any minute. It made it hard to do anything because who knew what was going to happen. I was a mess, just waiting.*

Most participants indicated that the initial diagnosis was more a psychosocial emergency than a medical crisis. At the time of diagnosis, the majority of the men who had not yet experienced any physical symptoms of the illness spoke about getting caught up in the idea of having HIV, not so much in the actual physical experience of it. As one participant illustrated:

> *I got very caught up in, in the emotional part of it, in other words, the body may be not so bad but the mind can take you on these horrific journeys to hell or you know obsessing about what could happen, or how long have you got or who gave it to you or you know all of those things that can contribute to your poor health through stress... looking back and thinking what about this and what about that, what about all of my losses? There is so much baggage attached to the disease and the virus that the diagnosis alone can send someone into a funk for 10 years.*

The climate surrounding the diagnosis for men in the early 1980s when AIDS was a relatively new and much feared epidemic, had very much to do with the way in which they responded towards their illness. Many men experienced ostracism, isolation, bigoted views and behaviors from society with respect to disclosing their HIV status. The disease also carried enormous social baggage that created a unique set of stressors no longer associated with other chronic illnesses such as cancer or tuberculosis. Participants mentioned facing external judgement as well as internal anguish. This association between AIDS and negative messages about homosexuality created feelings of guilt and depression about their lifestyle. Because of this hostility, many felt that they had no option but to keep their status a secret. Many men tried not to acknowledge their HIV status and proceeded to carry on with life as usual, not disclosing their status to others in order to avoid discrimination in terms of employment, housing, personal relationships and health care. In discussing these circumstances surrounding his HIV diagnosis in the 1980s, one participant concluded:

> *There was a government here, a really oppressive government, the Vanderzalm government and they were threatening actually to quarantine people with HIV and AIDS. The health minister said that it was a self-inflicted wound, that is how he described AIDS. It was really scary. And I didn't feel any comfort in having it. I had to deny it really.*

This individual was not alone in mentioning the denial around their HIV status. As interviews progressed, it became evident that this reference to denial did not imply a disbelief around their HIV, and were instead suggesting that they had to keep their status a secret by not disclosing and concealing it.

In addition to these circumstances, not much was known about the illness in the 1980s and many were told that survival rates were not likely to be more than a decade. This became a fatalistic, self-fulfilling prophecy and a majority of the men began to disassociate from society and started preparing to die:

> *The doctor went on to explain and this was the thinking at the time that you know the average person diagnosed with this disease had a 10-*

> *year life span and in which time they would probably have fair health and then you know the disease would progress and then your life span would be greatly diminished. Just got ready to die you know?*

Conversely, men who were diagnosed with HIV in the past five years have dealt with very different circumstances surrounding their diagnosis, predominantly the rise and development of anti-retroviral drugs. In the past decade, the drug cocktails have been somewhat effective in managing HIV infection and changing the face of AIDS in terms of survival rates. They have significantly altered this experience of hopelessness around an HIV diagnosis. The men who found out they were HIV positive in the late 1990s discussed feeling overwhelmed with information at the time of diagnosis, in particular around treatment decisions and anti-retroviral therapies. Many were faced with the decision of going on these drugs and dealing with the severe side effects created by them. These anti-retroviral therapies minimized much of the physical evidence of HIV, which for many created the conditions conducive to carrying on with life as though nothing was much different.

Another circumstance that influenced the reactions to the HIV diagnosis and resulting behaviors was that many men were the primary care givers for their partners, many of whom in much poorer health than themselves. It was necessary for them to be able to carry on and maintain this role as a caregiver. One respondent described this position as:

> *I persisted, it became a little more challenging when my partner who was diagnosed with me in 86 started to have failing health. I was embarking on a new career plus dealing with the fact that my partner's own business had just collapsed because of failing health and that he was now living at home and now he was needing constant care lots of trips to the emergency room and whatever. So during that time I was sort of playing the martyr. You know I had to you know keep going, come home to a very sick person who I was emotionally involved with and it was very difficult. But there is something that sort of reared up in me and said you know you have got to keep going. I mean my health was still good and there was no reason for me to physically hold back. So I persisted.*

These circumstances inherent in one's experience of Finding Out sets the tone for the way in which Finding a Way to Live was carried out in these men's lives.

Sustaining Wellbeing

All of the men felt scared and uncertain and started to look for ways to best manage the current situation and find means to make them feel that everything was going to be okay.

Loss of control was a huge concern for many of the men. In some cases, their bodies began to change as the illness progressed and the uncertainties of the disease left medical professionals in charge. Loss of jobs and alienation were often accompanied by social embarrassment and an exaggerated need for control. Many participants mentioned these events being the impetus to find a sense of control within the context of this very uncertain illness. This meant doing things that would maintain their pre-HIV life, to sustain their wellbeing. Symptoms were addressed as they came up but the men indicated their initial intention in dealing with their illness was to maintain the status quo. In retrospect many participants indicated this type of behavior was not especially purposeful and was an indication of concealment; it helped the participants to "feel ok, feel normal" during this time. For example:

> *I made peace with it fairly quickly, if not immediately, I didn't go into some huge depression or why me, or who did this to me? I don't know why I didn't focus on any of that I just didn't and I just carried on life as usual. It was like I did what I needed to keep going. So I just did it- no time to stop and reassess or anything. I was in utter denial but I thought if I stopped I'd die.*

Searching for Tools to Sustain

This quest for a means to sustain wellbeing and a sense of normalcy was referred to by many as "searching for tools". The underlying criteria for deciding what constituted "tools" were anything that helped them to manage the HIV better, maintain the level of health they were at prior to diagnosis, cope with everyday things and take their mind off of their illness:

> *They make me the healthiest person I can be and are there to prepare myself for any sort of disaster that might happen whether it is losing my partner or getting full blown AIDS. The name of the game is to stay as well as possible for as long as possible so that I can keep on with my normal life.*

The men continued their search for tools until certain things felt right to them. Determining this "fit" involved weighing the congruency of the tools with personal beliefs about health and illness as well as with time commitment, expenses, conventional therapies and their relationship with their healthcare practitioners. One man described the qualities he was searching for in these tools:

> *You know I was just trying to get by. I wanted to feel like my old self again, you know? Like if I felt sore, I would go for a body massage. I took herbs for my liver so it didn't get damaged from the meds. My complementary therapy use is now in conjunction with my prescription drug use. My complementary therapies helps my body deal with the toxic side effects of the medication. You know, just getting by. Trying not to feel it (HIV)... In a sense, pretending it away.*

Frequently, men when finding out about their HIV status, on the advice of a physician or friend, would seek out information on treatment options through different means. Support groups where there were individuals with years of experience living with HIV were common venues to get information on treatment alternatives. References were made to the valuable information received on various herbs, AIDS Service Organizations and when dealing with physicians. Conversely, the participants who had cited sharing to be a key tool in maintaining their wellness felt the most important information shared was that of gaining a perspective on where the HIV fit in one's life and what they had done to achieve this. Many of the men who revealed this also recognized that much of what they shared was acknowledged by others but what was only "*needed and appropriate for their age and stage was taken and the rest left*".

A number of the men turned to tools that they had in place prior to their diagnosis. For instance, someone who had already been practicing yoga or who had a spiritual practice prior to the diagnosis kept with the practice and intensified it to meet their new needs and challenges:

> *I started using complementary therapies even before I found out I was positive. I think it is because of curiosity, as well as a little suspicious that western medicine knows the answers to everything period. At the time I was diagnosed I was thinking there are different forms of treatment you could take. You hear about people's stories of how they did the healing thing on their own and things like that and I tended to*

> *want to have the time to look at what my options were. I just knew what had worked for me before to stay healthy and I stuck with that for then. These things were in place already and I guess I just turned up the volume or intensity you know, a bit?*

Tools led to other tools and the more time one spent experimenting with new means with which to make themselves feel better, the more familiar they became with themselves and how they interacted with the various tools. This awareness and familiarity provided them with an acute sense of when a tool was needed for a particular concern. As described by a man who had just experienced a serious bout of Kaposi's Sarcoma:

> *I am kind of lacking something right now. I feel that I have to get into a group somewhere right now. I haven't been in a group out here yet and I really think that is what is going to help pull me out of this.*

The tools that one usually started off using were many of the complementary therapies typically described in the literature: massage, yoga, naturopathy and herbs. However, many respondents also mentioned activities not typically thought of as therapies, arguing that these activities were therapeutic and contributed as a stepping stone to sustaining their health, such as quitting their jobs or volunteering.

Taking a Turn for the Worst

Sustaining wellbeing carried on until the participants experienced a crisis of sorts, taking a turn for the worst that many described as coming up against a brick wall. Participants saw limits to their present ways of existing in ways they had not seen before and this decline in day to day quality of life brought about questions pertaining to the meaning of it all. One participant described how his life had no meaning or purpose anymore aside from just surviving. Many felt that they were unable to do anything more for their health:

> *I took about 95-100 pills per day plus various fluids, you know sleeping medications, anxiety medications. My whole life was you know, number one trying to be pain free, number two trying to stay alive. That wasn't even really that important. It was all about ok I have to see this physician tomorrow, this specialist tomorrow, have this test tomorrow. You know, did I have any real purpose left?*

This sense of reaching the end for many was a combination of the HIV compounded by other significant issues in one's life that existed prior to their diagnosis. Many participants mentioned that prior to being diagnosed with HIV they had been experiencing unresolved philosophical and spiritual issues that had to do with their homosexuality, low self esteem and stigmatization throughout their life. For many participants, HIV was an addition to their lives and only accentuated the previous issues:

> *I had been burned out on life before HIV so that spiral has kind of accelerated. When I got HIV I went down hill. I really felt like I was giving up on life. My heart had not been in it for a long time before I got the notice that I was HIV positive. I was completely and totally unwilling to participate in life. It had been a real cruel joke- I had worked my butt off for nothing. I believe that HIV doesn't bring anything new into my life, it just turns up the volume of what is already there. I had a lot there that needed to be addressed.*

With such events, one's sense of vulnerability was heightened and reawakened as the tools and strategies previously used in the sustaining stage were no longer effective. A number of the men described themselves as being exhausted with sustaining life and started to disconnect from their lives, isolating themselves and avoiding any activities that were fruitful to their wellness.

> *I was disconnecting, I thought I was dying. I am disconnecting with body, I am disconnecting with friends, I am disconnecting with family, I am pulling back, pulling back sort of you know, it is sort of looked like a preparation thing. I just have a general feeling of blackness and depression and not knowing how to get out of it and my health being really poor at the same time.*

Going Inside

This disconnection and disassociation from everyday life involved focusing more on one's emotional and spiritual dimensions. Many of these men's bodies had "broken down" and the only relatively safe place to go was to "*retreat inside*".

> *I started becoming hugely aware of spirit because I felt that I was becoming more of a spiritual being than a physical being. My body failed and I felt that my spirit was growing... I didn't have the energy to do anything but think and pray and meditate. My body stopped and my mind and spirit carried on.*

They perceived this turn for the worst as an indication of their life falling apart; the end. As they became aware of the absence of their fighting spirit, it seemed to many that their only options were to commit to life or to commit to death.

In this time of retreat and inner reflection, this choice between life and death caused many men to re-evaluate their lives and question the meaning of it all. In this process, many indicated that they did not know how to truly live. Many spoke of feeling mentally and physically exhausted at this point as much of their energy had been directed towards resisting and concealing the HIV. They perceived themselves now as just surviving. Many participants began to acknowledge that if they were to commit to life they needed to deal assertively with some deeply rooted issues they perceived to be holding them back from growing and leading a fulfilling life and achieving their higher purpose. It was after this reassessment of their lives that they realized they did not want to live out the remaining part of their life with this extra baggage:

> *I knew that I had to make some changes in my life if I wanted to go on. I had to accept this was the path that I was on and needed to fully embrace these secrets I had been keeping locked away for so long. You know, like the sexual abuse and I guess just feelings of alienation. They were what was bringing me down. Yeah, I guess no more running?*

A number of these men mentioned that a significant turning point was the realization that if they were to commit to life, they had to first accept their feelings around the HIV. Many mentioned that accepting they had HIV was a big point of surrender where they finally said 'yes' to their condition as being a part of them. Up until then, it had been much easier to keep the illusion of separation between themselves and the virus with the hope it might disappear one day. They had very little energy left to "fight life" and could no longer deny such intense feelings around their HIV, such as anger, fear, guilt and shame. So instead, they began to accept all of their emotions. Getting in touch with this inner self was a difficult process for many as they described having to pass through layers of anxiety and fear. To achieve this type of connectedness with oneself, they had to find a degree of comfort with oneself in solitude.

From this time of self-reflection came the acceptance of living positive and then becoming comfortable enough with themselves to start looking inside. By accepting their anger and despair and giving themselves permission to feel their feelings, they accepted the frightened and doubting parts of themselves.

> *It is about looking past the HIV a little bit more. I had to go, 'OK this it not what I thought'. I guess some things happened along the way that got me into this place. I needed to accept that and move on or else it was going to be all over. I had to accept myself and let go of this baggage and guilt I had been carrying around for a good part of my life, you know?*

Through this process of acceptance, they have discovered a new form of freedom by being comfortable with themselves. They looked deep into themselves and embraced all of who they are and explored their resistance to anger, fear and despair. As they began to recognize all the various fragmented parts of themselves, they were able to recognize where they were conflicted.

This was more than just about accepting the HIV. The HIV was a reflection of how they needed to deal with other significant issues in their lives. This acceptance had to do with forgiving themselves and others and being willing to drop the past and live in the present. This was an important step to take in learning to live in the present moment. It was accepting that the past is the past and one cannot change it. As they started to release these emotions, many spoke about the resistance melting away and this creating an opening for healing, for most it was an enormous emotional catharsis.

Searching for Tools to Go Inside

The tools to 'Go Inside' shifted to bring the individual into their body and focus on the mind. Participants emphasized techniques they had learned to unite the mind and the body such as meditation, developing a relationship with a higher power, prayer and journaling. As one participant illustrates:

> *For a long time I was taking care of the physical but got to a point in my life where the mental, physical spiritual came together as one. That was within the past year. I could feel it…I realized that I had to heal the spirit. The body was ok, the body was going to be ok. I had to work on healing the spirit and I worked on that by doing things that informed me of what I needed, like when I listen to music, my spirit soars. But for some reason I don't concentrate on the body anymore.*

As this attention shifted from tools that focused on physical health to those more related to the mind and spirit, their physical health became almost incidental to their quests for personal growth:

> *I did 6 ten-day retreats almost back to back which wasn't a good idea for me to do. When I started getting the KS and getting sick, I lost a lot of weight because I didn't eat enough. I kind of knew what was*

> *happening but I felt it was more important since I had invested 50 days of silent meditation in a retreat. I knew if I changed gears from looking after myself spiritually and psychologically to physical I could never give back what I had invested in it. I continued on the last one and then when I came back from the last retreat I ended up in the hospital with pneumonia. But I felt okay because of the things I had gained from the retreat.*

These tools used to facilitate Going Inside were often practices that one could do independently, without any assistance or support and in the comfort of their own home or hospital room. They were an integral in creating the appropriate environment for self- acceptance in addition to encouraging self-reflection; qualities neccesary for the next stage of transcendence to occur.

Transcending the Experience

By addressing the issues of spirituality, resolving associated denial, and surrendering themselves to the "mysteries of life", the men experienced a life transformation that fostered personal growth, self worth and purpose in life. This was a time of learning about themselves; becoming more aware of who they are and how they relate to the world. This new understanding about their true self and how they relate to others, provided the men with a new direction on how they may want to better live their life. The men described a general change in attitude toward life as a result of their HIV. Others discuss how the HIV helped to put things in the right perspective so that little things didn't worry them anymore.

As a result of all the internal processing that occurred in the previous stage, significant shifts in their wellbeing occurred. Denial, resistance and control slowly disappeared and were replaced with an inner strength that had not been available to them before previously. Many cited that it was during this time when they were overwhelmed by the circumstances of life and felt that they had reached their limit. They became open to the possibility of transforming the HIV, they "transcended the experience". It is through this painful passage of surrendering control that they found themselves on the other side of darkness, feeling reborn with the opportunity to rediscover life and begin living from a totally different perspective:

> *I felt really open. I felt like I started to let go of all of the closedness of living in my physical world and started opening up my spiritual being and letting in spirit. It had changed me. I had shifted. I was reborn in a way. I became totally nonjudgmental of people, became much more loving, much more accepting because I was, (tearful), becoming someone else.*

Most participants could recall a specific time or incident where they experienced this shift within themselves; a transition where they felt different and where the world appeared different. Many described it as an inner shift, the unification of the mind, the body, and the spirit; a new way of looking at life. There was a definite point in time at which their life was changed. Several people spoke of feeling a release, having a rebirth or an epiphany:

> *There was something that took place. There was a light, an acknowledgement, something happened because after that I had power. I had energy. I had a life force that I didn't have before this you know?*

Shifts in wellbeing were reflected in several areas of the participants' lives in the way that they perceived the HIV and how they engaged in life in terms of relationships and planning for the future.

Through transcendence, the participants reflected on the past and clarified personal values. More specifically, their perspective of HIV shifted as well as the way in which they approached life. They started to assess their health in ways that had less to do with their seropositivity than it did with creating a sense of peace, satisfaction, and personal fulfillment.

This transformation appeared to differ from person to person in terms of changes that had taken place but, in general, there were several broad shifts. The first being the way in which the meaning of HIV had changed from that of a death sentence to a catalyst for personal discovery; a learning experience:

> *I know that an HIV diagnosis is very dramatic. It changes your life forever. It makes you realize that you are mortal. Most people live in denial and believe that they will live to be 80 or 90. It is only those*

> *people who have serious illnesses early in their life who are forced to stop and look at the fact that their life is so fragile. Nobody knows how much time you have left. Somewhere along the line I decided that I was going to use this as an opportunity to strengthen myself. I guess to take charge and get rid of all of this baggage I have been carrying around for the past twenty odd years or so.*

As the participants came to be more self-aware and to know themselves on a deeper level, they found the way in which they conducted their lives changed. They described their lives before they contracted HIV as being shallow and devoid of meaning. And now having HIV had changed that. They began to engage in life in different ways. They were able to get in touch with themselves and now had a different sense of who they were. The person who developed the HIV no longer existed. Many men indicated that because of this, they were able to make more conscious decisions, understanding themselves and their reactions to the world around them. One participant considered himself to have merely existed in the first 35 years of his life and to have "lived" for the 5 years since he had transcended the illness:

> *What I found helped me put the HIV in perspective was the realization that there is a bigger picture. I am grateful for this and I want to be in the moment of conscious living. I want to fully embrace my higher purpose and HIV is helping me to get there in a way. I am seeing the*

> *world through new eyes I guess; truly living life now. I am totally different now than I was before it all.*

This is carried out in several ways; most reflective in the ways the men approached personal relationships and the future. Many focused on their relationships with others and indicated that as they became more self-aware and knew themselves on a deeper level, they found that their relationship with others changed. If previous relationships could change to connect at this deeper, more authentic level then those relationships remained. For other relationships, there was a falling away as described by one participant:

> *It is like cutting garbage away from my life, you know? Re-evaluating my relationships really made me see how much energy was going to unfulfilling things. Like I could redirect that energy somewhere else more important.*

Many of the participants described changing or planning to change their day to day activities to make more time for themselves and for more worthwhile causes. Some had started to make plans for the future and embark on creative or desirable activities, such as returning to school or starting up their own business.

Securing Wellbeing

This new way of living in harmony with a new sense of meaning, purpose and personal control translated into better regulation and competence with managing their illness to "get on with life".

Once the men had transcended the HIV, all acknowledged feeling more secure and confident in terms of managing their disease and knowing that everything was going to be okay. They attributed this to their newfound awareness and experience with the HIV and to the tools to manage it:

> *I know if the day comes, I will do well because I have already set in place that discipline, responsibility, control, observation, I will be more aware, of how I feel, of how to tweak this, to tweak that. I have already set this in motion.*

Attention shifted from the HIV being their number one concern to becoming secondary in their lives. There was a sense of freedom from not having to worry about the imminent threat of the HIV. Putting their body to the test, remaining symptomless, and feeling normal all contributed to these feelings of security and wellness. This realization is referred to as securing wellbeing. One individual described this feeling of confidence as being:

> *I don't know if I would say my body is healed of the HIV but to me healing is more about the spirit and freedom that comes from the reality that is within me. It was like being able to wake up and not*

> *having to worry if this small dot on your arm is going to turn into KS, just knowing that if I had a bit of a cold, it wouldn't turn into pneumonia.*

In the stage of sustaining wellbeing, when speaking about wellness, participants used physical health as benchmarks, whereas in this stage, they spoke of wellness in terms of their sense of balance and overall wellbeing. A number of the men described the early part of this stage to be somewhat tentative, feeling confident and secure in their mental capacity but still uncertain and apprehensive about placing trust in their physical selves. This changed once confidence was earned in terms of physical benchmarks such as an undetectable viral load, declining CD4+ counts and absence of symptoms. They tended to be less vigilant about any symptoms that may be related to the HIV. Many men once feeling secure in their all around wellness, put themselves to the test, proving to themselves that they had a foothold in their wellness:

> *I have noticed that my body has been progressively getting stronger and stronger and stronger, to the point where I literally took on a full time job this summer. It was grueling work, with toxic chemicals, very tough, toughest work I have ever done in my life. I loved it…I got the self-esteem of saying I could do anything that I wanted and I felt great confidence.*

With this newfound confidence and trust in life, they tended to be less vigilant about any symptoms that may be related to the HIV. This security brought them to a point where they allowed the HIV to become secondary in their lives, where the HIV was no longer in the forefront, where they had a stronghold on it. One man described the HIV as "being wallpaper" in his life, and a few others described it as "fading into the background":

> *It has become a way of life for me. But in a container, in the background...It is not going all over the place I have got control over it. So, the word I am looking for is manageable. It is in the category of a manageable illness, as in I could live to be 70 or 80 and manage this no problem.*

For a number of participants, this newfound confidence and general trust in life was the impetus for some to take a drug holiday from the drug cocktails they had been taking for years. This was a great leap of faith and an enormous step towards freedom. They acknowledged the risks a drug holiday could pose, but it was this security in knowing they would be okay and that allowed them to go through with it:

> *I would take a chance on not taking the medications. You know there is so much fear associated with them and you deal with fear constantly in your life on all levels that eventually it will stop you from living your life. So you have to take a chance, so to speak... I am taking a chance that I am willing to risk being sick. It is not like there is anything that cannot*

> *be done if I should get to that point and can't handle it. My mind is secure and my body will follow.*

Once the men had secured their wellbeing, several had experienced relapses in terms of their physical health. A number of men spoke of losing their balance and subsequently falling ill. However, recovery time was considerably faster as many were aware what was needed to get them back on an even keel. They also described these relapses as only being a physical breakdown whereas before they had transcended their illness, it was a mental, physical and spiritual breakdown. As illustrated in Figure 1, a relapse may occur but the individual does not return to the stage of Sustaining wellbeing. Instead, they Take a turn for the worst and use the knowledge that they have incurred throughout their journey about various tools, the HIV and themselves and repeat the rest of the process, but this time at a faster pace.

Searching for Tools to Secure Wellbeing

Throughout this whole process of searching for tools, they have gained great self-awareness and knowledge around what tools work the best for them. By this stage, the participants had a core set of tools that they had picked up along their journey. These tools have been incorporated into their lives as some referred to as "positive habits". Men at this stage typically altered this wellness regimen by reducing the intensity of what they were using and shifting to more of a maintenance approach where they relied on a minimal set of core tools. Many had the attitude "less is more" when it came to using tools.

Tools in this stage were not so much about alleviating a specific HIV related symptom but more about contributing to an overall sense of wellness. Those who were experiencing this shift believed that anything that contributed to a sense of well being strengthened the body's natural capacity to fight disease and were therefore therapeutic. As demonstrated by a participant:

> *It is very important that I respect what I am doing…If it is nothing more than improving your well being about what you are taking than there is no harm in it- I think it is damn fine magic to change your attitude and that should be the basis for it. I feel that the condition of the body is a reflection of the mind.*

The two most important tools according to the participants are awareness and balance. This balance and awareness go hand in hand, almost a symbiotic relationship. The biggest key to securing their wellbeing was not to let their lives become too unbalanced so as to lose the awareness within themselves.

Many of the tools utilized in the period of inner reflection, particularly meditation, were used to maintain this balance through awareness. Tools such as these continually act as monitors and many men described this as a time to "check-in":

> *I check in with myself, I get a sense of what is happening. It is a wonderful tool for disease management. Some of these things will creep up on you and if you are very distracted you probably wouldn't even notice it. But when you have that quiet time, you have this heightened sense of how you are feeling and there is something about when you are doing something on a daily basis, you notice change. You are in that same place for the same time, every single day. So you notice this is unusual and happening daily, you know when it started and that it is still happening, so you are more likely to act upon it. So awareness is a very powerful tool for managing this disease and also knowing how you are feeling.*

Awareness and balance became central components in many of the men's new ways of living. Priority was placed on activities that supported these tools. Focus had shifted to accommodate their needs first and to eliminate things that might lead to imbalance. Many men described this as simplifying their previous life as many of these activities were conducive to enjoying each moment of the day.

> *I no longer try to do a million things in a day. I get lots of rest I try to eliminate unnecessary stress from my life, This is really important to my sense of balance and I just try to be as involved in life as I possibly can be in a way that suits me and have eliminated ways that don't suit*

> *me. I very much live life on my own terms and enjoy each moment more.*

Balance is the means to remain well, the conscious act of weighing and dealing with complex demands and putting aside unacceptable impulses for a temporary period of time. Balance helps them to remain knowledgeable in terms of how far they can go until they go off kilter without losing their foothold.

> *I am very conscious and aware of where I am going off, like not sleeping or anxiety or anything that could possibly happen. Any thing could possibly happen if you allow them to accumulate you get into a deficient on your energy level that is really hard to bring back. So having learned that I will go close to the line, I will go over and under the line but will try to stick as closely to the line because it takes time and energy to bring it back that you could be doing something like raising the line.*

Another tool commonly attributed to securing wellbeing is that of sharing. All the participants who had reached this stage highlighted the importance of giving back and getting involved in the HIV community. For many this also was evident in the form of returning to school or going back to work. Working and studying provided personal satisfaction to many of the participants. All of the participants spoke of a commitment to helping others with chronic conditions. This help came in different forms. They spoke of initiating support groups, providing workshops and acting as resource people for those with HIV. They had a heightened awareness and sensitivity to the needs of others that they wanted to share. The most common form of this was sharing their experiences of living with HIV with others in the form of volunteering at ASO's, facilitating workshops and writing articles of their journey. One individual explained that:

> *I have started to do my own workshop in the past years. And I think that because I speak personally from my own heart, people I am working with alot of them are living with HIV or other difficulties and they can relate when I talk about my story, they can relate to it you know, I also give them practical tips for what they can do in a few minutes here and there.*

Another participant defined his commitment in these terms:

> *A very big part of my healing strategy is to be proactive in the process. I think that anybody who is sick with any disease, like Michael J Fox, has come public with his disease, this is huge empowerment stuff! And they are taking their disease and they are doing something that is going to hopefully benefit everybody including themselves. And they will live longer and healthier lives because of it- and more fulfilling lives.*

In summary, this study intended to examine the social psychological aspects of complementary therapies in HIV/AIDS health care and identify the process that individuals incorporate them into this care. However, in addition to identifying this process, it was discovered that complementary therapy use is an integral part of how people living with HIV find wellness within their illness.

CHAPTER 6

Discussion

Finding a Way to Live, was a three phase, six stage process that emerged from the data, that differentiated and accounted for variations in the participant's behavior, a finding which satisfied one criterion for asserting discovery of a BSP (Glaser, 1978). These temporal stages; finding out, sustaining wellbeing, taking a turn for the worst, going inside, transcending the experience and securing wellbeing influenced behaviors in the succeeding stage. The three phases and six stages were, as Glaser (1978) states, "an integrating scheme" (p.99), which accounts for change over time without losing conceptual grasp of the overall process, was most apparent in that the goal of the purposive action in each stage was the same: to find the best way to deal with their illness.

The participant's operationalized the conceptual constructs of Finding a Way to Live by employing three major strategies, each of which has been discussed earlier. These are, searching for tools to sustain wellbeing, searching for tools to go inside and searching for tools to secure wellbeing. Figure 1 depicts a summarizing conceptual diagram of Finding a Way to Live.

A number of the findings in this study have been previously identified in some of the literature on wellness within illness, particularly in the area of psychosocial wellbeing in HIV positive individuals. The significant role that tools had in this process of finding wellness within HIV raises obvious questions about current health care approaches and the way in which we approach HIV.

The original intent of this research was to identify why people living with HIV used complementary therapies and how they went about incorporating them into their HIV care. When asked what they did to make themselves feel better aside from whatever conventional medical therapies they engaged in, participants instead described how they had found a new way of living where complementary therapies were an integral part of facilitating learning, self discovery and ultimately healing.

This emergence of unexpected findings is indicative of the men's own ability to find wellness within illness. Their use of CT led to a much greater journey and one that has transformed the way in which they live their lives. In order for the researcher to understand their use of CT, they needed to tell their full story of the circumstances surrounding their HIV in their life to get a clearer picture of what the CT have contributed to their whole experience.

The question of what happened in a person's illness management process when CT were incorporated into their HIV care slowly became the story of finding a new way to live, and how the individual used particular tools such as CT to get there. CT were not so much the focus of the stories they told; rather CT were facilitators or rather enablers to a new way of living. Initially, the men used a specific tool to alleviate symptoms and side-effects but this shifted to more of a broad selection of tools that were combined to achieve a sense of balance, awareness and a new way of life for many.

Participants were spread out in different stages along the continuum although the majority had secured their wellbeing and experienced a number of relapses since. Several interviews were with men who had also not moved out of the stage of Sustaining wellbeing.

After the emotional catharsis experienced by the men in the stage of Going Inside, many remained in their minds, continuing to focus on their spirituality and reflecting on the major emotional releasing that occurred. At this time the individual attempted to negotiate and conceptualize between self-identity and the identity that had been shaped by the HIV. It is in this stage where it is the inner self, not the sick body that becomes the source of identity. This is the beginning of the transformation that takes place and enables one to transcend the illness. However, while there were often references to one or two major periods of emotional release, the men were not instantaneously changed and did not experience a dramatic shift. The period leading into Transcending the Experience was one where there was a subtle shift to thinking "what next"; a time to look to the future and also review the major events that occurred. Once this focus started to shift into more forward thinking, they moved out of themselves and into how they relate to the world.

The rationale, perceptions and pacing of the tools changed over time to fit each person's stage. The meanings attached to each tool changed according to this process and in each stage, they were fit into the disease management process in different ways. Initially, in the stage of sustaining wellbeing, the intention for using CT was to place themselves in the best position to fight AIDS; preventing opportunistic infections and addressing various side effects of the anti-retrovirals so that they could carry on as best as they could without truly having to face their illness. They were used more reactively and helped them to sustain wellbeing.

When they took a turn for the worst and the tools which they had been previously employing were no longer effective in managing their physical illness, new tools were sought to address symptoms that were not being treated or addressed by conventional medicine, such as mental and spiritual concerns. These tools to Go Inside, helped them deal with the less physical symptoms and more emotional and spiritual manifestations that were not so much related to the HIV. These were tools to facilitate inner reflection and were used more proactively. Whereas, in the stage of Securing Wellbeing, tools were means to maintain this foothold they had achieved in their wellness, a way in itself of keeping balance. It was more of a lifestyle, a way of living, for some these tools were even described as "healthy habits".

While Finding a Way to Live encompasses more than a means to cope with HIV, the intention to cope is a significant part of the process and rationale behind the initial stages. In the process of Finding a Way to Live, a clear, developmental progression from reactive to proactive, less control to more control, and self centered to other centered was evidenced in the use of coping strategies by study participants. It took time for the men to reach the stage of Going Inside. In the earlier stage of Sustaining Wellbeing, the men buffered passively with their illness and treatment, addressing concerns as they arose. Whereas, once the men were in the stage of Securing Wellbeing, they responded proactively, not just approaching their illness with a "Band-Aid treatment" as before. Morse's model of enduring (1999) supports this pattern of behavior as she has identified that responding proactively was highly individualized and included responding holistically addressing the mind, body and spirit. These characteristics were prevalent in the tools to Secure Wellbeing identified on Table 1.

Additionally, Courtenay et al. (1998) note a period of initial reaction after an HIV positive diagnosis that resembles the stage of sustaining wellbeing where initial reactions involved strategies to maintain the status quo and suppress evidence of the HIV. Patterson's Shifting Perspectives Model of Chronic Illness (2001) suggests that living with chronic illness is an ongoing and continually changing process. Similarly to the process outlined in Finding a Way to Live, Patterson found that as the reality of the illness experience and its personal and social context changed, the individual's perspective shifts in the degree to which illness is in the foreground or background of their world. In the early part of the illness experience, much like the behaviors indicative of Finding Out and Sustaining Wellbeing, she found that many tended to hold the burden of their illness in the background, in effort to sustain their sense of wellbeing that permitted them to live as they desired.

Similar movement was found in a study by McCain and Gramling, (1992) where the process of coping with an HIV diagnosis involved a period immediately following diagnosis of extreme awareness of death and a resulting anger as was in this study characteristic of those in the stage of Finding Out and Sustaining Wellbeing. This eventually shifts to finding control and taking responsibility for their illness similar to that of Securing Wellbeing.

A period of shifting the ways of coping similar to Finding a Way to Live has been reported by Reeves et al. (1999) where a process of coping became more adaptive as the individual became familiar with their illness and responses to various factors. This is also supported by Ironson et al. (1995) where healthy self-care contributed to feelings of mastery and control over their illness. CT provided a sense of control and hope, especially in the beginning, when the participants were actively sustaining wellbeing. Once they reached the stage of securing wellbeing, this sense of hope and control came from within, as did a sense of trusting and feeling competent in their own ability to be well and relying on the tools to maintain this sense of competency. It was more of a satisfaction that was sensed, a feeling of accomplishment in doing this all by themselves. Several men referred to themselves as "makers of their own healing".

This notion of feeling competent and secure in knowing the means in which to maintain a strong foothold in one's wellness is supported by Aldwin, Sutton & Lachman (1996) who assert that during the process of coping with an illness, individuals are constantly adding to their coping repertoires and thereby increasing their sense of self-esteem and mastery over the illness. This idea is echoed by Gloersen et al (1993) who refers to this sense of security and competency as mastering living. This is a means to successfully cope with the crisis of living with AIDS, which encompasses one's determination to live, create their own reality and the freedom to choose their destiny. These feelings are reflected in the stage of securing wellbeing whereby the men pursued new ventures and manifested hopes and dreams once thought to be impossible.

This sense of mastery is referred to as compartmentalizing the HIV by Troop et al. (1997) and is similar to that of backgrounding the HIV in this study. They suggest that once control is felt over the illness such that it no longer demands the attention and vigilance it once did, it is reduced to a smaller part of one's life. In both cases it no longer consumes the person's everyday life and the majority of their energies.

Although participants did not discuss at great lengths the specific process by which they searched for tools to sustain wellbeing, they did indicate a period where there was some informal testing of various tools to see if there were any ascertainable differences in their health concern. For many Searching for Tools to Sustain involved detecting changes in such benchmarks as pain, side effects and fatigue. In the latter stages of this process, testing no longer utilized such specific physical benchmarks rather, a sense of control and inner peace were monitored as indicators of efficacy for tools. The process of searching for tools is consistent with those suggested by Reeves et al., (1999). They found a period of transition that served as a testing ground for people living with HIV for various adaptive strategies such as humor, faith and balance. Motivation to continue along this trajectory of Finding a Way to Live was largely dependent on the individual's readiness to move on to the next stage. The time it took for each person to move along the continuum and how long they spent at each stage was predominately influenced by the person's stage of illness, level of energy, state of mind, the experiences-both positive and negative- of other people living with HIV/AIDS, the presence or absence of strong social support for a particular approach, access to AIDS service organizations, and the development of new and more effective drugs for HIV/AIDS.

Tools that did not require much interaction or deep emotional or spiritual commitment such as herbs, massage and exercise were often used in the initial stages whereas tools that required such work on an emotional and spiritual level such as meditation or tai chi were often discontinued or not pursued until the individual was at a point where they were comfortable in dealing with these internal processes. Participants spoke of these therapies that encouraged inner reflection to draw attention to deep-rooted issues that invoked great discomfort and a range of unpleasant emotions. Men had to be in a place where they were capable and prepared to face and deal with these issues if they were to move through the process of Finding a Way to Live.

Many of the tools used in the latter stages addressed various aspects of emotional and spiritual health. These behaviors are supported by Barroso (1990) whose research suggests that taking care of one's mental and spiritual health is key to long-term survival with HIV. Interestingly, spirituality is a tool that is used to address emotional and mental health concerns in this study.

One of the less tangible tools cited of great importance was that of self-acceptance. Ramsum, Pope, Mulkins, Newman, Braithewaite & Findlay (2001) and Gloersen et al., (1993) both found acceptance to be an important concept in achieving a sense of wellbeing among people living with HIV. Acceptance in this instance included acceptance of not only their HIV status but being true to the one's self, forgiveness of issues in the past, accepting death as a possible outcome of the disease and a general acceptance and faith in life itself.

Additionally, a dimension of many of these tools utilized in the latter stages were those involving both the mind and body. Ramsum et al. (2001) and Gloersen et al. (1993) identified a similar awareness of the relationship between the mind and the body that attributed to maintaining a sense of wellness. They believed they could alter, modify, enhance or deny this relationship to facilitate doing well. This belief in the mind-body relationships was based in both cases on the assumption that healing came from within. In both instances this mind-body connection was reflected in various techniques such as meditation, affirmation, relaxation and visualization.

Additional critical tools used by the men to secure wellbeing was that which promoted balance in their lives. This concept of balance has been identified in the literature as being a key part of the process of finding wellness within illness. Jensen and Allen (1994) suggested that finding this balance requires regaining and sustaining a degree of control in one's life and over one's illness. Once achieving this, the individual is filled with a sense of harmony and fulfillment. This sense of peace and contentedness is what the men describe after transcending the experience and securing wellbeing. This idea of maintaining balance through a constant awareness is supported by Beck (1991) who concedes that the balance brings them in tune with themselves, others and their environment.

A number of participants who had remained in the stage of sustaining wellbeing for some time displayed similar characteristics to those identified by Barroso's (1999) study as having a shattered meaning. Those having a shattered meaning were unable to get a perspective with respect to the HIV and move past the illness. A number of participants who remained in the stage of sustaining wellbeing were still angry and very much focused in the past. Some fixated on their impending death and had negative thoughts and feelings towards life in general. This lack of movement may be attributed to the person's readiness to move to the next stage. This is a process that created a number of unpleasant emotions. Many men had a lot of fear around their HIV and this possibly inhibited them from moving out of their 'comfort zone' in the stage of Sustaining wellbeing. Readiness for change also went hand in hand with motivation and one's commitment and outlook on life. It is not known if a general dissatisfaction with life in general was a quality in those men prior to contracting HIV and if these sustaining behaviors are a continuation of their personality. Barroso (1999) found that this shattered meaning and inability to adapt positively to living with HIV prevented them from making new connections with others, becoming active in their healthcare, and performing the self-care behaviors that would assist them to stay healthy, similar to what was suggested in this study in terms of Finding a Way to Live.

Perhaps the most commonly found dimension in this process found in the wellness- illness literature is that of transcendence; the idea that HIV fosters change in a more positive, growth-oriented direction. Aldwin et al. (1996) notes the potential for a life threatening illness such as AIDS was an opportunity for personal growth.

In addition to a shift in how one perceived their HIV, the way in which the men engaged in their lives was altered. Many of the tools that provided the means to stay well became a focus of their everyday life, such as awareness and balance. An appreciation for life became very important. Relationships were re-evaluated and meaningful activities were emphasized. This behavior is consistent with the findings of Solomon et al. (1987), who recognized that long-term survivors had formed a conscious reconnection with their life. Many felt they were ill prepared to die and still had unresolved issues, unfulfilled experiences and wishes they had to address and was reflected in a new way of living life.

This was also mirrored by O'Connor, Wicker & Germino (1990) who documented the importance of finding meaning in their illness among long-term survivors. Transcending the experience resulted in a shift in how the men perceived their HIV. For many it was considered to be a catalyst; encouraging the process of self-reflection and discovery. The men were able to find purpose in their illness. This search for meaning focused on themselves, looking inward and thinking about themselves and reviewing their life.

Similar to the qualities of transcending the experience and the resulting behaviors, Jensen & Allen, (1994), refer to this transcendence as that of reflective transformation. In this phase, people with illness find meaning in life and in this process finds a stimulus to live. This is reflected in openness to change, and a peace and contentment in responding to life. Coward (1990) reported similar findings where an ultimate transcendence occurred- a connectedness to what has been and what will come. This draws many parallels to Transcending the Experience where the act of surrendering to life and accepting whatever comes along brings about this sense of connectedness and faith in life. In a third study by Coward and Lewis (1993), men experienced a self-transcendence that resulted in participation only in activities that had meaning and let go of painful issues from the past. This was similar to the way in which the men in this study shifted their behaviors and means of engaging with the world once they had transcended the experience. In this study, transcending the experience included believing that having the HIV was a blessing and that it had acted as a catalyst for discovering who they really were and believing that they could live with AIDS.

This resulted in a re-establishing of priorities and eventually day to day activities.

This process draws many similarities to that which Ballentine (2001) refers to as the 'radical nature of holistic medicine'. In discerning the major concepts of holistic medicine, Ballentine outlines 3 main themes that are similar to a number of qualities identified in Finding a Way to Live. Ballentine describes the first concept, self-awareness, to be a stage similar to that of Going Inside, where much of the learning process is achieved through a process of inner reflection. Therapeutic interventions used to maintain this self awareness are used based on their ability to create a sense of wellbeing, boost energy and bring about clarity of mind.

The second theme is that of transformation, where fear surrounding the illness is replaced with a sense of self learning and the illness viewed as an opportunity and is no longer the primary concern in the person's life. This is similar to the stage of Securing Wellbeing, where the HIV is now perceived as more of an opportunity than a death sentence and it becomes wallpaper in one's life.

The third concept in Ballentine's holistic paradigm is that of wholeness, where there is no longer any separation of spiritual from physical health issues because each dimension reflects and expresses the other. In this case, symptoms are thought to be indications of what is going on deep in the psyche. Some men in this study referred to these as emotional manifestations. While wholeness was not a concept in this study, a similar notion was balance. Balance and interconnectedness are what the men attributed to remaining secure in their wellness and involved taking care of all aspects of their health.

Some of Ballentine's assumptions implicit in this paradigm are that healing requires letting go of the familiar and stepping into the unknown, reconnecting with lost aspects of oneself and finding purpose in life. These are similar to the qualities and rationale inherent in some of the tools utilized by men in various stages.

The process and the stages experienced by these men draws similarities to Morse's praxis theory of suffering (in press). Although most of her research has been done in the areas of chronic illness, dying and trauma, there are parallels in what she refers to as enduring behaviors and tools to sustain wellbeing. Men, while in the initial stages of finding a way to live, searched for tools that would mask any evidence of having HIV.

Many of the men when reflecting back recognized it as a means to cope but also as an indicator of concealing their situation. This type of behavior and the rationale behind it is similar to that which Morse (in press) illustrates as escapes from enduring; ways of dealing with a situation that enables the preservation of the self, similar to the intention the men had when searching for tools to sustain wellbeing.

Another similarity can be drawn from the stage of Going Inside and relating it to that of Emotional Releasing where by Morse (in press) suggests a state of emotional releasing where there is a dispensing of emotions. This is similar to the behaviors experienced in the stage of Going Inside where there is a great emotional release that leads to a transformation of sorts. This is similar to what Morse describes as going from despair to the reformulated self, where once the suffering has been worked through people live life more deeply. As in the process of finding a way to live, key elements in the trajectory of Morse's model of suffering are awareness, acknowledgement and acceptance which lead to what she refers to as the reformulated self. This stage appears to be similar to that of transcending the experience where a new way of engaging with life is initiated.

As Finding a Way to Live describes not only the process of finding wellness in one's HIV, but also the tools that facilitate this process, several bodies of literature can be drawn upon. The literature on wellness within illness, suffering and enduring and holistic medicine all provide support to the various aspects of this process.

Contribution to Grounded Theory

Use of the Grounded Theory method to explore this previously undescribed experience of gay men using tools to live with HIV has allowed the generation of a theory which has "fit" with the data from which it derived, and "grab" (Glaser, 1978). "Grab" means that a grounded theory speaks in a relevant manner, makes-sense, and feels right way when it offers a construction of the reality of the participant's perceived experience. Ironically, the persuasiveness of a grounded theory is such that it appears to portray clearly evident processes of human interactionism, obvious to all through common sense, even where the phenomenon had not previously been described. Such were the results of this study. Nonetheless, these discoveries have advanced knowledge about how people use various tools to deal with their HIV. Hopefully, others will build on these findings to expand theoretical coverage of this process.

CHAPTER 7

Summary, Implications and Conclusions

Summary of Findings

The discovery of what people living with HIV do to make themselves feel better was not about specific therapeutic interventions but rather a part of an ongoing process of finding a new way to live. One may argue that there are two separate and distinct processes occurring in this study, however, it is important to realize they are closely interrelated. HIV is a complex disease and in recent years has been considered to be chronic in nature. Searching for these tools and the process by which they are incorporated into one's life is indicative of the important role they have in attaining an improved state of wellbeing. Each stage in the HIV experience is intimately related to various tools.

Glaser (1978) states that the generation of grounded theory occurs around a core category, which accounts for a major portion of variation in the observed behaviors. If this core category incorporates two or more clear, emergent stages, it may be termed a Basic Social Process (BSP). "BSP processes a social or social psychological problem from the point of view of continuing social organization. Irrespective of whether it solves the problem to some degree, it processes it" (Glaser, 1978, p. 97). The core category, to which all other categories in this study related, was the men's way of engaging with their illness. This process encompassed dimensions of denial, suffering, taking responsibility, finding control, transforming and finding confidence in this wellbeing. This process has a defined time dimension, which begins at the time of finding out they were HIV positive and will likely continue for as long as they are alive. This process, accountable for change over time, has been identified as a BSP and has been termed Finding a Way to Live.

This core category is comprised of six interrelated phasic stages: finding out, sustaining wellbeing, taking a turn for the worst, going inside, transcending the experience and securing wellbeing. There is subsequent process that is more of a strategy of these phasic processes, that is searching for tools appropriate to each stage.

Implications

Responses from the participants in this study and the characteristics of HIV/AIDS outlined in the literature review draw many similarities to those found in research in the areas of HIV/AIDS and chronic illness (particularly those with treatments with low efficacy and an unpredictable course). I have created a model that has linked components of Finding a Way to Live with others research in various areas that is logically consistent in both theory and literature, which are indicators of generalizability. Therefore, this study contributes to chronic illness and HIV/AIDS research in several ways. First, it illustrates the specific ways people have transcended the illness and feel competent in their wellbeing. Second, it extends the concept of using therapeutic interventions (particularly CT) as currently understood in the literature beyond behavioral and cognitive categories to include interpersonal, attitudinal and existential dimensions. Finally, it contributes to the body of knowledge of information around for whom and when health care professionals might intervene to further promote wellness within illness.

Practice

This study identified strategies to foster a new way of engaging in life. This information has the potential to offer health care providers and people living with HIV insight into strategies that may assist people in all stages find health within the context of their illness by fostering better coping over long periods of time and helping to resolve existential dilemmas. As a result of this study, the following implications for practice are suggested as approaches to further promoting wellness within HIV.

The highly individualized tools that accompany the process of Finding a Way to Live indicate the need for health care practitioners to acknowledge that the pursuit of wellness for people living with HIV is a decidedly personal process where most of the strategies explained reflect those aspects of personal value and lifestyle.

There is much discussion in the chronic illness literature with respect to making a fundamental shift away from a predominantly illness care model to a reconceptualization of health and illness with the focus shifting to the promotion of health. This reconceptualization poses a tremendous challenge to health promoters, not only because of the severity of the syndrome and its complications, but also because of the complex physical, emotional and spiritual needs which can affect care at all levels (Belcher, Dettmore & Holzemer, 1989). Because holism has emerged as a vital component of health, it becomes necessary for it to become valued as an integral component of individual health and wellbeing (Hilsman, 1997; Warner-Robbins & Christiana, 1989; WHO, 1986). It is imperative that body, mind and spirit be emphasized as a core part of care and not just as an adjunct to that of a conventional nature. Health care practitioners must relinquish their emphasis on investigating the problems of persons living with HIV and consider other forms of engagement which provide opportunities for the promotion of their health and wellbeing.

This reinforces the need to implement holistic models of care that address the psychosocial, spiritual and physical dimensions of living with HIV infection. Interdisciplinary models should include recipients of care as full members of the team alongside professional care providers, allowing them to have full input into their health care and ensure that their voices are heard with regard to treatment decisions. Health promoters have a critical role in helping individuals assess personal needs and strengths as well as planning interventions that will help them set and meet goals of optimal wellness. Health promotion programs need to be developed that encourage self discovery and their own pacing while still offering comprehensive care and the right amount of pressure and encouragement to stay interested and motivated.

This trajectory has important implications for the way in which health care providers appropriately care for people in these particular stages. According to Patterson (2001), the role of health care professionals becomes to assist people with chronic illness to identify and understand their perspectives about the illness. As a result, practitioners must be committed to hearing what people see as important in health care (Lindsey, 1993). Patterson argues that health care professionals must realize that there is a huge individualization of the chronic illness experience and therefore care should be led by the individual living with the illness. Care would be more appropriate if health care providers were able to recognize behaviors related to whatever stage the person was at and could for example, differentiate between those who were Sustaining Wellbeing or those who were Going Inside and make the care better suited to the individual's needs. Intervention strategies such as an interdisciplinary model of care may address the individual's needs at various stages in the process more closely. This model includes such components as nutritional counseling, mind-body programs, support from other people living with HIV, vocational rehabilitation, spiritual care, psychological services, and coordination of health care services.

The procedures surrounding the initial diagnosis of HIV need to be reconsidered. Many of the men indicated that their feelings around being HIV positive were compounded when bombarded by information about treatment options and pressure to commit to the highly active anti-retroviral therapies (HAART). Both the men in this study as well as those in the Sowell et al.

(1998) study reported the need for support from people who too were HIV positive in order to feel trust and ease when making these decisions and discuss any new issues that may arise as the disease trajectory evolves. Participants have suggested that perhaps a better approach would be having an option to meet with a peer or some type of 'case worker' who could explain treatment options and give the person some time to process it all before having to decide immediately about HAART and CT. This brings into question whether or not health care professionals are the most appropriate people to be delivering this type of information.

Future Research

The relationships between the healing process and the tools used along the trajectory begs further development of studies with similar methodological, conceptual, and comparative rigor. Such studies are both viable and important in the development of a framework of analysis of health and health promotion for people living with HIV. Further work needs to be done on the concept of health within illness. Because of the complexity of this process, similar methods of inquiry are recommended for future studies until an ample knowledge base is established. This study should be replicated with a wider variety of subjects. Replication is essential to determine if these results are transferable to other situations, as it would be worthwhile to study people living with other terminal illnesses, to ascertain if a similar process is described.

This study illuminates the process of how men find wellness within their illness and an opportunity for self-actualization. A clarified understanding of the concept of wellness is essential to health promoters if we are to promote health rather than illness care. Theoretical relationships may exist between the stages described in this study and the experience of other people with chronic and terminal illnesses such as cancer, lupus, multiple sclerosis or cardiovascular disease. Furthermore, the question of how this model does apply to people who are not living with a chronic/terminal illness in their everyday life needs to be explored? How might this model apply to health promotion initiatives and healthcare in general?

Longitudinal studies, which may provide further insight into how these stages and tools change over time would also be worthwhile. Factors related to recognizing and defining the tools utilized in the various stages needs to be examined more carefully. Studies must explore not only how tools are defined but how they are assigned priorities at each stage. In longitudinal research, the links between individual's tool definition, choice of tool and desired outcome could be a subject for examination.

These findings support the need for research in this area to take into consideration the different stages and level of readiness for change as this readiness may have a significant impact on the effectiveness of particular interventions. A person who is in a stage where they have achieved heightened awareness will likely have a different experience than someone who is still in the stage of sustaining wellbeing and taking a more reactive approach to their health and illness. This was found to be the case in Ramsum et al's (2001) study looking at a breathing and meditation intervention for people living with HIV. A large factor that influenced people's experience of the program was that of readiness and where individuals were in terms of being ready to engage in inner process work.

Qualitative research is appropriate to the subtleties and complexities of research in the area of mind/body/spirit. According to many of the men in this study who have secured wellbeing, HIV is predominantly something that exists in the mind or even deeper in consciousness. It is important to use methods appropriate to these types of interventions and that will accurately reflect these processes that are not reflected in the physical self so much as in the mind.

This research brings about several unanswered questions. Ways of supporting decisions related to these tools need to be explored. Factors influencing the pacing of the process and reasons why some people remain in the earlier stages of Finding Out and Sustaining Wellbeing for the entirety of the time they have lived with HIV need to be inquired upon. There is a reason to examine if HAART affects more than physical wellbeing, if it alters one's perception of HIV and if this influences the process of Finding a Way to Live. Is there a relationship between HAART and those who have yet to progress through this process?

Conclusions

Conventional medicine is on the verge of a transition, where conventional means of treating people with drugs and surgery is slowly giving way to a more comprehensive system that includes therapies based on integration, balance and harmony of the mental, physical, spiritual and emotional components of wellbeing. There is no longer an option to ignore these dimensions or treat them as something outside of the normal processes of science and medicine. People are using these tools for good reasons.

The relationship between one's use of CT and their experience of living with HIV is extremely complex and ever changing. In order to provide the best care to those living with this illness, it is important to understand not only what it is they do to make themselves feel better but when it is they use it and how that is a significant part of their healing journey. The tools are a reflection of where the individual might be at in terms of their wellbeing.

Accordingly, health promotion initiatives must be approached from an interdisciplinary perspective with the apperception of the fact that Finding a Way to Live is a highly variable and independent process influenced by the dynamics of a complex nexus of factors in the context in which it occurs.

The existence of individuals who have been able to forge life-transforming benefit out of HIV infection is a testament to the resilience and durability of the human spirit in meeting profound adversity. The notion that various tools helped them get to this place of wellness provides reason that we design health care initiatives to accommodate their use. Learning more about this process is apt to prove illuminating and beneficial in understanding the ways in which people find new life.

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Appendix A: Demographics List

Participant #__________

Please fill in the following information. The researcher is interested in this information to see what the people in the study are like as a group. Please do not write your name on this sheet. The information in this sheet will be kept separate from your tape-recorded interview. There are no right or wrong answers. You may refuse to answer any of these questions.

1. Age ______

2. Education Level high school or less undergraduate degree/diploma
some post secondary graduate degree

3. Occupation ___________________

4. Annual Income <$12,500 $12,500 - $24,999 $25,000 - $39,999
$40,000 - $59,999 >$60,000

5. Religion ____

6. Approximate date of HIV diagnosis _______________________________

7. Health concerns unrelated to HIV infection _________________________

____

Appendix B: Letter to Intermediary Individuals

May_ 2000

Dear ---------:

My name is Andrea Mulkins and I am a graduate student at the Centre for Health Promotion studies at the University of Alberta. I have developed a project which is designed to explore and describe the experiences of gay, Caucasian, adult men who are living with AIDS and who are using complementary therapies to address their AIDS related symptoms. Although research has been conducted investigating the HIV/AIDS and complementary therapy use, little is known of the experience of someone using these therapies. Because complementary therapy use is becoming so common as a strategy to manage HIV/AIDS, I feel that there is a need to understand what people who are using these therapies are experiencing. Findings from this research will help illustrate the perceived benefits of using these therapies and may be used to argue the need for integration into our current health care system.

I am aware that many of the people who frequent your clinic are complementing their AIDS care with a variety of complementary therapies. For research purposes, complementary therapies are defined in this study as anything not normally given or prescribed by their doctor. I am writing to request your assistance in contacting individuals who are living with AIDS who may want to talk with me about their experiences. People wishing to participate in the study will be asked to speak individually with me in person or on the telephone at a time and place convenient for them to discuss their experience. The research design may require meeting with me from one to three times. During the interview I will ask them to tell me about their experiences of being a person living with AIDS and their use of complementary therapies for AIDS related symptoms. All interviews will be taped and each interview will take approximately an hour.

If you know of any gay, Caucasian males who are using complementary therapies to manage their AIDS related symptoms and who would be interested in the study, please contact me and I will provide you with a formal letter for the possible participants. I have enclosed a copy of this letter for your perusal. If you have any questions or concerns about the study, I can be reached during the day at 732-8201. Once the study is completed I would more than pleased to provide you with a summary of the findings.

I appreciate your consideration and assistance in this matter.

Sincerely,

Andrea Mulkins

Appendix C: Information Sheet and Consent Form

Purpose:
This research project hopes to find out what gay, white males are doing for their HIV to feel better on top of taking the treatments from their medical doctors.

Methods:
You will be asked to talk to the researcher about what you do to manage your HIV in addition to what your physician prescribes to you. The researcher will ask you questions and you can answer in your own words. There are no right or wrong answers. A maximum of three interviews will be conducted and may be either face-to-face or telephone interviews. These interviews will be done individually and each interview will last approximately an hour.

Confidentiality:
The interview will be recorded on tape. The tape will be typed out by the researcher. The name of the person in the interview will not be recorded on the tape or the paper. Instead, a number will be given to that interview. This number, or a fake name, will be used on anything that gets written about the interview. Only the researcher will know the name of the person on the tape. All of the information that has a person's name on it will be locked up. Interviews will be done at either Friends For Life or the BCPWA. It is possible that people at either organization will know that you took part in this research study. But, they will not know what you said.

Benefits:
This study may not have any direct benefits for you. It is hoped that how people manage their HIV will be better understood.

Discomfort or Risks:
It is not expected that being in this study will harm you.

Withdrawal from the study:
Even after you have agreed to do the interview, you can decide you do not want to do the interview. This can be done before the interview. It can also be done in the middle of the interview. You can also decide after the interview that you do not want what you said to be used. The researchers then cannot use what you said.

Consent Form

Title of the Project: Complementary Therapy Use Among People Living With AIDS

Principal Investigator:
Andrea Mulkins

Consent:
Please circle your answers:
Do you understand that you have been asked to be in a research study?
Yes No
Have you read and received a copy of the attached Information Sheet?
Yes No
Do you understand the benefits and risks involved in taking part in this research study?
Yes No
Have you had a chance to ask questions and discuss this study?
Yes No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You can also stop your information from being used. You do not have to give a reason and it will not affect you in any way. To withdraw, ask the interviewer to stop the interview and tape-recorder. Then, if you want, tell the interviewer that you do not want your information to be used in any research papers.
Yes No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?
Yes No
Do you understand who will be able to see or hear what you said?
Yes No
Do you understand that people at FFL or BC PWA may know that you participated in this study, but they will not know what you said?
Yes No
Do you know what the information you say will be used for?
Yes No
Do you agree to have your interview tape recorded?
Yes No
This study was explained to me by: ____________________

I agree to take part in this study.

____________________ __________ ____________________
Signature of Research Participant Date Witness

__________________________ __________________________

Printed Name Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

____

Signature of Investigator or Designee

Would you like to receive a short version of the report? Yes No

If you would like a copy, please print a mailing address where this information can be sent. Your address will not be used for any other reason than to send you a copy of the report.

Apt# __________
StreetAddress____

Town/City______________________ Province_____________

PostalCode_________

Appendix D: Interview Question Sheet

As this is an unstructured interview, the leading question is;

"Please tell me your story about living with HIV and what you are doing to feel better."

Appendix E: Recruitment Notice

Request for Research Participants-

Andrea Mulkins is a student completing a Masters of Science degree in Health Promotion at the University of Alberta. She interested in hearing about people's experience of living with HIV and what they do to get better. She would like to learn more about what people are doing in addition to what their doctor prescribes for HIV to get better. The information that is collected from you may help us understand how persons living with HIV care for themselves. She will be conducting interviews of approximately one hour, either over the phone or in person at Friends for Life or BC PWA.

She is looking for gay, Caucasian males who are experiencing symptoms of HIV infection to participate. They must be using treatments that are not normally given or prescribed by their doctor for their HIV related health problems.

If you are interested in participating in this study, please call Andrea at 732-8201.

Appendix F: Telephone Consent Script

This explanation and telephone consent form will be read to persons living with HIV over the phone. After introduction, briefly explain the purpose of the phone call, the purpose of the consent form and the necessity of tape recording the consent. Put the consent tape in the recorder and after confirming that the recorder and tape are functional, notify the participant that the tape recorder is turned on.

Read: I am conducting a study to learn about what people living with HIV do to feel better in addition to what their medical doctor has prescribed. I am interviewing gay, Caucasian men living with HIV who are taking or using anything not normally given or prescribed by their doctor for their HIV related health concerns. Your story will help us to understand how persons living with HIV care for themselves. If you decide to be a part of this study, you will be asked to tell your story over the phone. A tape recorder will be recording our conversation. The interview will take about an hour. During the interview you may refuse to answer any questions you don't want to answer and you may stop the interview at any time. Once the interview is complete, I may phone you back for clarification. If I call you back, our conversation will be taped once again. The information that I collect as part of this study will be shared with other researchers and health care providers. Although you will not be identified by name in any of these reports, your words may be published in articles.

Participation in this study may be of no personal benefit to you. However, based on the results of the study, it is hoped that HIV care can be improved.

Do you have any questions at this time? (I will answer any questions)

Do you agree to take part in the study?

Are you aware that you can refuse to take part?

Are you aware that you may withdraw from the study at any time without jeopardizing your health care?

Are you aware that you may refuse to answer any questions at any time?

Are you aware that you may request that the tape recorder be turned off at any time?

Do you think that you have been informed to your satisfaction about the risks of the study?

I am going to give you my name and phone number and I want you to write it down for your reference. (give name and phone number)

Thank you. Would you please tell me your name? The Date is ________.

(Turn the recorder off and ask the participant to wait while you check that the consent was recorded properly. Once this has been confirmed, remove the consent tape WITHOUT REWINDING. Put the interview tape in, turn the recorder on and begin the interview.)

Appendix G: Debriefing Script

Of course the debriefing needs to be sensitive and tailored to the needs of the participants and issues as they arise. However, a sample of this script might include the following:

1. Thank you for your valuable time and for your honest input.
2. Now that we have completed the interview, you may have questions or unresolved issues relating to what we have talked about here today. Maybe a phrase or thought may keep coming to your mind.
3. If you are comfortable and want to discuss these now, I will do my best to answer you. If I do not have the answer, I will try to find the answer to your question.
4. If you would rather not discuss your questions and concerns with me now, or questions come up later, you can contact me using the information on the information letter.

To discuss personal questions or concerns about HIV/AIDS and complementary therapies:

Tamil Kendall
B.C Persons With AIDS Society
1107 Seymour
Vancouver, B.C
Phone: (604) 681-2122