

**A DESCRIPTIVE STUDY OF THE PSYCHOSOCIAL IMPACT OF AIDS  
ON FAMILY CAREGIVING**

**BY**

**SONIA JABLONSKI-PRAZNIK**

**A Thesis  
Submitted to the Faculty of Graduate Studies  
in Partial Fulfilment of the Requirements  
for the Degree of**

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**A DESCRIPTIVE STUDY OF THE PSYCHOSOCIAL IMPACT  
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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
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of  
MASTER OF NURSING**

**Sonia Jablonski-Praznik<sup>1997</sup> (c)**

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## ABSTRACT

The purpose of this qualitative ethnography was to describe the psychosocial impact experienced by family caregivers residing with a person living with AIDS (PLWA). The purposively selected informants consisted of seven family caregivers, four female and three male, between the ages of 29 and 74. Face to face, semi-structured interviews guided by an eclectic model of social support, constituted the primary data collection method. The constant comparative method of data analysis was employed to identify the main categories and themes. As prescribed by Patton (1990) and Field and Morse (1991), the interviews were transcribed verbatim, coded and analyzed to discover themes and categories. The major themes and categories are exemplified by "thick description" using verbatim quotations. The findings reflect the psychosocial experience of AIDS family caregivers as work. This work is further defined by the themes and categories of 1) Monitoring: Surveillance, Vigilance, and Hypervigilance; 2) Letting In: Becoming a Caregiver: Engaging the PLWA, Engaging the Caregiver, and Mutual Engaging; 3) Labouring the Emotions: Labouring in Exile, Labouring of Losses and Labour of Uncertainty; 4) Protective Labour; and, 5) Caring Transformations: Discovery of Self Perspective and Discovery of System Perspective.

The study may contribute towards a framework for preventative, supportive and therapeutic interventions with family members living with a PLWA in the community. Several implications for nursing education, practise and research are noted. Implications for nursing education suggest the need for basic nursing curricula to address concepts of family composition, caring and support. Implications for nursing practice suggest a need for a case managed, family centred approach to caring for a PLWA within tertiary and community



settings. Studies on interventions to promote healthy transitions along the family AIDS caregiving trajectory are recommended for further research.

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## CHAPTER I

### STATEMENT OF THE PROBLEM

#### Introduction

Since June 1981, when the first case of what would later be known as Acquired Immunodeficiency Syndrome (AIDS) was reported by the Centers for Disease Control (Centers for Disease Control, 1981), a vast medical literature began to accumulate on the physical health aspects of this disease (Schofferman, 1988; Woo, 1988). AIDS has been identified as the number one public health problem facing the world (Mann, 1990). Statistics compiled by the World Health Organization and presented at the XI International Conference on AIDS (July 1996, Vancouver) indicated that worldwide almost 22 million people are infected with HIV, and approximately 8,500 new cases occur daily (Curran & Murray, 1996). It has been estimated that 4.5 million people have already died from AIDS; however, exact numbers are difficult to obtain because of under-diagnosis, incomplete reporting and reporting delays in many countries. The AIDS epidemic was projected to become the second leading cause of death for individuals under sixty-five years of age in 1992 (Smith, Stevenson, Keeling and Herrick, 1989). In 1993, HIV infection in the United States (U.S.) became the most common cause of death among persons aged 25-44 years and accounted for 19% of deaths in this age group (CDC, 1996). In 1994, HIV infections in the U.S. became the fourth leading cause of years of potential life lost before age 65 (YPLL-65) (compared with fifth in 1993), accounting for 9% of YPLL-65 from all causes (CDC, 1996).

In addition to being viewed as a primary health problem, AIDS-related disease has been referred to as a psychological emergency (Batchelor, 1984). One common theme in the

literature is that the mental health consequences of human immunodeficiency virus (HIV) infection are more numerous and devastating than those associated with any other disease (Health and Welfare Canada, 1990). The marked uncertainty created by the nature and prognosis of AIDS-related disease, as well as the highly negative social stigma associated with the disease, has led to a greater sense of social isolation than that experienced with other chronic or life-threatening illnesses (Dipasquale, 1990; Flaskerud, 1987; Tiblier, 1987; Wolcott, Fawzy, Landsverk & McCombs, 1986).

The psychosocial impact of the disease is not, however, limited to persons infected with HIV, but also extends to those affected by the disease, including significant others, family and professional caregivers. Living with a chronic illness is a complex experience which involves living with a long-term incurable disease that leaves a legacy of disruption and disability in many domains of human functioning. Although the individual is diagnosed with a chronic disease, an immense burden is placed on the family who experiences life with the illness (Collier, 1990; Woods, Yates & Primono, 1989). Nurses have a limited understanding of the lived experience and coping with AIDS (Gregory & Longman, 1992).

In studies related to other chronic illness, the burden experienced by family members appears to be mediated by how caregivers perceive actual stressors as problematic. That is, the caregivers subjective experience is the major variable in determining their level of burden (Morgan & Laing, 1991). The stress associated with helping a loved one through the course of illness and death may be a particularly potent cause of mental distress and physical illness (Dean, Hall & Martin, 1988).

Given the increasing incidence of AIDS, the segment of the population experiencing

social losses due to AIDS is also growing. Thus, the health problems of the family associated with actual losses, anticipated losses, and hardships because of AIDS are serious and multiple. Although there is considerable clinical literature on the psychosocial needs of significant others caring for someone with AIDS, few empirical studies have addressed the concerns of families.

### Statement of the Problem

The World Health Organization (WHO) has predicted that the worldwide number of acquired immunodeficiency disease syndrome (AIDS) cases will increase tenfold by the year 2000 (Mann, 1992). Mann (1992), suggests that the HIV epidemic is unprecedented in its threat to global health and now merits designation as a pandemic. In 1991, The WHO estimated that nine million people in 163 countries world wide had already been infected by the human immunodeficiency virus (HIV) and about 1.5 million had already developed AIDS (Winnipeg Free Press, 1991 p. A20). In 1996, the WHO Surveillance Program documented 196 countries reporting 1,393,638 AIDS cases and 7,000,000 AIDS cases estimated (Health Canada, 1996). World wide the adult HIV prevalence is estimated at 21,000,000 (WHO, 1996). A Delphi study conducted by the WHO in 1989 predicted that as many as twice the number of HIV infections may occur in the 1990s, than had occurred in the 1980s (Chin and Mann, 1990). By the year 2000, the WHO estimates that 40 million people may be affected by the pandemic if current trends continue (Centers for Disease Control [CDC], 1991a).

Estimates of the prevalence of HIV-infected individuals in the United States (U.S.) in 1992 were between 650,000 to 1.2 million (CDC, 1991a). The cumulative number of AIDS

cases in the U.S. for the 10 year period 1981-1991 exceeded 179,000, of which 63% were reported to have died (CDC, 1991b). Through June 1996, 548,102 men, women and children with AIDS have been reported to CDC, and 343,000 (62.7%) have died (CDC, 1996). Over 80,000 persons have been reported with HIV infection in the 28 states that also conduct surveillance for HIV cases. The number of AIDS cases reflects only the severest clinical manifestations of HIV infection (Turner, 1993).

The incidence of AIDS in Canada follows the epidemic pattern of the United States, delayed by about 18-24 months (McLeod & Silverthorn, 1988). In Canada, 8,640 AIDS cases had been reported to the end of October, 1993 (Health Canada, 1993). These included 5,801 deaths (67%) (Health Canada, 1993 p.1). Of the 2,839 surviving, 2,673 are male and 166 are female. Through June 30, 1996, the number of AIDS cases reported increased by more than 40%, to 13,643 AIDS cases and 9,936 deaths (72.2%) of those infected occurred (Health Canada, 1996).

Within Manitoba, three women and 72 men were diagnosed with AIDS as of June 30, 1992 (Lyons, 1992). As of December 1993, there were 103 reported cases with 79 deaths due to AIDS related causes in the province (Manitoba Health, 1994). As of June 20, 1997, seven women and 146 men were diagnosed, representing more than a 50% increase in incidence in the five year period (Manitoba Health, 1997). As well, 588 Manitobans, 64 of them women, have tested positive for the HIV virus. When reported cumulatively, AIDS in Manitoba resembles the national epidemiologic picture. The largest number of AIDS cases are among 30-39 year old men (49.3%), the most frequent mode of transmission is homosexual/bisexual intercourse (73.8%), and 83% of those infected are urban residents within Winnipeg

(Manitoba Health, 1997). It is now thought that probably all, or nearly all, individuals infected by HIV will eventually develop AIDS. The cumulative mortality is approximately 50%, with a five year survival of between 0 and 10% (Mansell, 1988). However, with more access to testing, many individuals are being diagnosed while they still are well (Health and Welfare Canada, 1992). Presently, many people with HIV disease can maintain their health and live 10 years or longer with the illness. For most of the time, they will be well and free of clinical symptoms, but still coping psychologically and socially with a communicable and life threatening disease. Therefore, AIDS must be viewed as a chronic disease interspersed with acute episodes that remains inevitably fatal.

It is estimated that, as of mid-1996, between 30,000 and 45,000 Canadians are infected with HIV, but have not developed AIDS. Expressed in another way, approximately one out of every 666 to 1,000 Canadians is currently infected with HIV (Curran & Murray, 1996). In those affected, the virus can cause serious social, spiritual, psychological and neuropsychiatric damage and have a severe impact on mental health. As a result, the mental health of partners, family members, and friends may also suffer.

Although the tragedy of AIDS is now widely recognized as an epidemic, little attention has been given to the impact of the disease on the family who is affected by the diagnosis. The diagnosis of an individual with a chronic illness places an immense burden on the family who experience life with the illness (Collier, 1990; Woods, Yates & Primono, 1989). The diagnosis of AIDS in a family member is described as more devastating to families than other illnesses because of the social stigma attached (Brown & Powell-Cope, 1991; Cowles & Rodgers, 1991; Giacquinta, 1989).



It is predicted that families will be the main support system for the individual member with AIDS (Sussman, 1989). Increasingly, they will assume the burden of providing not only the economic support, but also care for the infected individual throughout the various stages of treatment. Nurses must consider the nature of the chronic illness and describe its demands on the family (Woods, Yates, & Primono, 1989). Through this process, the impact on the family can be identified and the necessary interventions to support the family as the unit of care be implemented. Such research is not only important for our understanding of human behaviour, but will also facilitate the design, development, and evaluation of appropriate preventative and treatment programs for AIDS family caregivers (Anderson, 1989).

Although some research has been conducted on the psychological aspects of HIV, research which articulates how to best intervene and assist families is required. As well, research evaluating models of care and nursing interventions with family caregivers is required (Health and Welfare Canada, 1992). Substantive knowledge concerning the nursing care/needs of families caring for persons living with AIDS (PLWA) and persons living with HIV (PLWHIV) is limited. A review of the literature on the impact of AIDS on mental health was conducted by Health and Welfare Canada in 1988 (1990). The material gathered through the review is limited because it was based on data and experience in the United States, where both the epidemiology of the disease and the organization and funding of the health services are different (Health and Welfare Canada, 1992, p.79). To date, little is known about the Canadian family experience related to AIDS caregiving.

### Problem Statement

The purpose of this exploratory, descriptive study was to examine the impact of AIDS on the psychosocial health of family caregivers of persons living with AIDS. The study was undertaken to describe the needs related to caregiving experienced by family members caring for a PLWA. The following research question was addressed: What are the psychosocial effects on the family when caring for an AIDS-diagnosed individual? The research question was broadly stated to complement the exploratory-descriptive design of this study and to capture the full range of psychosocial effects.

### Definition of Terms

To assist with the conceptual clarity of the study, the following definitions were used to operationalize the study variables.

#### Family

"Family" used in this context was defined by the PLWA and included: one's family of origin, family of procreation, and one's family of function. The term "family of function" refers to those individuals who constitute an ongoing social and affectional intimate support network of one another and may include co-habiting couples and friendship networks (Anderson, 1989; Kristjanson, 1992; Tiblier, 1989).

### Family Caregiver

An individual identified by the person with AIDS as a family member who provided emotional, physical, financial, or spiritual care.

### Persons Living with AIDS (PLWA)

Individuals diagnosed with AIDS defined as per the Canadian Communicable Disease Surveillance System: Disease Specific Case Definitions and Surveillance Methods (Health and Welfare Canada, 1993). The PLWA was identified through the HIV/AIDS clinical nurse specialist at a major teaching hospital.

### AIDS

An acronym for Acquired Immunodeficiency Syndrome. According to the Laboratory Centre for Disease Control (LCDC), a case of AIDS is defined as a clinical diagnosis of at least one of the specific infectious diseases or cancers associated with AIDS (Health and Welfare Canada, 1994).

### Significance

As chronic disease continues to have an impact on the health status of Canadians and consume limited health care dollars, health promotion has begun to take on a new significance. Health and health care promotion have been identified as fundamental concepts for nursing practice (Spellbring, 1991). Health promotion consists of activities directed

toward increasing the level of well-being and actualizing the health potential of individuals, families, communities and societies (Pender,1987). As the incidence of AIDS continues to rise, nurses need to focus on quality of life issues in addressing health.

Assessing the potential risks of individuals and families is the first step in health promotion. Nurses' understanding of what the family perceives to be its needs regarding AIDS caregiving is foremost. As well, nurses need to be aware of how the family's relationships can influence their attitudes toward functioning in a caregiver role. An understanding of the family's history and prior relationships in which the caregiving occurs can allow nurses to work with caregivers and determine which interventions might be most helpful to them. Research needs to focus on how families help each other, how they cope, and how they grow. With identification of these variables, nurses can focus on prevention of health disruption and promotion of quality of life for family caregivers.

Nurses play a primary role in responding to the needs of families as primary health care providers. They face multiple decisions about the type of comprehensive care and support systems needed by the family. As an individual's disease progresses, nurses are called on to provide counselling to family members and make recommendations to meet physical and psychosocial needs. Family caregivers themselves may not be consciously aware of why they are distressed. Working with caregivers to untangle their web of emotions may lead to improved coping for the caregiver and improved care for the affected person. It is necessary to identify the nursing care measures required to assist these families as they progress from one stage of AIDS caregiving to the next. How nurses can best assist the family to adapt and cope as the illness progresses has yet to be substantiated. Decisions

regarding the type and location of care provided can be enhanced by the knowledge of what family caregivers perceive to be their strengths and needs and lead to innovative approaches in care delivery. Hospital care of PLWA may be more than five times as expensive than that of care of persons maintained in the community (Jenna, 1987), further supporting the need for nurses to take a proactive role in ensuring both quality of life for family caregivers and the development of community based services.

Nurses are in the forefront of providing hands-on care to PLWA where the risks to the health-care provider of possible contamination are greatest (Siminoff, Erlen & Lidz, 1991). Education of caregivers (nurse as well as family) about the course of the disease as well as the types of care required at various stages in the illness needs to be identified within the context of caregiving. According to Kelly, St. Lawrence, Hood and Cook (1988), many nurses have negative attitudes toward HIV positive and AIDS patients, resulting in an unwillingness to interact with them, even casually. Nurses who are increasingly exposed to AIDS-risk groups perceive that caring for them augments their risk of HIV infection, despite implementation of universal precautions (Jemmott, Freleicher, & Jemmott, 1992). Reluctance and discomfort about coming into contact with these patients are related to fear of contagion and negative attitudes towards homosexuality and intravenous drug users (Flaskerud, 1991; van Servellen, Lewis & Leake, 1988). Negative influences of spouses, family members, intimate friends and religious beliefs also affect nurses' decisions to provide care for these patients (Kerr & Horrocks, 1990; Mcleod & Silverhorn, 1988). Thus, individual nurses' fears and anxieties about caring for AIDS patients and their lack of knowledge, may interfere with their ability to provide care in a competent, and compassionate manner (Siminoff, Erlen

& Lidz, 1991). The possibility then exists that the quality of nursing care given to AIDS patients and their families may be adversely affected by the stigma associated with AIDS (Eliason, 1993).

The needs of the family caregiver must be systematically researched to assist nurse to know what is important and relevant to family caregivers. Developing this knowledge base may permit nurses to provide family caregivers with meaningful and relevant education, support, and compassionate care. Education of the family caregivers which addresses contracting AIDS related to care delivery and teaching infection control techniques which are both adequate for protection and humane, is needed within the home setting. However, cognitive based knowledge alone is not sufficient to overcome irrational or emotionally charged fears about death and homophobia. Family education needs to combine realistic cognitive learning with affective relearning regarding the PLWA's unique care situation.

### Conclusion

A major challenge facing nursing is the provision of compassionate physical and psychological care to persons with HIV or AIDS and their families. The Canadian Nurses Association believes that person with AIDS are entitled to high quality health care. Nurses have an obligation to provide safe, competent and humane care to all clients including those with AIDS, their families and significant others (Canadian Nurses Association, 1992, p. 140). The need for more nursing knowledge about AIDS has been well documented (Flaskerud, 1988; Flaskerud, 1989; Kelly, Lawrence Hood, Smith & Cook, 1988; van Servellen, Lewis & Leake, 1988). The purpose of this study was to identify the psychosocial

impact on the family when providing care to a PLWA.

## CHAPTER II

### REVIEW OF THE LITERATURE

A review of the literature focusing on articles related to family caregiving and AIDS between 1984-1994 was conducted. Five major categories were identified and are reported here: (1) physical impact of AIDS on the individual; (2) psychosocial impact of AIDS on the individual; (3) psychosocial adaptation and social support of the individual with AIDS; (4) psychosocial impact of AIDS on the family; and (5) psychosocial adaptation and social support of the family caregiver.

In a review of the nursing literature between January 1983 and April 1987, Larson (1988) reported that more than 150 articles regarding AIDS and HIV were published, none of which were research based. A later review of more than 16,000 citations between May 1987 and June 1990 revealed 731 non-research and 54 research articles (Larson & Ropka, 1991). The review demonstrated a continuing gap in the research literature related to the care aspects of AIDS/ HIV infection. No studies examining the families of PLWAs in any context were cited. Turner's (1990) review of the existing nursing literature on HIV/AIDS identified the need to establish an empirical knowledge base, including the psychological and social impact of AIDS on family function. In the 1988 review, research priorities were established and in 1991 they were reaffirmed to include the area of family adaptation to AIDS.

Feetham's (1984) examination of family research in nursing from the earliest efforts through 1983 concluded that there was increasing attention to the family in both nursing practise and research within the prior decade. However, measures of family health or well being were not reported as central concepts in this review. No studies were located that



addressed the impact of AIDS on family health.

The substantive knowledge known as family research in nursing or family nursing research is currently being classified and evaluated. Whall and Loveland-Cherry (1993) reviewed research that focused on the family unit (i.e., measured family system variables) for the period from 1984 to 1991. Research that focused primarily on a family member or aspects of a specific illness, with the family unit as context or secondary variable, were not considered. They reported that although the number of family unit studies in nursing had increased exponentially, further attention was needed to understand how family health is promoted and maintained.

#### Overview of the Physical Impact of AIDS

Acquired Immunodeficiency Syndrome (AIDS) occurs in individuals infected with the human immunodeficiency virus (HIV) retrovirus. HIV causes an immune deficiency that leads to a decrease in cell-mediated immunity. The salient features of decreased cellular immunity include a decrease in antibody production, cytotoxic T-cell activity, and T-cell proliferation (Jacobs & Piano, 1987). These defects in cell-mediated immunity are due to the HIV's suppression in helper t-cell (T4) lymphocytes. The latent or incubation period may last up to ten years or be only several months depending on host factors. Factors known to effect this period include: the quantity of viral inoculum, the frequency of reinfection and a number of co-factors such as drug use, intercurrent infections, nutrition (Flaskerud, 1992; Mansell, 1988), the use of medication, and a solid support system (Kelly, 1992). With progression, the PLWA becomes susceptible to multiple opportunistic infections, rare neoplasms, and

AIDS related dementia. A growing body of research into the functioning of the immune system strongly suggests that through hormonal and autoregulatory mechanisms, reactions to stress and intense feelings of distress have a direct effect on health and on the development of viral attacks and tumours (Kiecolt-Glaser & Glaser, 1988).

The person living with AIDS (PLWA) experiences a physical disease trajectory that progresses through several stages. As active aggressive treatment decreases with disease progression, palliation efforts increase (Health and Welfare Canada, 1989). As many as 70% of people with HIV will develop an organic mental disorder (delirium or dementia), 25% will have a major affective disorder (depression) and 17% will have panic disorder (Health and Welfare Canada, 1992, p. 18). Symptoms of severe AIDS dementia include an inability to perform daily activities or to recall recent events, or persons, including the partner and family (Katz, 1994). As people with HIV are living longer they are more likely to develop AIDS dementia and pressure on the family will grow. Multiple resources and increases in the level of physical and emotional care are required to maintain quality of life for the PLWA in the community.

#### Psychosocial Impact of AIDS/HIV on the Individual

Individuals who are infected by the HIV virus experience both physiological and psychological distress (DiPasquale, 1990; Flaskerud, 1990; Stapelton, 1986). Much of the distress experienced by the individual begins at the time of diagnosis and has similar characteristics to the distress experienced by the individual with cancer (Donlou, Wolcott, Gottleib & Landsverk, 1985). To look at AIDS through a biopsychosocial lens leads to two

separate, but interrelated perspectives (Tiblier, Walker & Roland, 1989). First, one can describe the psychosocial issues associated with the illness at each of the medical stages from wellness to death, including the worried well; report of HIV seropositivity; diagnosis of AIDS related complex (ARC); diagnosis of AIDS; death and bereavement; and family reorganization. Secondly, all chronic and life threatening illness can be described in terms of time phases: crises, chronic and terminal (Roland, 1987). AIDS time phases have been described as consisting of four stages: initial crisis, transitional stage, deficiency stage and preparation for death (Melby, 1992). Each phase has its own developmental tasks and requires different coping and adaptation skills from the individual and the family. However, as there is considerable overlap of issues associated with the stages and phases in the literature, these perspectives will be combined in the review.

Individuals with HIV/AIDS must face all the stresses associated with chronic and life threatening illnesses including concerns about their future, longevity, and quality of life (Health and Welfare Canada, 1992; Tiblier, 1987). As with any life threatening illness, the individual will be coping with loss: loss of future, bodily comfort, customary social roles, and activities. A diagnosis of AIDS is comparable to being given a death sentence and often leads to hopelessness and despair in those individuals infected with the virus (Health and Welfare Canada, 1989).

The psychological effects of an HIV-positive diagnosis have been described as an adjustment reaction in which the stress is severe enough to be considered catastrophic. The distress experienced by PLWA begins at the time of HIV diagnosis (Flaskerud, 1987) and is similar to the distress experienced by individuals with cancer (DiPasquale, 1990; DonLou,

Wolcott, Gottleib & Landsverk, 1985). The PLWA often loses his/her job, self-sufficiency, self-esteem, and sometimes friends and family (Ribble, 1990; Stapelton, 1986). The vast range of psychological symptoms reported in PLWA includes: grief, depression, fear, guilt, suicidal ideation, anger, anxiety, low self-esteem, loneliness, self-pity, powerlessness and alienation (DiPasquale, 1990; Flaskerud, 1987; Health and Welfare Canada, 1990; Stapelton, 1986). According to Weiss (1988), these threats to well-being elicit increased attachment emotions and behaviours in the PLWA. It is not unexpected then, that many PLWA attempt to cope with the disease effects by enlisting the support of others.

#### Psychosocial Adaptation of the PLWA and Social Support

The literature cites widely the benefits of support groups for the psychosocial adaptation of the PLWA (Alley & Foster, 1992; DiPasquale, 1990; Newmark, 1984; Ribble, 1989). Support groups are reported to provide: understanding, a sense of alliance, access to information, and an opportunity to review thinking with knowledgeable others (DiPasquale, 1990; Korniewicz, O'Brien & Larson, 1990; Ribble, 1991; Weiss, 1988). Individuals who report adequate social support networks are psychosocially able to adapt to illness, are better informed about health opportunities, perform health promoting or health risk reducing behaviours, and understand the influence of psychological changes on the immunologic response (Korniewicz, O'Brien & Larson, 1990).

Individuals who have greater social support networks are better able to adapt to the disease, since they have high levels of self reported quality of life and lower levels of mood disturbance (Wolcott, 1984; Wortman, 1984).

In a study of the relationships among depression, anxiety, anger, and self-esteem and the AIDS diagnosis, the influence of social support on the psychological well being of 21 male out-patients with AIDS or AIDS related complex (ARC) were examined (Donlou, Wolcott, Gottleib & Landsverk, 1985). Results were consistent with the clinical impression that the person living with AIDS or ARC as a group are more distressed than are most other groups of chronically ill patients. A marked decrease in social functioning following diagnosis of their illness and self isolation from friends, families, and partners was reported. Wolcott (1986) reported that individuals may hide the diagnosis out of fear of family crisis and social stigma. The total social support scale was not significantly correlated with mood disturbance or with a measure of self esteem ( $p < 0.05$ ).

In contrast, Korniewicz, O'Brien and Larson (1990) did not report that HIV infected individuals become more socially isolated. An explanation for this difference was cited as the social network becoming more responsive to the needs of the PLWA. Utilizing a descriptive, cross sectional design, Korniewicz and colleagues identified selected aspects of psychosocial adaptation at various stages of infection among individuals. The subjects were divided into four groups: (1) HIV risk group ( $n=24$ ); (2) HIV infected-asymptomatic ( $n=10$ ); (3) early stage AIDS ( $n=10$ ), and (4) late stage AIDS ( $n=19$ ). Theories of social stigma and social identity were used as a theoretical base to hypothesize that high risk individuals would have higher levels of self concept, self esteem, and social functioning and lower levels of alienation than those with HIV. As well, it was hypothesized that individuals with HIV would demonstrate differences in self concept, self esteem, social functioning, and alienation at various stages. No significant differences among the four groups for the dependent measures

of self concept, self esteem, or social function were reported ( $p < 0.05$ ). The small number of individuals within each group (Type II error) or the sensitivity of the instruments may have contributed to the insufficient statistical power for the detection of differences. There was, however, a significant difference in alienation scores for the asymptomatic and HIV risk groups; both scored significantly higher, particularly on measures of powerlessness. The study results indicate the need to offer nursing interventions as close to diagnosis as possible to lessen the psychosocial impact on self concept and to prevent alienation.

Zich and Temoshok (1990) used a longitudinal design to examine the perceived adequacy of social support of gay/bisexual men with AIDS ( $n=50$ ) and with AIDS related complex (ARC) ( $n=53$ ). They reported that the greater the number of physical symptoms a person reports, the less likely he is to perceive social support as available. According to Zich and Temoshok, these results highlight the possibility that the number of self reported physical problems may be more reflective of psychological distress than of medical status. For the PLWA and those with ARC, the more available social support was perceived to be, the less hopelessness and depression were reported. One limitation of the study was that only perceived social support (self report) was measured. The problem with self report measures based on a person's perception is that measures may not be independent (Zich & Temoshok, 1990). Other dimensions such as network size and structure, characteristics of support providers, and objective indices of social-support episodes, may indicate actual support received is different from perceived support.

Ribble (1989) reported that an analysis of five cases revealed that individuals lives were changed by empowerment through AIDS support groups. Empowerment was reported

to have maintained and reinforced behavioral changes such as discontinuing I.V. drug use, seeking reproductive counselling, sustaining sex and relationships, changing adaptive focus from denial to internal issues and a collaborative holistic treatment approach to disease management. Her case studies suggest that some of the negative outcomes of stress and anxiety of AIDS are reduced through support groups. However, DiPasquale's (1990) hypothesis, that individuals infected with the AIDS virus would have significantly less anxiety and hopelessness after participating in a support group, was not supported ( $p < 0.05$ ). In this study of PLWA and persons with ARC ( $n=32$ ), it was reported that the subjects equally considered their family and the support group as their strongest contacts. Consequently, it has been suggested that counselling of the PLWA needs to include the counselling of partners, friends and family members (Melby, 1992).

### Psychosocial Impact of AIDS on the Family

All of the emotional and social reactions that occur with PLWA also occur with families and friends (Flaskerud, 1987; Health and Welfare Canada, 1990; 1989). When someone is diagnosed with HIV, the psychosocial stress on the persons' partner, family and friends is almost as great as on the person (Health and Welfare Canada, 1992). As the cornerstone of care provided to the PLWA in the community, the psychosocial needs of families are multiple, complex, and demanding (Chekryn, 1989; Flaskerud, 1987). For many PLWA, family members not only imply the biological family (parents, sibling) or the family of origin, but also their lovers, friends, and volunteers or their family of attachment (Chekryn, 1989). They face a myriad stresses that are common to chronic life-threatening

illness and unique to HIV (Chekryn, 1989; Frierson, Lippman & Johnson, 1987). In some cases, biological family members may have been estranged from the PLWA for a substantial length of time, but may subsequently become the primary caregivers (O'Donnel & Bernier, 1990; Weiss, 1988). Many parents will blame themselves as well as their adult child, the PLWA, for not having developed as they wanted. The parent may find reparative value in caring for the PLWA (O'Donnel & Bernier, 1990; Weiss, 1988).

Among the psychosocial issues that families of PLWA must cope with are: fear of contagion, stigmatization, dealing with death and dying, issues related to alternative lifestyle and sexuality, feelings of helplessness and inadequacy concerning patient care (Chekryn, 1989; Flaskerud, 1987; Health and Welfare Canada, 1989; Macklin, 1988; Tiblier, 1987; Tiblier, Walker & Roland, 1989); demands associated with being a caregiver (O'Donnel and Bernier, 1990; Tiblier, Walker & Roland, 1989); uncertainty about the disease and its course (Brown & Powell-Cope, 1991); and loss and bereavement (Health and Welfare Canada, 1990; Tiblier, 1987; Tiblier, Walker & Roland, 1989). The most frequent sources of stress identified among caregiving families include: the stigma of AIDS, fear of contracting AIDS, and multiple and premature losses (Brown & Powell-Cope, 1991; Chekryn, 1989; Newmark, 1984).

### Psychosocial Adaptation and Social Support of the Family

The empirical literature did not contain studies specifically examining the fear of contracting AIDS, therefore, only those studies examining the stigma, bereavement/losses and caregiving issues were examined within the category of literature entitled "psychosocial



adaptation and social support of the family".

### Stigma

The social stigma that AIDS carries because of its associations with homosexuality means families are faced with unique issues. Chekryn (1989) used a qualitative design to conduct a retrospective exploratory study of Canadian family members (n=10) of deceased PLWAs who had received care from a hospice home care program. Subjects included families of origin (n=5, parents and siblings) and families of attachment (n=5 lovers, friends and volunteers). The purpose of the study was to describe the experience of AIDS as a terminal disease from a family perspective. Interviews revealed that the families faced the same fundamental stressors of any family coping with a dying member. Additionally, they faced a host of stressors related to the newness of the disease, the stigma attached to AIDS, and the complex management and caregiving issues. Families were less able to draw on their usual network or community resources for support because of the stigma associated with the disease and the secrecy of the diagnosis. Keeping the diagnosis secret meant family members were unable to reach out to their own friends for support, thus increasing their strain. Furthermore, their reluctance to disclose the diagnosis was associated with the fear and reality of withdrawal of one's friends, even those from the gay community. The experience was characterized by feelings of anger, fear, helplessness and unfathomable loss. These feelings were further compounded by the untimeliness of death.

Similarly, Atkins and Amenta (1991) reported that the decreased availability of a social network was related to the stigma attached to the disease. They used a nonprobability

convenience sample to compare the adaptation of families of PLWA (n=26) to that of the adaptation of families of terminally ill patients with other diseases (n=26) who were in hospice care. The families of PLWA demonstrated a significant difference ( $p < 0.05$ ) on the trust, anxiety, and rules prohibiting emotional expression items, as measured by the Family Adaptation to Medical Stressors (FAMS). As well, more illness anxiety and stress were reported for these families according to the Family Inventory of Life Events (FILE) ( $p < 0.05$ ). The increased anxiety experienced was attributed to several factors including: the younger age of the PLWA, higher accrued costs associated with the length of hospice care required, and stigma. Increased family stress was reported to be associated with fewer persons in their social networks.

In a comparison study, Baker and Seager (1991) examined the amount of psychosocial support given by hospice staff, family and neighbours to AIDS (n=11) and non-AIDS (n=11) hospice patients. Hospice staff (n=13) were surveyed regarding their perceptions of caregiving support required for both groups. They reported that AIDS patients required contact more than 2 1/2 times as often by telephone and over two times as often in person than non-AIDS patients. As well, a significant difference existed in the amount of family and congregational support offered to both groups ( $p < 0.05$ ). Most caregiver respondents (92%) reported that working with AIDS clients required more time and was more stressful (64%) than working with non-AIDS patients of similar ages. Reasons for this were cited as: younger age, more physical and emotional needs and social stigmatization of the AIDS group.

### Loss and Bereavement

Each person who dies from AIDS will leave family and friends to face the consequences particular to this type of loss. Loss of a loved one from any cause represents a risk to the mental health of any surviving family member. However, the risk is compounded in the case of the survivors of AIDS related deaths (Health and Welfare Canada, 1989 p.60). Surviving family members are often afraid to discuss their loved one's death due to stigma attached to AIDS. As a result, they cannot obtain the support available to other bereaved persons (Chekryn, 1989; Flaskerud, 1987; Health and Welfare Canada, 1989; Worden, 1989). Survivors of those who die from AIDS constitute a population of mourners with few existing guidelines for care (Oerlemans-Bunn, 1988). What Oerlemans-Bunn termed the unspeakable nature of AIDS related grief is an influential factor for surviving partners and family members. Hiding the secret of a deceased loved one's sexual orientation and AIDS diagnosis hampers the resolution of the grief and compounds the agony (Worden, 1991). Given the present societal norms, persons dying from AIDS face a stigmatized death, while surviving partners, particularly those in homosexual relationships, may experience a stigmatized grief (Ferrel & Boyle, 1992).

A field study to describe the experiences of surviving male partners who provided care to persons dying from AIDS was conducted by Ferrel and Boyle (1992). Data were obtained using face to face interviews of a network convenience sample (n=5). The constant comparative method yielded four major caregiver strategies and three common themes in the bereavement experience. Caregiver strategies included: commitment to care, taking care of oneself, managing alone, and dealing with the health care system. Themes identified in the

bereavement experience were: identifying with the dying partner, seeking support of friends and families, and accepting loss of the partner, both intellectually and emotionally. Survivors who failed for whatever reason to find support and acceptance from friends or families, experienced increased loss of control over events. In particular, the survivors who had been rejected by their partners' families reported difficulty with bereavement resolution. Reasons for failure to find support and the incidence were not cited. An unknown number of the informants (most) joined a support group after the loss of their partner. This was reported to be influential in helping them resolve the loss and develop motivation to continue on with their lives.

### Family Caregiving

Although there is a vast amount of clinical literature on the psychosocial needs of families and significant others, few empirical studies have addressed these care needs. Little information exists about AIDS family caregiving and much of the general family caregiving research focuses on tasks and related effects on the caregiver (Bowers, 1987; Brown & Powell Cope, 1991). There is growing evidence of government policy which clearly supports the AIDS psychosocial health promotion/ prevention effort at both the individual and family level. Several documents discuss initiatives aimed at enhancing mental health and the capacity to cope with chronic conditions (Epp, 1988; 1986). The Caring Together survey supports the federal governments' concern regarding the impact of AIDS on the larger Canadian community (Health and Welfare Canada, 1989). Concern regarding the impact of HIV on the mental health of individuals and

family is indicated within the Review of the Literature on HIV infection and Mental Health (Health and Welfare Canada, 1990). Recent government initiatives have been undertaken to assess the Canadian caregiving experience (Health and Welfare Canada, 1989; 1992) and will be examined first.

### Palliative Care Model

In 1988, in an effort to establish a model of integrative palliative care, a survey to elicit the experience of Canadians who had been caring for the PLWA was conducted (Health and Welfare Canada, 1989). The holistic nature of the palliative approach to HIV/AIDS has been espoused to improve the quality of life of the PLWA and their families (Davies, Chekryn Reimer, & Martens, 1990; Health and Welfare Canada, 1989; Morrisette, 1990; Ribble, 1990). Perhaps not surprisingly, both the PLWA (Mansell, 1988) and the family (Brown, 1990) identified that they preferred palliative care at home over care in any institution.

The professional caregiver respondents identified the provision of psychological support (including help in managing feelings of loss, anger and fear), as the most important issue in palliative care. The second priority identified was the need for PLWA to receive interpersonal support from parents, siblings, friends, lovers, and caregivers. Their role in offering emotional support was overwhelmingly identified as important to enhancing the PLWA' quality of life. The family was also described as a particular group of individuals requiring support throughout the illness and after the death of their loved one. With exploration of needs, early intervention and ongoing support, it was hoped the PLWA and

family suffer less stress (Health and Welfare Canada, 1989). The prolonged illness experience of the PLWA combined with great needs for physical, emotional, and financial assistance can deplete family resources and drain family members emotionally and physically (Flaskerud, 1987; Macklin, 1988; Sussman, 1989).

### Canadian Needs Assessment

A needs assessment of Canadians with HIV, family members, significant others, and caregivers was conducted between August, 1989 and August, 1990 (Health and Welfare Canada, 1992). The 1,262 respondents in four major urban centers were surveyed using a detailed questionnaire. The sample consisted of 581 people with HIV; 459 caregivers; and 222 friends and family members. The needs assessment reported a mean distress level of two thirds that of people infected with HIV. Eighty percent of the partners, families, and friends surveyed had daily contact with the PLWA and were important sources of social support. Of these, 36% claimed that the PLWA was either completely or partially dependent on them.

Caregivers (operationalized to include professional, volunteer and family members) identified a paucity of emotional support either professional or peer. Self reported stress and burnout were characterized by symptoms such as: depression, loss of interest in life, easy irritation, withdrawal, and inability to participate in regular hobbies and activities. Caregivers dealing with PLWA at the end stage of illness may develop feelings of hopelessness, depression, constant anticipatory grief reactions, and a persistent sense of bereavement. Availability of respite care, palliative care or hospices for PLWA was virtually non-existent. Although not always organized or recognized, a significant amount of care and psychosocial

support was found to be provided by the family.

### AIDS Family Caregiving

#### Uncertainty

Uncertainty is a recurrent theme in studies of PLWA (Weitz, 1989) and their caregivers (Brown & Powell-Cope, 1991). Brown and Powell-Cope (1991) reported "uncertainty" as an important concern for AIDS caregivers similar to that experienced by members of cancer patient families (Davies, Chekryn Reimer & Marten, 1990; Halliburton, Larson, Dibble & Dodd, 1992). Interviews were conducted with (n=53) lovers, spouses, parents of either adults or children with AIDS, siblings, and friends who were taking care of a person with AIDS at home. A substantive theory of AIDS family caregiving was developed utilizing a grounded theory approach. Uncertainty was identified as the basic social psychological problem and transitions through uncertainty, the core category of AIDS family caregiving. Whereas much of the uncertainty reported in the cancer related family caregiving literature was associated with the illness itself (Davies, Chekryn Reimer & Martens, 1990), the uncertainty in AIDS caregiving also pertained to loss and dying, interpersonal relationships, fear of contagion, and the presentation of self. Because the research represented caregiving experiences between 1985 and 1988, limitations were related to the timing of the study. Caregiving was inextricably linked to: a silent government, a vocal gay community, an unresponsive bureaucracy, inexperienced health care providers, and a frightened uninformed and homophobic populace. Replication of the study is required to ascertain any changes in the familial caregiving characteristics in the 1990s.

### Caregiver Burden

The psychosocial impact of AIDS on the family has been compared to that of family caregivers of the elderly and of cancer patients. One concept frequently cited in the research is caregiver burden. No nursing studies were retrieved that examined this concept within the context of AIDS, therefore related literature will illustrate the concept.

Baille, Norbeck and Barnes (1988) examined the effect of perceived caregiver stress and social support on the psychological stress of family caregivers ( $n=87$ ) of the elderly. A stress buffering model of social support was used to test both the main and buffering effects. Perceived stress and satisfaction with support accounted for 32% and 36 % of the variance in psychological distress or depression ( $p<0.001$ ). Years of caregiving and mental impairment of the elder accounted for the 44% and 48% of the variance in distress or depression of the caregiver, with negative findings associated with greater length of caregiving. Although there were no buffering effects for social support, main effects accounted for 19 and 22% of the variance in psychological distress or depression. These findings indicate that caregivers who are caring for a mentally impaired elder, who have been providing care for an extended period of time and who have low social support, are at high risk for psychological distress or depression. The ability to generalize these findings is limited by the nonrandom, predominantly white, female, middle class, spousal, nature of the sample.

Robinson (1990) examined the relationship between social skills, self-esteem, social support and burden in a convenience sample ( $n=31$ ) of adults caring for a cognitively impaired elder. The majority of the subjects were white females over the age of 50 and were either the spouse or adult child of the patient. Caregivers who felt more discomfort in a



given situation were reported to have less available social support. Those who had significantly less aid, less affirmation and less affection, also had less available social support. A significant positive relationship was reported between functional social support and self-esteem. However, cautious interpretation of these findings must be considered in light of the questionable adequacy of the measurement instrument selected. This population of caregivers identified, that even though a person was named in their network, for various reasons they would not call upon this person for help in caregiving. Therefore, the dimension of perceived social support may not be the best indicator of social support. Replication is required with other measures to attempt any generalizability.

Carey, Oberst, McCubbin and Hughes (1991) conducted an exploratory study of the family caregivers (n=49, 25 women and 24 men) of patients receiving chemotherapy. The study was designed to describe the time and difficulty associated with caregiving tasks, examine caregivers appraisal of their situation, and to explore variables predictive of caregiver mood. Family reported giving emotional support as the most time consuming and difficult task. Therefore, it received the highest burden score. Caregiving burden was associated with managing illness-related finances, assisting with household tasks, and providing patient transportation. The nature of the caregiving activity influenced the caregiving burden associated with it. More than half the caregivers reported receiving help from one or more sources, usually family members, but friends and neighbours were also cited. Negative appraisal and age of the caregiver predicted 49% of the mood disturbance. This indicated that those individuals who viewed the caregiving situation negatively, were also likely to experience greater mood disturbance. This finding underscores the importance

of assessing not only how family members are managing specific caregiving tasks, but how they personally perceive the family environment and caregiving situation. The family characteristic of hardiness which reflects the internal strengths and durability of the family and is characterized by the ability to work together to solve problems, was an important mediating variable. A family exhibiting hardiness is characterized as sharing the belief that they can control outcomes of life events and hardships and may view experiences such as caregiving, as opportunities for growth. This finding suggests that the family environment, as measured by the Family Hardiness Index, influences caregivers appraisal of their situation and may mediate the effects of illness.

#### Summary of Review of the Literature

An analysis of the studies attempting to describe and measure the relationships between caregiving, social support, and ill health, burden, strain, depression and other negative variables reveal inconsistencies. Many confounding variables such as personal relationships, attitudes and demographics of those involved and the duration of caregiving make it clear that caregiving and its effects are very complex factors, not easily isolated or measured. Although these studies differ in sample characteristics, sample variables and theoretical underpinnings, the results identify stress/burden and social support as important variables in the future design of studies to investigate the AIDS caregiving experience. What nursing care measures are required in order to assist these individuals and their families, as they progress from one stage of HIV infection to the next?

### Conceptual Framework

The proposed conceptual framework combines the theories of family systems stress (Meister, 1991) and family social support (Kane, 1991). The most important feature of a family system approach is that of a unitary conceptualization of family. Family is assuming more of the responsibility of care of members with acute and chronic health conditions (Ell & Northen, 1990; Tiblier, 1987; Tiblier, Walker & Roland, 1989). The family is thought of as existing within a web of relatives, friends, neighbours and community services or "social network," ready to provide needed assistance or "social support." The constructs of family and social network have a number of commonalities (Meister, 1991). Social network is the more general construct and refers to a constellation of cohesive and regularly activated bonds. Social networks are actually aggregates of social bonds. Family, therefore is a specific form of a social network defined by particular types of bonds.

A number of potent variables are associated with the family as a support network. The family develops a paradigm or framework of shared assumptions, constructs, fantasies, and expectations about the world. This paradigm provides a central organizing force for the family. Stress disrupts the texture of family life and challenges the substance of the family paradigm. The finding that social network support is important in families' responses to the stressors accompanying illness, is consistent with family stress theory (Ell & Northen, 1990). As well, the family has a set of vulnerabilities which alter the effects of stress. Both the type of family organization at the time of a stressful event, and the nature of the larger social environment in which the family functions, have a major impact on the manner in which the stressor is perceived (Meister, 1991). For example, a precipitous loss of a member has a

major impact on the family, but even a normative loss is a powerful variable in family stress. Effective family functioning and equilibrium is critical to engaging in effective coping responses.

The basic conceptual model underpinning social support research is shown in Appendix A. This simplified model depicts stress as being related to health outcome(s) (arrow d) and shows that social support buffers the effect of stress (arrow a) on health outcomes (arrow c). Social support may also have a direct effect on health outcome (arrow c) or may mediate the effects of stress on health outcome (arrow b). Dimond and Jones (1983) have expanded this model to include six classes of variables necessary for a comprehensive model of social support. These include (1) the nature of the stressor, (2) characteristics of the social network, (3) nature of the support offered, (4) perceived adequacy of the support, (5) short and long term responses to the stressful situation, and (6) environmental resources. These are further delineated to demonstrate main or buffering effects.

The conceptual model of family social support as proposed by Kane (1991) is founded on three major assumptions dealing with the nature of the family and the nature and benefits of social support. These assumptions are: (1) the family is a system, (2) social support is a social process and, (3) social support is positive and helpful. Together, Kane's (1991) assumptions regarding family support as a concept are that the family is a system interdependent with other human systems and that family support is a process that is positive and not stressful.

Family social support is defined as a pattern of social interaction characterized by interdependence in a social relationship. Social support arises for a family out of long term

relationships with the extended family, neighbours, coworkers, and community. The model emphasizes that family social support is a process that occurs over the life span. The various consequences depend of the particular needs and life stages of the family. One consequence may be that of increased family well being or health. Social support is not viewed as an outcome or a resource, but rather is a process of interactions through which the family develops versatility and resourcefulness in its functioning. This development exposes the family to a greater variety of goods and services, leading to the experience of health. Family social support makes resources available at the appropriate time and promotes the responsiveness of the social network of the family in crisis. If the family fails to engage in reciprocal relationships or refuses to engage in the process of receiving feedback, it diminishes family social support capacity and limits the resources available by restricting versatility and resourcefulness.

Empirical studies of the relationship between social support and family adjustment to AIDS are virtually non existent. Nonetheless, a large literature supports the conclusion that social support is a critical variable to include in any psychosocial study of AIDS specific behaviour. Support can have a direct effect on health contributing to well being, or may buffer some stress effects (Cohen & Syme, 1985). A review of the social support literature (Norbeck, 1988) confirms the effects of social support. The existence and viability of affective support has been demonstrated in several contexts: adjustment to job loss, prognosis and complication outcomes of pregnancy, hospitalization and maintenance of mental health (Norbeck, 1988). In each instance, emotional support was associated with or predictive of an aspect of well-being. Research demonstrates a modest reliable association between social

support and well being and the strength of that association also is associated with the degree of stress in the person's situation. The theoretical value of social support lies in its dynamic effects within peoples lives and its contribution to adjustment and wellbeing. Lack of social support is suggested to increase stress, which in turn increases the perception of burden in caregiving (Baille, Norbeck & Barnes, 1988; Robinson, 1990).

Based on these theoretical writings and empirical support for these relationships, an eclectic model of AIDS Family Psychosocial Health is proposed. With the growing recognition of the stressful nature of caregiving, researchers can focus their investigative efforts on how to best support the family caregiver. The concept of social support is of central importance in this investigation. Within the proposed model, family social support is considered a coping resource which may mediate stress appraisal as well as mediate caregiving burden. For a situation to be stressful, it must be perceived as potentially harmful, unpleasant or overwhelming (Dimond & Jones, 1983). An assumption underlying this framework is that the caregivers unique perception of appraisal of the caregiving situation is likely to affect emotional health outcomes (Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, Hughes, Chang & McCubbin, 1991). Antecedent variables can be clustered into the categories of a) AIDS Patient Illness Characteristics, b) AIDS Family Caregiver Characteristics, c) AIDS Family Resources and d) the Cognitive Appraisal of AIDS family caregiver. The first three antecedent variables interact to influence the cognitive appraisal of the caregiver. Family social support and the perceived effects of caregiving are viewed as antecedents to the Family's Psychosocial Health Outcomes. Benefits from caregiving such as the caregiver's appraisal of hopefulness (Herth, 1993) and strengthening of the family

relationship are perceived as mediating factors which effect the impact on the psychosocial health outcome. The outcome variable is conceptualized as emotional health or distress. The hypothesized model is depicted in Appendix B.

In summary, the premises that family social support and some of the demands associated with AIDS illness caregiving are unique are central to this hypothesized model. The family's role in providing care to their member with AIDS will depend on a number of factors. The distinct qualities of the AIDS illness substantially influence: the social support network, the way that caregiving is performed, the appraisal of caregiving as stressful and the subsequent impact on the caregiver's psychosocial health. Stress is determined not only by the difficult events in the environment but also by the caregiver's appraisal of the situation (eg. stress or benefits), their resources (eg. social support) and their capacities (eg. age, health) to meet the caregiving challenges. The AIDS' family caregiver's psychosocial health then, is an outcome of many complex and yet unknown interactions.

### Conclusion

This chapter has highlighted the unique nature of AIDS and family caregiving. A framework of Social Support will be used to conceptualize the psychosocial responses of family as they caregive throughout the disease trajectory.

## CHAPTER III

### METHODOLOGY

#### Background: Quantitative and Qualitative Research Designs

Two schools of thought or intellectual traditions, are reflected within the nursing research traditions using quantitative and qualitative methodology (Munhall & Oiler, 1986; Polit & Hungler, 1991; Wilson, 1989). The first school of thought, the positivist tradition, is most frequently associated with the scientific method and quantitative methodology. The second school of thought, the naturalistic or post-positivist paradigm (Ely, 1991), represents the phenomenological (Munhall & Oiler, 1986) or neo-idealist (Wilson, 1989) tradition, and is frequently associated with qualitative methodology. Quantitative and qualitative methods differ in their epistemology, which subsequently influences the research question and design.

The quantitative or reductionist paradigm, involves a mechanistic world view, in which reality is viewed as static and objective, and knowledge is viewed as received (Munhall & Oiler, 1986; Polit & Hungler, 1991). Central to this deductive method are the concepts of: control, generalizability, determination of causal relationships and testing of hypotheses (Polit & Hungler, 1991; Wilson, 1989). This method is most appropriately used when variables are well defined, as in experimental research designs, or where attempts to identify and test differences between groups, causal relationships, and theory are made (Brink & Wood, 1989; Polit & Hungler, 1991).

In contrast, the qualitative or paradigm of constructivism, includes an organismic worldview, with emphasis on the dynamic, holistic and individual aspects of the human experience (Boyd, 1990; Ely, 1991; Marshall & Rossman, 1989; Munhall & Oiler, 1986;



Polit & Hungler, 1991; Wilson, 1989). The qualitative paradigm attempts to capture the human experience in its entirety, through subjective meaning within the context in which it occurs, from those who live the experience. Knowledge about human experience is rooted in a humanistic view and derived inductively by describing, explaining, and interpreting participants or informants feelings, perceptions, and actions (Morse, 1991; Munhall & Oiler, 1986). This research is based on the underlying assumption that knowledge about human experience can only be derived through the informants themselves, using the researcher's self through intensive contact to extract the experience. As Munhall and Oiler (1986) suggest, "subjective experience is not merely a private, inner world; but rather, inextricably bound with objective reality" (p.xiv). Reality is therefore "co-constituted" (Smith, 1989, p.14).

The qualitative method is used to describe phenomena that there is little known about, generate hypotheses, illustrate the meaning of or the descriptions of relationships, understand relationships and causal processes, and develop theory (Boyd, 1990; Brink & Wood, 1989; Polit & Hungler, 1991). Qualitative approaches are indicated when the question concerns complex human phenomena about which we need detailed description and explanation for genuine insight (Boyd, 1990). Qualitative approaches allow for rich descriptions of the phenomenon or experience explored (Morse, 1991).

### Selected Research Methodology and Design

As both qualitative and quantitative research have complementary strengths and limitations, the selection of an appropriate method depends on the researcher's personal philosophy and to a larger degree, the nature of the research question (Polit & Hungler,

1991). The type of research approach selected was determined because of the purpose of the study and the specific research question to be addressed. The main **purpose** of this research was to discover the psychosocial aspects of the AIDS family caregiving experience. Specifically, the research asked "What is" questions and focused on the exploration, observation, and description of AIDS family caregivers.

This study would be characterized as a factor-naming or factor-searching study (Polit & Hungler, 1991; Wilson, 1989). Such studies describe, name, or characterize a phenomenon, situation, or event in order to gain familiarity with it or achieve new insights. Brink and Wood (1989) characterize this as a Level 1 or exploratory-descriptive design, which is appropriate when little or no theory or prior research has addressed the specific variable under study. The decision to use an exploratory design is frequently made when the researcher has no specific problem to study, but is interested in a particular population or experience. Artinian (1988) suggests that the descriptive mode must precede all others. This mode is used to present a detailed description of what is happening in some setting or with a particular group of subjects, so that the point of view of the subjects can be understood. As demonstrated within the literature review, there is a need for exploratory-descriptive research in the case of AIDS family caregiving.

Level 1 or exploratory-descriptive data "are most frequently collected by means of a qualitative field study subjected to inductive analysis" (Brink & Wood, 1989, p. 21). As well, the purposes and uses of qualitative data bear a close relationship to the kind of data produced. One such purpose is that of sensitization, which may be accomplished by providing thick rich descriptions. Boyd (1990) suggests that the purpose of sensitization is

served by qualitative studies to the extent that these studies effectively communicate insights about experiences we need to understand vicariously. I have noted through my clinical practice, including observations and interactions with families of AIDS patients within the hospital setting, that there is need for such sensitization. This research function to sensitize research consumers and practising nurses to AIDS family caregiver's experiences and eventually contribute to developing interventions to help families.

As a result of the review of the quantitative and qualitative research methods, the nature of the research question, as well as my philosophical beliefs, preferences and resources, the qualitative paradigm was determined to be the most appropriate methodology.

#### Ethnography: Selected Research Design

Ethnography, a process and a product, is a method used to develop theories of culture and to produce descriptions of the ways of life in cultures or subcultures (Boyd, 1990; Germain, 1986; Fetterman, 1989). Ethnography is, at its core, a process of mediating frames or meanings (Wilson, 1989). Similar to grounded theory, one underlying theory which guides the ethnographic study is that of symbolic interactionism, which is used to describe and interpret social interactions between people. What people do, say they do, and say they want to do, provide beginning ethnographic information to nurse researchers (Aamodt, 1991).

Ethnography encompasses both exploratory and descriptive designs (Brink & Wood, 1989; Germain, 1986). It is congruent with answering the research question "What is this?" at the factor-searching level of inquiry (Level 1) producing naming or descriptive theory (Germain, 1986, p. 149), as well as "What is happening here" or "What do these happenings

mean" to the people engaged in them (Brink & Wood, 1989; Wilson, 1989).

The ethnographer writes about the routine daily lives of people (culture), where the focus of inquiry are the predictable patterns of human thought and behaviour (Fetterman, 1989). Culture is viewed as a system of knowledge used by human beings to interpret experience and generate behaviour, and as linguistic expressions used by informants during social interactions (Aamodt, 1991). As well, linguistic expressions used by informants during social interactions are the structural blocks of meaning for constructing systems of cultural knowledge (Aamodt, 1991). The focus of data collection is to understand and describe a social and cultural scene from the "emic" (insider's) perspective. Analysis, both ongoing and on completion of the field work, focuses on the presentation of the scientific analysis or "etic's" view.

Fieldwork is the heart of this research design which is exploratory in nature and seeks to extract experience through participant observation and interview (Fetterman, 1989; Morse, 1991; Wilson, 1989). Information gathering proceeds inductively. As the principle research instrument, the ethnographer participates in the events of the subculture and with the help of key informants, looks for connection, patterns, themes or relationships, that have meaning for the people in it, producing descriptive or explanatory theory (Brink & Wood, 1989; Germain, 1986). This process becomes product through analysis at various stages in ethnographic work, notably field notes, the log, and memo's, but most dramatically within the published report (Fetterman, 1989).

Ethnography was selected for this study because the perspective of AIDS family caregivers has not been widely studied within its contextual setting and is congruent with my

intended research question, philosophical beliefs, and personal interest in the development of these research skills. As well, this approach affords a degree of flexibility that permits the revision of questions as new discoveries are made (Germain, 1986). Interpretation of the situation becomes an interactive process and is iterative.

### Research Design

This section discusses the major components of the selected design and includes: participants, research instrument, time, setting, method of data collection, method of data analysis, measures to enhance rigor, and human subject/ethical considerations.

### Data Collection

#### Informants: Sampling and Recruitment

The theoretical population of interest is the "AIDS family caregiver(s)" within the Province of Manitoba. The size of this population is unknown, however an estimate of the population may be made from the numbers of HIV/AIDS cases in Manitoba. Within the province, three women and 100 men were diagnosed with AIDS as of December 31, 1993 and 86% of those infected are urban residents in Winnipeg. As well, 417 Manitobans, 28 of them women, have tested positive for the HIV virus (Manitoba Health, 1994). Because the population of those affected by AIDS is quite small, the accessible caregiving family sample will likely also be small. However, if each PLWA has one family member caregiver, than it is possible that there are presently 100 family caregivers in the province.

According to Brink and Wood (1989) exploratory designs call for small samples that

are chosen through a deliberate process described as theoretical or purposive. Morse (1991) states that in this type of sampling the researcher selects participants according to the needs of the study, based on the informant's experience or knowledge. As well, sampling must be both appropriate and adequate (Morse, 1991). Appropriateness refers to the degree to which the choice of informants and method of selection "fit" the purpose of the study, as determined by the research question and the stage of the research. Adequacy on the other hand refers to the sufficiency and quality of the data. Therefore, the following were offered as inclusion criteria:

Informants/Participants will be:

- 1) convenience sample of 5-10 families who are caregiving to an individual with AIDS within the community setting,
- 2) available, able and willing to be interviewed about their caregiving experience for 1-2 hours, a minimum of twice and a maximum of five times.
- 3) able to understand and to verbally communicate in English,
- 4) available by telephone in order to arrange an interview,
- 5) accessible by car within the perimeter of the city, and
- 6) informants will be 18 years of age or older.

The unit of analysis was to be the family versus family member. In all caregiving situations, however, only one family member was identified, consistent with allowing the PLWA to define the true "functional family" that are providing care. The number of informants was not preset by the researcher. I conferred with the PLWA and the family to determine the number of family members to be included.

Initially, three strategies for sample recruitment were identified. Informant recruitment was anticipated as one of the more difficult aspects of the study design. Informants for this study were anticipated to be difficult to recruit because of the stigma associated with AIDS and because the family caregiving population is unknown. Recruitment of family members may have been negatively influenced by the stigma associated with disease and/or by the fear that confidentiality of the caregiver and the person living with AIDS may be breached. However, my experience has been that of unsolicited expression of support and the stated willingness of families who have participated in AIDS caregiving, to participate in this study. Subsequently, only one method of recruitment was employed. The method for recruitment was the "**solicited sample**" (Morse, 1991).

Informants were recruited through a major hospital. A clinic nurse agreed to speak to the PLWA and asked his permission to have his name released for the research (Appendix C). If the PLWA consented, I would approach him to explain the study and invite the PLWA to identify family member(s) who they believed was the primary person responsible for helping with his care, to participate (Appendix D). The PLWA contacted the identified family member(s) and determined his or her willingness to participate and be interviewed. The written invitation to participate (Appendix D) was given to the family member by the PLWA. Once willingness to participate had been verbally established, my name was given to the family member. If agreeable, the PLWA gave their verbal consent to the clinic nurse to allow her to contact the researcher by phone with the family members name and phone number. I then contacted the participant by phone and gave a verbal description of the study (Appendix E) and obtained their verbal consent for participation. The written explanation of

the study (Appendix F) was given to the participant, and informed written consent (Appendix G) was obtained at the time of the first interview.

The study data then, were collected using a purposive, solicited, non-probability convenience sample of seven AIDS family caregivers. Nine families caregivers were recruited, however, two family caregivers were unable to participate in the study. One family caregiver could not be located and subsequently had undergone the death of her son, and another suffered a medical illness and was unable to participate as a result of undergoing surgery.

### Research Instrument

In ethnography, the researcher is acknowledged to be the primary tool for collecting data (Lipson, 1991). This use of self is often described as "reflexivity." This term refers to observer/interviewers being part of, rather than separate from the data, and capitalize self awareness as a source of insight. Knowledge of the use of self is important, because it influences one's participation in the process, and because one's values, assumptions, and experience influence the researcher's ability to collect valid data. Therefore, as Lipson (1991) states, this instrument must be "tuned" to increase self-awareness. Strategies to accomplish this included the ongoing writing of a field log. To assist with reflexivity, I discussed progress, interpretation of field notes, hunches and log material with a member of my thesis committee.

Consonant with the use of self as research instrument, the specific interview questions evolved through the process of data collection and analysis. From this process, a tentative



interview guide was developed. As well, a nursing peer who was not involved or knowledgeable about the study was approached to provide ongoing critique of my sensitivity to the major themes inherent within the data.

### Time

Data collection was completed within a 12 month period and was prospective, examining the AIDS family caregiver's experience as it evolved. This prospective focus allowed the elicitation of data regarding content and context of the experience. I recognized that the nature of questioning in the study may have affected the caregiver's need for counselling or outside assistance, and I had a list of resources within the community if the family member expressed a need. On one occasion, a caregiver was given information regarding support available within the community. As well, I have throughout my nursing practise and teaching experience, developed an extensive ability to communicate effectively in a therapeutic manner when working with family in the community and hospital settings and drew upon this ability as an interviewer.

### Setting

The interviews were conducted in one of two settings: the home setting, or a mutually agreed upon neutral setting, where tape recording of the interview was accomplished (for example, for one informant the interviews occurred within a private office at the workplace). The interviews were scheduled to accommodate the informant's availability.

### Data Collection and Analysis

The research focused on the discourse of AIDS family caregivers, using an ethnographic methodology. Field work was used as the method for data collection, primarily involving face to face interviews in a natural setting. The interviews were taped recorded, lasted approximately 60-90 minutes and a minimum of two and a maximum of four interviews were conducted. Data collection occurred over a 12 month period. The criterion of "category saturation" also guided the data collection decisions.

The **Ethnographic interview** as espoused by Spradley (1979) was the primary data collection method. The ethnographic interview employs indepth, informal interviews as a particular speech event, is word oriented, and assumes that language and in particular words and phrases are windows into the reality experienced by other people. Ely (1991) suggests that interviews are at the heart of doing ethnography because they seek the words of the people who are studied, the richer the better, so that their situations can be understood with increasing clarity. This type of interview is characterized by Bogdan and Bilken (1982, p. 135) as a "purposeful conversation usually between two people (but sometimes involving more) that is directed by one in order to get information" (cited in Ely, 1991, p. 58). The **major purpose** of the indepth interview was to learn to see the world from the eyes of the informant (Spradley, 1979). In striving to have a closer understanding of people's meanings, the interviewer learns from the informants and seeks to discover how they organize their behaviour. In this sense, the researcher becomes student and the informant the teacher, where both are co-participants.

The three specific skills used in ethnographic interview are preparing and asking

global questions, identifying cover terms, and eliciting descriptors for cover terms.

### Global Questions, Cover Terms and Descriptors

Global questions are open-ended questions and general in nature. In-depth interviews using open-ended questions and nonspecific language to frame the interview were used. For example, "Can you tell me something about what it was like when you first learned your family member was HIV positive". "Can you tell me about your life since you began caregiving". "How has this affected you." "What did you mean by..." "You said you...tell me a bit more about that please." The use of probes will be used to facilitate the discussion.

The interview was purposely left flexible to allow the informants to relate information that was meaningful to them, and for the development of questions from the ongoing data analysis. The informant's story then serves to structure the interview as it unfolded (May, 1991). Unstructured interviews allow the interviewer considerable freedom in exploring whatever seems important to the informant, and promote what Brink and Wood (1988) call the likelihood that responses will be spontaneous, self-revealing, and personal. The use of informant-specific language (cover terms) was adopted and employed as this became known, to facilitate the discourse. Cover terms are the key words or phrases used by informants in response to a global question.

During the initial phase of fieldwork, a broad overview of the caregiver's situation and descriptive accounts were elicited. Demographic data was collected using focused, closed-ended questions (Appendix H). The first interview focused on the establishment of trust, reviewing the purpose of the study, and obtaining informed consent. I invested in building a

trusting relationship with the caregivers. The development of trust between myself and the informants was instrumental in generating greater depth of data. Data was collected only by myself and I developed the interview guide. The presence or absence of the PLWA was left to the discretion of the family and PLWA, and field notes regarding this aspect of the interview were taken into account in the analysis process. For one family, the PLWA was present and participated in the interview process during two interviews.

In the second interview, more structured questions (descriptive, structural and contrast) guided by a tentative interview guide were conducted with informants (Appendix I). Such questions led to the elucidation of descriptors, or the fine attributes of the cover terms. Cover terms later became the foundation for follow-up global questions. The interview process, then, entailed cyclical use of open and closed ended questions to complete data collection.

As "the tasks of the interviewer include providing focus, observing, giving direction, being sensitive to clues given by participants, probing, questioning, listening, amalgamating statements, and generally being as involved as possible" (Ely, 1991, p. 59), interviews were tape recorded. This freed me to be attentive to the informants discourse and to focus on the development of the conversation.

Following each interview, the interview were transcribed verbatim, using the Ethnograph (Seidel, Kjolseth, & Clark, 1985). This word processing package facilitated the process of data analysis and retrieval as it organized typed data in a logical, sequential fashion. Following the transcribing of the interview, tapes were reviewed to help me recall the experience, expand the detail and provide perspective on the discourse. The audiotapes

provided the nuances of the person's voice and were used to enhance the richness of the printed word.

### Memoing and Field Log

In addition to interviewing, memoing and the use of a field log were employed as additional sources of data. Field notes were taken directly following the interaction. Taking notes in the field was essential to the development of the written log. Ely (1991) suggests that a field log is the repository of all data that have been gathered through participant observation and interviews, including transcripts of interviews. The written log entries were numbered to provide a chronological record of what was learned and include insights into the process and product. It afforded the opportunity to use reflexive jotting, to "face self as instrument" through a personal dialogue, and provide what Bogdan and Bilken (1982) call "data about data" (cited in Ely, 1991, p. 70).

Analytic memos or researcher's memos, were used to move the methodology and analysis forward. Essentially, analytic memos can be thought of as conversations with oneself about what one has learned, what has occurred in the research process, the insights this provides, and the leads these suggest for future action (Ely, 1991). These memos are written about entrées in the log and they themselves became part of the log.

### Analysis

During the field work period, the interviewer searched for patterns or recurring themes as part of the process of constant comparative analysis (Burden, 1991; Grove, 1988). Content analysis constituted the main analysis effort. The process was iterative and cyclical, building on successive interviews, through questioning, listening, probing, comparing and contrasting, synthesizing and evaluating information. The tape recorded interviews were transcribed verbatim immediately following the interview and assisted with the analysis. Triangulation of data was ongoing, occurring through the use of the constant analysis of data, using the multiple data sources of audiotaped interview, interview transcripts, fieldnotes, and log (Knafl & Breitmayer, 1991). The use of comparative questions such as "some families say.." facilitated the crystallization of my observations and assisted with data triangulation.

Verbatim quotations were used to illustrate the typical or characteristic experiences described. The analysis was guided by the concept of mini-ethnography as described by Kleinman (1992). Quotations have been used to allow the reader to judge the quality of the work and to assess whether the data are used appropriately to support the conclusions. Themes, categories, similarities, differences and hypothesized relationships among variables were identified. The findings offer a beginning theoretical framework that can be tested and validated in subsequent hypotheses testing. Publication of findings in a peer reviewed referred journal is anticipated.

### Measures to Enhance Rigor

In contrast to the rigor criteria appropriate for research in the positivism mode, that of reliability, internal and external validity, and objectivity, the parallel criteria for evaluation of qualitative research are that of **trustworthiness and authenticity** (Guba & Lincoln, 1989). The trustworthiness criteria consider the unique contribution to goodness or quality by the nature of the hermeneutic process itself, while the authenticity criteria are embedded in the basic belief system of constructivism itself. Lincoln and Guba (1989) identify four criteria that are used to evaluate trustworthiness and authenticity within a constructivist inquiry: credibility, transferability, dependability and confirmability.

#### Credibility

Truth value in naturalistic inquiry means that the "reconstructions that have been arrived at via the inquiry are credible to the constructors of the original multiple realities" (Lincoln & Guba, 1985, p.296). Truth value is analogous to internal validity in positivism research and is achieved in research conducted within the naturalistic paradigm by achieving credibility. Sandelowski (1986) suggests a study is credible when "it presents such faithful interpretation of human experience that the people having the experience would immediately recognize those descriptions or interpretations of the experience as their own" (p. 30). Truth value or credibility resides in the discovery of human phenomena or experiences as they are lived and perceived by the participants.

Truth value or credibility can be attained through the use of prolonged engagement, persistent observation and progressive subjectivity (the reflexive journal) (Guba & Lincoln, 1989). Prolonged engagement occurred through sufficient investment of time with the

informants, serving to establish rapport and build the trust necessary to uncover constructions of reality (Lincoln & Guba, 1985). The informants participated in determining whether the two interviews were sufficient to capture their experiences. A joint decision for the need for further interviews was made by the investigator and the informants. For several informants, their experience as AIDS caregivers had ended as the death of the PLWA had occurred. The researcher brings to the process her own subjective and experiential views, which may add to the richness of the description and data. The use of a reflexive journal was used to capture these perspectives. This process of monitoring the researcher's own developing construction is referred to as progressive subjectivity (Guba & Lincoln, 1989).

Lack of development of trust can be considered a potential threat to the credibility of the study (Brink, 1991; Fetterman, 1989). The ability of the researcher to be natural and honest assists in the development of trust between informant and researcher. In this study, I engaged in repeated and prolonged engagement, established informed consent and confidentiality of the study participants thus addressing this issue. Persistent observation was used and enabled the researcher to add depth to the characteristics and elements identified as relevant to the research question.

### Transferability

According to Guba and Lincoln (1989), transferability may be thought of as parallel to external validity or generalizability, where findings from one study can shed light on the situation in another setting. It is based on similarity between two contexts, what Lincoln and Guba (1985) call "fittingness," and is defined as the "degree of congruence between sending and receiving contexts" (p. 124). The major technique for establishing the degree of



transferability is "thick description" in which the presentation of the data is complete enough to facilitate transferability judgements on the part of others who may wish to apply the findings of the study. In order to provide enough information about the context of the study so that another investigator has a basis for deciding whether transferability is feasible, the investigator provides an account of the process of analysis with examples of the original data and a description of contexts within which the study was conducted. Thick description was accomplished through the written presentation of the informants' narratives.

### Dependability and Confirmability

Guba and Lincoln (1989) describe "dependability as parallel to the conventional criterion of reliability, in that it is concerned with the stability of the data over time" (p. 242). Dependability is achieved by documenting the logic of process decisions. The technique for judging the logic of process decisions is the dependability audit.

Confirmability, the parallel of objectivity, "is concerned with assuring that data, interpretations and outcomes of inquiries are rooted in contexts and persons apart from the investigator" (p. 243). This means that data can be tracked to their sources and that the logic used to assemble the interpretations into structurally coherent wholes is both explicit and implicit in the narrative of the findings.

The confirmability audit is the usual technique for confirming the data and interpretations of a given study.

The confirmability and the dependability audit are carried out together, as an "audit trail," which describes the investigator's decisions regarding both process and methods. I will keep the study's raw data (reflexive journal, audio tapes and transcriptions of the audio tapes) for a period of seven years as a part of the audit trail. As well, sharing of the data with my thesis chair during data collection and analysis assisted with the verification of the accuracy and promote the consistency of the process and product.

### Ethical Considerations: Protection of the Rights of the Informants

The proposal for this study was submitted to the Ethical Review Committee of the Faculty of Nursing, at the University of Manitoba. Ethical approval was obtained before

seeking informant participation. Approval for request to access to St. Boniface General Hospital as a nurse researcher was also obtained following Ethical approval.

Every attempt was made to ensure that participants were fully informed and their rights were protected. The informants seeking to be part of the study, telephoned me in response to the invitation to participate. Potential participants received a verbal description of the study when they contacted me by phone. Questions, concerns or ambiguities regarding the study were clarified to the potential informant's satisfaction at that time. If they verbally agreed to participate, they received a written explanation of the study when we met in person. At that time the informed written consent was obtained. It was stressed to the participants both verbally and in writing, that they could withdraw at any time and they could refuse to answer any questions.

The psychological and physical comfort of the informant was carefully monitored during interviews by observing non-verbal and verbal cues. The interviews took place at a time and place convenient for the informants and myself, usually the home, but for one respondent, a private office at work. If an informant became distressed, the tape recorder was turned off and a joint decision was made as to the appropriateness of continuing the interview.

A number of strategies were used to ensure that the confidentiality of all participants was protected. All interview information was kept confidential. To assure anonymity, participants were assigned code numbers that were used on all tapes and transcribed interviews. Names and locations will not be published in any written form emanating from the study. The names of the participants appear only on a master sheet of codes and codes

were used on the consent forms, both of which were kept in a separate locked filing cabinet.

I am the only person who has access to these codes. Audio tapes will be kept for a period of seven to ten years in the locked files.

Transcripts and audio tapes contain only a code number, which can be matched to a name. Access of audio tapes was restricted to myself and my thesis Chair, Dr. Linda Kristjanson. Access to transcripts was restricted to the researcher, Dr. L. Kristjanson and my thesis Co-Chair, Dr. David Gregory. Dr. J. Campbell had access to grouped summaries of the data. In the findings chapter of this study, only code numbers appear with transcript excerpts and caution is exercised to ensure that identifying facts are not included with the excerpts provided. Informants names as they appear in the text have been changed to protect anonymity. In summary, confidentiality and anonymity were achieved by the coding and access methods described above.

### Conclusion

I have explicated the methodology for the research design of my thesis topic. The methodology was qualitative in nature and made use of the ethnographic interview. The study informants were recruited employing a solicited sample. Data analysis was ongoing and the findings illustrate the similarities of the AIDS caregiving family. The rights of the participants to confidentiality and protection were addressed.

## CHAPTER IV

### ANALYSIS

#### Introduction

In qualitative studies, the researcher serves as the "instrument" through which data are collected (Boyd, 1993; Rew, Bechtel & Sapp, 1993). As the research instrument, the interviewer uses responses of the participant to guide data collection, probing for further information for depth and clarity. Although the interviews are guided by a tentative interview schedule, the interviewer must ascertain a balance of structure and flexibility (Swanson-Kauffman, 1986). The format, timing and sequence of questions may change as the data collection process continues. The researcher maintains control of the interview, but there must be sufficient flexibility to respond to important content responses and general nonverbal cues from the participant. Most interviews begin with open-ended questions and eventually narrow the focus as clarifying questions are asked and themes emerge.

The interview situation carries with it a unique intimacy that is shared by the interviewer and respondent (Sorrell & Redmond, 1995). Respondents known in ethnographic research as informants, can reveal information during an interview that they would not discuss in a questionnaire, evoking buried memories often accompanied by strong emotions. Since the informant may be unprepared to find their words mixed with tears, it is important for the interviewer to appreciate the intimacy of the situation and to plan time during the interview to establish and maintain rapport (Sorrel & Redmond, 1995). Good informants are not just those who have experienced the phenomena under study, but those who are willing and able to discuss and examine their experience (Morse, 1991).

Ethnographic interviews are designed to discover cultural meanings which exist within a social group, emphasizing interaction, social context and the social construction of reality (Lowenberg, 1993). The broad concept of culture used within this methodology, may be viewed from two distinct perspectives. The materialistic or "etic" perspective views culture as the totality of a social group's observable behaviour, customs and daily life. The ideational or "emic" perspective view defines culture in a cognitive way and refers to ideas, beliefs and knowledge which are characteristic of a group of people (Fetterman, 1989). This latter view requires the collection of linguistic research data from individual group members to help the researcher understand why group members do what they do.

The interview is the most important data collection tool for the ethnographer (Fetterman, 1989) being depicted by Spradley (1979) as a "series of friendly conversations". However, these informal conversations have a clear and specific research agenda. This informal approach is used by the interviewer to discover categories of meanings in a culture, such as the culture of AIDS caregiving families. Of interest is what people think and how one person's perspective compares with another. This comparison helps the interviewer to identify shared values among members of a cultural group.

Ethnographies describe the social reality of a particular group and focus on the felt experience (Kleinman, 1992). Kleinman (1992) suggests the ethnographer seeks to develop an appreciation of the meanings of the illness and care, beginning with a description of the informants' local moral world. Within each local world, the effect of the family, workplace, medical care, and other relevant institutions are related to the interpersonal experience. To best illustrate this reality, descriptive narratives are presented to allow for the informants to

be portrayed within the context of their humanness. Insight is gained into how the informant understands and visualizes his or her experience (Sandelowski, 1991).

The local worlds of the seven families in this research project are depicted in the analysis in two sections. The first section presents descriptive data regarding the informants. A brief orientation to each family caregiver is provided through a descriptive contextual profile. The intent of the profile is to provide readers with a lens through which they can view and develop a perspective of the informant's local moral world. The profiles contain data elicited through the interviewing process and data which may not have been captured within the formal interview, but obtained through fieldnotes and observations. A perspective and understanding of some of the intricacies of the caregiving relationship with the PLWA's is evoked. The contextual profile is not a complete composite of the families historical and personal data, but rather a framework through which practical knowledge gained from the family informant distinguishes the uniqueness of each caregiving situation.

Raw data from the informants' transcribed interviews are examined in section two. Transcribed verbatim interviews underwent content analysis. Content analysis is the process of identifying, coding and categorizing the primary patterns in the data (Patton, 1990). Like all research, the raw data is reduced, in this case to conceptual categories described in words (MacKenzie, 1994). The transcribed interviews were coded as words, phrases and themes written in the margins of the transcripts. Transcripts of the interviews and field notes were reviewed to inductively identify categories or themes of responses based on similar patterns in the data. Thematic commonalities were derived from the analysis of the informants' personal perspectives and experiences. Based on the qualitative assessments of the data,

inferences, conclusions and a proposed set of understandings about the nature of the impact of AIDS on family caregivers is presented. Several of the analysis matrices, listings, tables and diagrams detailed in Miles and Huberman (1994) were useful throughout the research process, as helpful techniques for data reduction and organization. Detailed, thick descriptions with direct quotations from the informants are used to illustrate the thematic and substantive coded data.

### **Section I - Family Caregivers As Informants**

A brief orientation to the seven informants is provided in advance of their profiles. Demographic data regarding age, relationship, education and occupation, is grouped and presented in Table 1. Seven family caregivers, four females and three males completed the study. Informants ranged in age from 29 to 74, the modal age was over 50 years. The majority of the caregivers were female (n=4).



Table 1

Demographic Profile of Informants and Caregiving Factors

<u>Age</u>		<u>Length of Caregiving</u>		<u>Gender</u>		<u>Education</u>	
<35	3	<6 months	4	males	3	Less than High School	2
35-55	3	6-12 months	1	females	4	High School	1
>55	1	13-48 months	2			More than High School	4

The informants represent quite different socio-economic backgrounds. The informants were: retired and living on a pension (1), a homemaker (1), living on social assistance (1), on disability (1), and employed full time in professional and semi-professional occupations (3).

Table 2Family Constellations

Informant	Marital Status	Relationship to PLWA
Isabelle	Widowed	mother
Jeremy	Single	friend
Margaret	Single	friend
Freda	Married	mother
Lizzie	Divorced	friend
Robert	Single	former lover
George	Single	former lover

One of the informants was widowed, one divorced, one married and four were single. All of the informants lived with the PLWA and within a large urban setting in Manitoba. All of the family caregivers care recipients were gay males. Further description of the informants is presented in their profiles.

Within the analysis, the source of the informant's data is identified. All passages from the informants' transcripts end with the notation system outlined in Table 3.

Table 3

Transcript Notation


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<u>Informant</u>	<u>Code</u>	<u>Number of Interviews</u>
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Margaret	100	3
Isabelle	101	4
Freda	102	2
Jeremy	103	2
Lizzie	104	3
George	106	2
Robert	107	2

For example, within the analysis, a textual excerpt from the informant Margaret (100),  
interview 1, lines 67-75 will be noted as: [100-1, 67-75].

## Section I - The Context of Caregiving: Family Profiles

### **Isabelle**

Isabelle is a retired mother in her seventies. She jokingly describes herself as being a caregiver all of her life. Isabelle proudly states she has raised eight children, five boys and three girls, ranging in age from 28 to 57 years. Her family constellation is large, with more than 30 grandchildren and great grandchildren living throughout Canada. Within her immediate family, two daughters reside within close driving proximity. Her thirty four year old son Jerald, who is living with AIDS, presently lives with her in a war-time two storey home.

Isabelle appears young and full of vitality despite her chronological age. Although retired, she has remained active in the community by bowling, participating in choir and prayer group meetings, and attending church on a daily basis. Once a week she has her hair done and nails manicured. She attributes her joy and zest for living to her commitment to family. In particular, she fondly credits her involvement with her youngest daughter and new granddaughter, as keeping her young. Isabelle's joys of motherhood have, however, been tempered by life's hardships. In 1969, her mother moved in with the family from overseas. The following year, Isabelle's husband died, resulting in Isabelle's need to return to full-time work in a local hospital to support her family. Isabelle states that it was during this period of transition that Jerald began to develop a gay identity.

I think he, when he, when he, that's another thing. I can tell you exactly when he told me he was gay. I may be 74 but I've told you stories over and over

and over and he called me a liar, "Never happened that way. Gus told you." I said, "No he didn't". I said, "I was sitting on the couch and I'm saying you came and I said you sat beside me and I was knitting" and I said you said to me, "Mom, I've got something to tell you" and I said, "I knew what you were going to tell me." "Yeah, because Gus told you." I said, "No he didn't. Gus never said a word to me because it was not until after he told me that" and I said "You told me you know." He didn't say he was gay but I knew what he was talking about. And I said to you, "Jerald, go out." And I phoned Father Joe, my friend and I told him and apparently Father Joe knew [101-3, 248-276].

Although this knowledge is long standing, Isabelle still emotionally relives Jerald's disclosure which occurred some thirteen years ago as if occurring in the present. It appears that she is still coping with her son's "coming out".

Jerald was living in Vancouver prior to reentering her home in July of 1993. His return to live with Isabelle coincided with her caring for her aging mother. At first, his return to the home was related as relatively smooth.

Well, as I told you, like when he came in, he was fine and everything was really, was good. No problems or, you know. Uh. He did have outbursts of anger and I was very sensitive. I was looking after my mom too. She was 93 so I had two people that were (who), needed my attention. [101-1, 51-58].

Upon reflection however, she relates the difficulty of his reentry and her own emotional response.

From the day he came to my house up to last November, I don't think there was a day went by he didn't have me in tears. [101-1, 65-68].

In coping with her son's return, she identifies issues which revolve around his need to control the routines of day to day living and the care associated with her aged mother.

Uh, he came in July. It was let's see, he came up from the Fringe Festival because he's in the theatre. And, like, I, personally, I think I keep a clean house but according to him, everything's wrong. Nothing's right. Uh. Mom didn't do anything right, she was 93 for God's sake. She put up what she could. She had a little problem with toilets and, you know, she'd jump and

maybe she didn't get there, you know. I'd go and look after it. Maybe I didn't get time to maybe wash around the toilet and that. He'd walk in. He'd blow his top. And I didn't like him saying this to mom because mom and I had been living on our own, like since my daughter got married, and we were quite happy and he come in. Then he came in and he wanted to be in charge. He wanted to take over, take over everything. [101-1, 73-100]

Isabelle eloquently articulates Jerald's anger and need for control as a result of a disease where uncertainty is paramount. She associates the loss of control of his own body as increasingly directing on his need to control daily occurrences. As his control behaviours becomes more pervasive, she experiences her own losses and a sense of nothing being right.

I felt that, um, he had control, he was controlling everything. Uh, I was, I didn't feel free in my own home. I felt like the, the visitor. Because no matter what I went to do, it was wrong [101-2, 68-76].

The sense of being imprisoned within her home parallels Jerald's imprisonment with AIDS in his own body. The strain becomes so intense, that she feels she is "losing her mind." She wonders whether her ability to cope with her son's anger would have been different if she was not also caregiving to her aged mother.

If, if I should have been alone when Jerald came home, I probably would have handled things a lot better. But you see I had mom here. And like, when he would make me mad and hurt me she'd say, "I don't see him doing anything wrong." That was like I was beginning to wonder, am I losing my mind? [101-2, 993-1007].

The living situation does not improve following Isabelle's mother's death. Within the month, Jerald's physical status deteriorates, resulting in his need for two hospital stays. The mounting tension becomes unbearable. Isabelle feels unable to tolerate their living arrangement and during the first hospitalization, requests that he move. Initially, Jerald lived with a nurse relative, but the arrangement is short lived as he is rehospitalized and the relative relocates to the north. A month long hospice stay follows, which is described by

Isabelle as a "complete disaster." Concerned for Jerald's well-being, Isabelle again accepts her son back into her home. Both have recognized this period as a time of growth for their relationship. There is a new perspective and a determination not to let things hurt.

Isabelle identifies both the development of new coping strategies and others of long standing, which help her with life's transitions. A connection with religion has served a long standing role in Isabelle's life. She views her faith as source of strength in accepting life's passages and losses. As a mother, she has previously survived the pain of bereavement, predeceased by a son at the age of 47. As well, she has survived the loss of her spouse. In addition, in November of 1994, after more than twenty five years of companionship and cohabitation, Isabelle's mother passed away. She relates with shock that it was so quick, despite the recognition that her mother was 93 years of age and in declining health. Religion, although a comfort in times of need for acceptance, has also served to remind her of family's lack of acceptance of her son's lifestyle.

Oh gosh, yes. (sigh) My grandson was going to make his confirmation so he was going to be a sponsor for my grandson and when my oldest son heard that he was gay, he said, gay, he said, "I don't want you to be sponsor for my son." [101-3, 294-300].

She recognizes that there is family stigma associated with Jerald's being gay.

Within the past year, in the space of one month, Isabelle has experienced many transitions.

In a month, in a month, I have had a friend of mine passed away suddenly and I had a grandson got married. And I had, my daughter had a little baby girl and then my brother passed away in Ireland. You know, all that in a month. [101-3, 741-746, 750.]

In spite of these stressors Isabelle perceives her life as positive and herself as healthy. She

recognizes her need for help and ensures she obtains it. She periodically attends a family support group and has sought the assistance of a group providing care within the community. Her son recently had a Peripherally Inserted Central Catheter (PICC) line inserted and his health has stabilized. Isabelle's daily living now reflects a recognition that there is an emotional limit and a way to cope with her son's AIDS diagnosis and his anger.

You know, we've had enough of that now today. I think maybe if I'd tried that approach, that I think that I can handle it. [101-1, 1314-17]

### Jeremy

Jeremy is a mid-thirties, striking, tall, gay male with model like features. He is currently not working outside the home because of both circumstance and choice. He describes his unemployment as related to back problems and society's stigma associated with AIDS and his homosexuality.

And uh, the person that I was working for, he was going to fire me if I did not quit. I did have to quit cause I just couldn't go on any more with my back but he was ready to fire me because he was getting complaints from the other workers that they didn't want to work with me. It wasn't that I'm not a good worker you know, and it wasn't, it was just cause they knew I lived with somebody that was HIV and they were afraid to work with me cause they were going to catch it. [103-1, 281-293].

And my sexuality was a big, you know, played a big part. [103-1, 346-347].

The stigma of his being gay affects his choice to not work where there is homophobic fear and "guilt by association" because of his caring for a PLWA.

Jeremy has been involved in Dean's care for the past four and a half years, having met him when he was contracted to do some work for Dean. This chance encounter became



the impetus for Jeremy's caregiving.

Actually when I met him and as soon as he started talking to me I knew that he was HIV. And, uh, I just came in the door and I saw that he wasn't living properly. He opened the fridge and I knew that he didn't have food as I thought I would want in my fridge. So ever since that day, I made sure he had some. And it was about a year and a half later that I moved up. He put his house up for sale and I put up my house for sale, whichever house sold first, then the first would have to move in with the other. [103-1, 378-390].

That Jeremy "moved up," is a reflection of his belief that caring for Dean has made a positive difference in his life. He is very committed to Dean, becoming involved because of his compassion and regard for Dean's well-being.

Jeremy has been involved in community support to PLWA for the past five years, but he has never before lived the daily experience of AIDS.

I am with this, uh, with home support, I and there's about 20 volunteers or so, and we, the most we can deal with is uh, a few people. We don't, we can't take care of six if we don't give them 100%. If we can't give 100% then, then there's, will not take any more people to take care of. I've dealt with quite a few besides living here. [103-1, 426-435]

His five years of working with the group has helped to prepare him for this undertaking.

Oh God, I was afraid. You know, I know how it feels to be afraid. Not understanding about AIDS. Because I was scared to touch them, I was scared to um, I was very paranoid. And I wouldn't feel comfortable going into the same bathroom as him. I was like anybody else, you know. So, I educated myself that way and this is where I am today, you know. [103-1, 460-469]

His fears concerning caregiving are dispelled through education which have been obtained through life's school of experience in AIDS caregiving.

You look at them because they are living with AIDS, but then they might die tomorrow. I've seen, I went to the point to get rid of some of my, like being scared of moving in here and Dean dying on me. I wouldn't know how to deal with it. So an opportunity came that somebody needed care 24 hours a day and I took midnight until 8 o'clock in the mornings, 8 hour shifts. And I saw this person desecrated from it. He was a very nice looking guy and I saw him turn

into the most ugliest thing. He was a skeleton with, as if you sprayed something and I could see the skeleton myself. To me that made me, gave me the power that I needed if anything ever has to, like anything happens here. Otherwise, I'd be afraid, I thought I would be afraid. [103-1, 574-593]

Ironically, this same group was preparing to take on Dean's care, when Jeremy had his chance encounter.

Jeremy has become Dean's live-in advocate and friend, describing Dean as his "number one." According to Jeremy, their relationship is perfect, the only thing missing is sex. Jeremy wishes every couple would get along as well as they do. Much of Jeremy's daily life evolves around ensuring Dean's well-being, both physically and emotionally. Jeremy equates this responsibility as "his child." In the fourteen years of Dean's living with HIV and AIDS, he has lost many friends, his lover, his driver's licence, his ability to work as a nurse, and his judgement and eyesight are deteriorating. Jeremy's commitment is ensuring that Dean's life is one of quality. Jeremy's enjoyment of the outdoors has been creatively captured as an outdoor heaven for Dean, noted by a lavish floral garden and a stocked fishpond. Fear has limited Dean's ability to venture out of doors. To their neighbours they project the image of two friends sharing a home. Having previously been assaulted in the neighbourhood, Jeremy takes care to protect this image.

So that's why you have a 6' fence, and you, you adapt to life inside of these walls, you know your lifestyle. And then as soon as you walk out the door it like you take a big breath and hold it in. And it's like um, now you have to pretend you're someone else.[103-1, 356-363]

Jeremy's cautious attitude has been developed after years of suffering the stigma of his sexuality, especially at the hands of his own family. His father was physically and verbally abusive toward the family, and threatened to kill any member with his bare hands if

they were gay. It is, however, the lack of his mother's acceptance when he was coming out and the loss of unconditional love that affects Jeremy.

When I needed help, uh, my mother told me, "Here's a knife, go kill yourself," you know. Well, thank you very much, you know. [103-2, 1428-1431]

There wasn't a nice word out of her mouth. It was always, "You're sick, you're filth, you're this, you're that." But I took it and I took it for so long. And I think that's why I like to, I need to be needed. [103-1, 1092-1097]

I need to be accepted and I wanted to be accepted by the one that I loved the most but..And you know, this is 16 years later and she's not accepting it, well then I guess you might as well just let her go on, you know, your way. [103-2, 1479-1485]

The struggle for acceptance seems to be a pervasive issue in Jeremy's life. He identifies his suffering positively and credits it for his involvement with home support and with caring for Dean.

The reason, why I did and I'm doing what I'm doing, I felt like I was unwanted. And I don't like that feeling. I, I like to be wanted you know, like I need that. [103-1, 375-378]

Jeremy stresses that although he himself is not HIV positive, he undergoes testing every six months to rule out the uncertainty of his past lifestyle.

But I still think that I'm going to get it though. It's something that it's always been me, you know, so. I've had lovers from the past that are HIV. Uh, there's a long period in between since we broke up that they could have got it then after, you know. But it's still, it's still there, you know. It's still that ghost in the closet.[103-2, 1352-1361].

For the time being Jeremy lives his life as one of the "worried well," fearing what would become of him if he tested positive and developed AIDS.

Like, would I be able to live with, you won't agree with what I'm going to say but uh, I don't think I could live with it you know. And if I have to live like Dean does, I would die very fast. You know, like I don't think I would kill

myself but, uh, I think it would just kill me by being at home.[103-1, 493-497]

He poignantly summarizes his perspective of living with AIDS from his experience as an AIDS caregiver.

And I wish, God, if that's one wish, I hope not. Like don't ever let me get that [AIDS]. [103-2, 1363-1365].

### Margaret

Margaret is a female in her late twenties in the process of becoming. Her two year journey toward being transgendered is nearly physically completed, with the final surgical intervention awaiting medical approval. Margaret identifies numerous factors which she perceives to be delaying the surgery. The process for concurrence by three medical doctors entails psychological evaluations and the passage of time to reap the benefits of hormonal therapy. As well, she is unable to have the surgery performed in Canada and lacks the financial means necessary to have the surgery performed in the United States. Perhaps the unstated overriding factor is her own HIV positive status.

I think it's just basically, um, that finding a doctor to perform a change on someone that was HIV positive was a battle on its own, you know. There's no one in Canada that'll perform, that'll do it. No one. [100-3, 867-872]

She anguishes awaiting approval. The mental challenge of waiting to embark into her new life being "straight" wears on her daily.

Ah, yes that alone, you know, adds a lot of stress too and at one point during one month there I was so, ooh (chuckle) I was so stressed out it was awful. Cause, it was, I couldn't see any point in me just carrying on going through this change and not having the complete change, you know, just because of the

fact that I was HIV positive. [100-3, 1001-1009]

Margaret's ability to carry on is lived within a philosophy of taking one day at a time.

Margaret lives with Harry her gay roommate, in an older duplex on a tree lined street within the downtown area of the city. Harry who is in his early thirties, moved in with Margaret following the ending of a live in relationship. This coincided with Margaret's loss of a lover and roommate. They share the expenses of living, emotional and otherwise.

It's me that's going through the roller coaster ride the past couple of months and it's like, I'm glad he's here [chuckle]. We help each other out. [100, 72-75, 80].

Their decision to become roommates was a mutual felt need for shared expenses and companionship. A supportive friendship quickly became established.

Margaret and Harry share similar family of origin characteristics, growing up in the same rural community, sharing the same cultural heritage, and speaking the same mother tongue. Margaret's immediate family consists of nine brothers and three sisters, who range from 28 to 47 years of age, the oldest being married by the time Margaret was born. Margaret states that her family is supportive of her and that she has maintained strong family ties. This contrasts Harry's family circumstances, where although he is "open" about being gay, his family is having difficulty accepting him.

From what I hear, I think I would be very stressed to have a family so..I don't know, that's not as understanding as mine would be. He talks a lot about his family. How rednecked they are even in today's society and it's like he said, they don't realize that they have children growing up too. [100, 454-464]

Margaret maintains her family relationships at a geographical distance. In the past year, she has visited her parents once. Although Margaret has discussed her perception of herself as female since she was about two years old, the reality of her transformation only recently

became physically evident for her parents.

You know they never really, it never really dawned on them that it would go this far and, you know, what they could have done to help or, you know [100-2, 293-296].

Integrating the changes in her physical appearance, she states her parents have now offered to support the financial cost of the surgical change.

Margaret relates that she can openly discuss gender issues within her family, and demonstrates a concern for the welfare of the next generation.

My nephew, he sat down and we talked about it (sex) yesterday, like asking about, one's old enough having sex already, and I says, "Where's your condoms?" I bought him a box of condoms. My brother kind of laughed. I says, not to mean it as a joke. Like if he can't supply his condoms and he can't afford them. I've have lots at home (chuckle) Not that I'm sexually active myself, but, it's like, you know. There's, I've seen too many people go down in all kinds of diseases such as not only AIDS but. [100, 468-487]

She feels a responsibility to ensure her family is aware of safe sex and that they have the means to practice it.

Where Margaret works at educating her biological family, Harry works with the gay HIV positive family. His roles are diverse and plentiful, including being an advocate, peer counsellor, educator, and activist for the HIV/AIDS community. Together, Margaret and Harry entertain in the gay community to fund raise for AIDS-related projects. Recently, Harry has become involved in the coordinating of HIV/AIDS related services under an umbrella group. Margaret states that Harry is her main AIDS information support.

Although acquaintances for eight years, Margaret was unaware of Harry having AIDS, a disclosure he made upfront and prior to Margaret's decision to accept Harry as a roommate.

He say's, "Well, there's something, a few things I should tell you." It kind of shocked me because he didn't, it never dawned on me that he might be sick.[100, 165-167]

Harry readily shares that he has been living with HIV since "they began testing it." An illness event in 1980 is pinpointed as the time of seroconversion. A diagnosis of AIDS was established in January of 1990, a fact he is open about. His well appearance is deceiving to most observers. Harry's openness as a PLWA contrasts Margaret's privacy and feelings about disclosure. Her HIV seropositivity was first established in 1988 and is related during our third interview.

Well, the first time I tested HIV positive, I went to a group that were meeting. And, um, I didn't see it [stating HIV seropositivity] necessary because I guess in the gay scene, it was like if you're seen at a meeting then you know. Just always an assumption and it's like, I don't need that in my life right now. Got enough stress to deal with than having people point fingers and going, oh, you know, that she's HIV positive or, you know. It's not anyone's business [100-3, 708-718, 722]

In the course of day-to-day living Margaret safeguards her privacy, recognizing the additional psychological stress it would generate to be "open." She copes with the psychological stress of her HIV positive status by denying it the ability to take over her life.

I just don't think I am [HIV positive]. Well, not that I really don't think I am, I just don't live my life with HIV on my mind all the time. I have other things in my life and other priorities and, to me, it's just another illness. Don't treat it with a lot of stress or with less stress or whatever, then you live longer. [100-3, 774-782]

Observing several of her friends and acquaintances rapidly succumb to the disease, Margaret does not understand what occurred to promote their rapid death. She has interpreted their deaths as a consequence of giving in to stress, however, she is unable substantiate this as the reason.

And I'm, I've had a lot of friends that have already died from the disease. It's like, uh, in a way I'm kind of left like with the misunderstanding on my part. Like, what did you really go through, you know, like you had it two, three years and you're gone already. Like what did, what happened and what kind of did, what part of that disease really to you so bad that you had to go ahead and die right away and.. it's all, I would think, from what I've seen, it's all psychological and part of it is your life. [100, 948-959, 965-967]

She identifies stress reduction as the fundamental key to maintaining health when coping with the knowledge of her own HIV positive status as well as that of AIDS in her roommate Harry.

The main factor is get rid of all the stress you can possibly get rid of, because you know, it's not healthy. Sometimes you can't you know, but I don't think there's a lot of stress you know going for us. You know, I would know. Like we're close enough that I can, I can tell if there is something bothering him. [100, 1144-1156]

Margaret asserts that she can tell if there is something bothering Harry. However, discussion of the issue, identified as the main strategy for stress reduction is not always the outcome.

He's very private, he's quiet you know. If something is really bothering him and he's got to talk about it, then he'll talk about it. Other than that he won't. [100, 871-878]  
(chuckle) Have to get it out of him sometimes, but he tells me, you know. I tell you, I tell him everything that's going on in mine. We try to talk. [100, 1161-1169]

Their ability to share their feelings and concerns with each other has helped them in their daily management of issues associated in living with HIV and AIDS. Margaret has shared with Harry the recent awareness that her youngest brother age 28, who has been living in Vancouver for the last six years, has tested HIV positive. For Margaret, this has elicited a "hitting home" response. There is the stress of uncertainty associated with the family's anticipated response and that of her brother's disclosure to yet be dealt with.



Just the, I guess, the reaction of my brothers would be really, I don't know. I don't know if they'd be, mm, hard to deal with this or they were prejudiced with the fact that I was gay so. I guess not knowing that my younger brother was, will really shock them... A lot of deep secrets are going to come out.  
[100-3, 389-395, 406-407]

Margaret's mother has been told by her brother of the diagnosis, but the rest of the family are currently unaware. Harry is able to empathize with Margaret, her family as well as his, has "rednecks".

Margaret and Harry share the belief that their quiet lifestyle which combines healthy eating, relaxation and reduction of stress, use of humour, and a positive goal oriented attitude, contribute to their long term healthy survival with HIV. On a daily basis, Harry's health is defined by Margaret as the ability to maintain a daily routine.

But just by his, his daily routine and activities and stuff, I know he's not sick sick sick you know. And I know he'll be here for a couple of years yet. He's got to see me go, come home with my change. (chuckle) And then he'll go. And then he'll get sick (laughter). [100, 832-839]

Margaret's perception of health has been grounded in their daily ability to be there for each other. It is this daily ability to be there for each other that blurs the boundaries that differentiate who is the caregiver and who is the care recipient in their relationship.

### Freda

Freda is a mother in her fifty's who had watched the AIDS virus kill her youngest son, Derek. Freda is a self-described homemaker. She lives with her husband James in a well appointed, large custom built home in the suburbs. James' business affords them financial security and the luxuries of many comforts, including travel. They are at the stage

in life where their blended family of three boys and three girls are grown and living independently. Their children range in age from 27 to 38 years of age, with two residing in Manitoba and the rest out of province. Derek, her youngest son has now succumbed to AIDS.

Freda illustrates the pervasive caring of motherhood, being attuned to her "motherly instinct," she had a feeling that something was seriously affecting Derek's health.

But I always say it must be a mother's sense that she can always tell whenever, you know, her offspring's not well because I would just look at him and I knew right away that, hey, you know, that there was...[102-1, 1280-1286]

Freda feared for Derek's health and the possibility of a diagnosis of AIDS for over five years, despite Derek being thirty years of age and living independently in his own home.

Previous to that (the diagnosis), uh, I would say, it was something you thought about before you went to bed and something you thought about when you woke up in the morning. [102-1, 425-430].

For two years Freda quietly watched from a distance as her son's energy declined to the point where he was unable to continue working full time for her husband. She was concerned for his survival. Freda recounts that she helped Derek "more or less, you know, exist."

And, uh, I knew that he didn't have that much money because he hadn't been working for, well, way over a year. But he had been working for my husband and I always made sure that he had like food in the house and everything and, ah. All of the bills came up and I make sure that those bills are paid. [102-1, 664-671]

It would appear that the unspeakable threat of AIDS was more than either Freda or her son could bear to openly confront.

Derek did not come out and tell us that, that he has AIDS but I personally knew that he was very sick and every time AIDS came to my mind I always said, I blocked it out. I thought, oh no, it can't be. And I did this for two

years. And finally one night I approached him and said, "Well why don't you go to a doctor?" But then he would say, "Oh, it'll go away." You know, or there would be some excuse like, or I'll get better or, uh, he would go into sort of a shell and not really answer and, or he wouldn't complain around me or anything because he knew that I, in the back of his mind, I know he knew that I was concerned. And, uh, he was sort of starting to die, you know, he was very private about it. [102-1, 450-468].

In the two months preceding Derek's coming to live with Freda, her concern for his health intensified. Although she was away on a six week trip overseas while Derek was in Halifax working, she maintained telephone contact once or twice a week with him. Recognizing her son's failing health, Freda offered her son the airfare home, but it was a work-related accident which motivated him to seek medical advice and return home. Derek protected his family from the knowledge of his AIDS status and his lifestyle, as he feared he would hurt his family.

You know, and what doctors he saw and what went on, it was all very private, just like very private. And I think he did say to one of my sons that asked him, you know, why didn't you tell us that you were this sick. And he said, I didn't want to hurt any of you. [102-1, 638-645]

The shroud of secrecy which permeated Derek's life was one which Freda describes as protective of his lifestyle and his need for privacy.

I don't know how he did it, I don't know how a person can live almost like two separate lives that he lived. I just, I don't know. [102-1, 1245-1248]

And we did not know of how many friends he did have because he actually lived two lives. I don't think his friends knew that much about his personal family. And I don't think that his personal close family knew his friends. And that's the way he wanted it I think. And that's why I think that he knew from the very start that he had AIDS and that he was going to keep it as his own personal problem. [102-1, 1514-524].

On his return from Halifax, Derek is described by Freda as being unable to do his laundry or to manage his home, or to be able to drive himself over for dinner. The decision

by Derek to reenter and stay in Freda's home occurred following much deliberation of the costs and benefits to be incurred by both of them.

Well, he'd come over after he got back for a meal and that. And, uh, and then when he phones he wasn't feeling good enough. I had to pick him up and I walked in, I knew that, you know, I guess this is, there's probably no cure for this. He seemed to fight everything else off but this time. So he came and stayed here. He wanted to go back and stay in the house and I said, "No. I would rather he be here instead of me driving over there everyday and looking after him, making sure you're o.k. I would rather you come and stay here". And I said, "besides you know, there's no one there. We have, the T.V.'s are here and everything and you'd have your own room and everything". So that was fine. So he came and he stayed here. And that was into March. Uh. And we had the greatest time.[102-1, 760-781]

Following this decision, coping with his illness although a "personal problem," was one which his entire family became involved in seeking a solution for. The family mobilizes their caring efforts to protect Derek when his grandfather from out of town comes to stay for a visit.

But at that particular time was when Derek was the worst that he had ever been. He was just on the verge of, uh, of I guess that's when everything started deteriorating, eh, I mean, he was on, very much on edge. And it was very hard because grandpa, we tried to keep, you know as much away from him as we could and he wanted to know why like Derek wasn't coming up to have meals and all that. But Derek at that point was getting so he couldn't eat by himself and that. Uh, and, uh, that was the very, that was very hard at that particular time. like you know. And so Derek said, "Well, I don't want grandpa and everybody to know how I feel, I want to go back home." And I said, "Well, you can't go, you just can't stay by yourself. I'll come and stay with you". And so anyway, at that particular point, I was very, very concerned and very upset and all.[102-1, 864-884]

As well, Derek's step sisters who live within the city, offer to stay with him at his place.

Freda surmises this offer was not acted upon because of its possible consequences.

And, uh, I think he figured, hey, that way, you know, uh, the family would get to know too much about his private life. So he figured that if he stayed here then, you know, everything would be O.K. and, uh, he would try and

conquer this, this time, for the final time, he would try and conquer this. [102-1, 889-897]

However, Derek does not conquer his illness and Freda's distress intensifies as she observes his daily suffering. She persistently encourages Derek to seek medical attention and herself seeks out resources within the community.

How, how the doctor was chosen was, my husband and I, we sat down and we talked and I said, you know, we've got to get him to the doctor, just have to get him, which he was fighting all along. No, didn't want to see any doctor. And, I couldn't sleep. I couldn't eat. I couldn't do nothing. I mean 24 hours a day I, my determination was to get him to a doctor but at this point I wasn't going to make him hate me. And all along I thought if I approach him and say, hey, I know that you have AIDS that he would turn around and he would hate me and he would run away, commit suicide, do something because he didn't want to face up to it. And face me. And I don't know, there was so many things. So I finally went, with my husband, for, to see a doctor. [102-1, 953-973]

Derek's reluctance to see a physician is perhaps grounded in knowledge of what this will entail. When he agrees to being examined he undergoes a battery of testing at a local hospital, which confirm the unspeakable diagnosis. Freda is appalled by this hospital experience.

But it was the most horrible thing ever, to ever happen to me in my life. And uh, he decided, uh, at that point when they did tell him, hey you know, you don't have long to live. He decided, he turned to me and he said, "Mom, I don't want to die in a hospital, I want to die at home." And, uh, I was hoping he'd say that. [102-1, 990-999]

Returning to the family home, the family rallies to provide the assistance to realize Derek's wish to die at home. His brothers fly home weekly. Since April they have been keeping daily vigil. The physician visits daily and engages the assistance of a trusted caregiver within the community. By June, Derek is losing the battle with AIDS. He is no longer able to feed or toilet himself and he is losing his eyesight. The hospital experience has been pinpointed as

"draining" his life force. In particular, the physician's recommendation to tell all the family members his diagnosis and status is identified as energy wasting. Freda loses all her nails using bleach as a disinfectant, afraid to place any type of barrier between herself and her son. Derek's wish to die at home is fulfilled in June.

Derek is fondly remembered by Freda as extremely creative, being a man of many talents, though a master of none. His creative legacy is captured within the interior decorating of Freda's home. It is manifested daily in his self portrait which is prominently hung in the living room, and in the use of his special recipes and plants. Freda's caregiving is a testament of her unconditional love for Derek.

He never ever came out and said I have AIDS to me. No right, ever, right up until he died, he never ever did. He assumed that we knew and I'm quite sure. And he, well, I don't know if he ever told anyone, I really don't know. And I, uh, never thought that it should be to my satisfaction of knowing he ever did that. It wouldn't make any difference, no. [102-1, 480-488, 494]

### Lizzie

Lizzie is a divorced mother in her 50's whose two children, both male have recently left her home to pursue independent careers. With a sister, she co-owns a stately three storey home nestled on a tree lined street in a well established part of the city. Their living quarters are separate, an arrangement which affords them the privacy of detached households. As well, this has allowed them the opportunity of residing in a home in an area which neither could separately afford. Their shared mortgage however, also equates to shared decisions regarding the home. Problems arose in their joint ownership when Lizzie recently allowed an

HIV positive male who she had befriended, to stay with her.

We got to the point a couple of months ago whether she wanted to sell the house. She wasn't comfortable with the boy in the house. Um, I'm O.K., just saying this boy, this boy, is that o.k. with you? [104-1, 501-504]

The "boy" Lizzie refers to came into her life following a request by a nurse in the community. The nurse identified to Lizzie that "the boy" was in need of a friend of the same ethnic background within the city. As the request had come from a colleague for whom she had previously done voluntary work, Lizzie agreed to meet with him.

I was called actually by Peter, you know Peter? I've done some volunteer work with his organization. He called me first. Anyway, I was called and asked if I would meet a young man who is {of the same ethnicity} and who has, who is HIV positive. Doesn't have AIDS. Not yet I believe, And, um, he wanted a contact in the community and I said, absolutely. So this was in um, December 1994. I met him at the ... hospital with the nurse and we didn't..., and then he had been in a car accident, he was on bed rest somewhere at his parent's home, and we didn't get together again until the end of January. And then, since then, we've had a very, very unusual and intense relationship. [104-1, 79-103]

What is not unusual is the need to protect Tommy's anonymity. Lizzie carefully always refers to "the boy" who I refer to as Tommy, in an effort to maintain his anonymity. As well, the interviews which took place at Lizzie's place of employment, were characterized by several disruptions as she checked the hallway and doorway for his presence. She feels obligated to fully share this participation, in a sense a need to seek his permission, but she also states she is afraid that this will betray his trust in her, a trust which has been carefully nurtured. It is not until the second interview that she is able to do so.

What is described by Lizzie as an "unusual and intense" relationship is clarified within a historical context. Three months after their initial meeting, Tommy asked if he could come to stay with Lizzie for a weekend and subsequently the weekend evolved into

months of stay.

"Can I just come and stay for the weekend," he said. Could I just. I'm just looking at this face and I'm thinking, of course you can. I have this big house. And how can I say no? How can I say no to somebody who needs a bed to sleep in when I've got four bedrooms upstairs on the third floor. I mean, I feel too guilty. [104-1, 401-409]

Lizzie speculates that she has difficulty setting boundaries on her caring relationships.

She had previously provided safe haven and shelter to a friend who was coming to terms with his homosexuality. However, she points out that that relationship was more egalitarian.

In her work life she attends to the needs of others.

Um, I don't, I don't. It's difficult for me to say no. It's difficult for me to, uh,. if somebody needs me, it's difficult for me to say no. And this person has been, has just come into my life. He's, he's just a very unusual boy and, um. He's just become like one of my kids. [104-1, 160-167]

Tommy is a year older than Lizzie's oldest child, a man in his late twenties. She describes her biological children as the sun and the moon, who epitomize perfection and self actualization, sharply contrasting her perception of Tommy.

And when I look at him [Tommy], he's the same age as my sons, a year older than my son and, you know, my kids, got to say this one wonderful thing about my children (chuckle) if you called central casting to send me two sons, they'd send my children. Because they're perfect.(chuckle) I mean they're just perfect. They're wonderful human beings. This boy [Tommy] isn't. He's damaged in a very, very basic way. He's very damaged. Damaged. [104-2, 1662-1674]

The damage that Lizzie alluded to is not the physical consequence of his illness, but rather the psychological trauma of his life she discovered is rife with deceptions.

He came into our lives and he lied. He told this unbelievable, excuse me, (tears), he told this story about who he was. And slowly it just started to unravel. I believed everything. And then after, I was on the verge of a nervous breakdown, felt I was. [104-2, 2037-2045]



Lizzie related that although she loves having him around, it is time for him to leave.

At present, she senses she has become "too involved" with Tommy. He has now lived in her home for two months. During this time, she has felt herself become estranged from her family and friends, because of her relationship with Tommy. She stated although he had said he had an apartment and furniture in storage, he does not appear to have the financial means to move. Lizzie feels he is afraid and reluctant to move. She too is afraid and uncertain about what the future will bring as result of this friendship.

I'm worried for him and I'm worried for me. I'm worried for the relationships in my life and I'm worried if I'm, I'm giving up too much. If I'm, if giving up is the right word, but if I'm, do I have priorities straight? I don't know, I don't know. [104-2, 137-143, 147]

### George

George is a single gay male in his early forties. He lives with a HIV positive roommate and Brian, his former lover who has AIDS, in a large estate like home. Their neighbourhood is a quiet older area of the city, close to a well established hospital. George is gifted with creativity, energy and a positive attitude. These combined characteristics have influenced his ability to work at three jobs, twelve hours a day, seven days a week, while caregiving. He chooses this work schedule to manage "all sorts of financial strains put on me, just to get me back on track." He is fortunate in that "work just comes" to him and that "it doesn't matter what it is, if I feel like doing it, I can do anything."

George met Brian, the "love of his life" 12 years ago at a restaurant where Brian was working.

We met at a restaurant where he was working and he invited me home with

him and I stayed 2 years. (laughter). We lived together for 2 years, um, and we are, we were very different people. He was a musical genius. Um. And had things that he wanted to do things and he was 10 years younger than me. So as I was rolling into my 30's, he was only rolling into his 20's, you know. [106-1, 118-131]

George's love for Brian was substantiated regardless of their age difference. However, Brian's youth was a factor in the demise of their live-in relationship.

And I knew that it was never going to go away [George's love for Brian]. It was comfortable for both of us. And it's kind of like of you love something, set it free. So I did. Um, but we still, aside from a 2 year interval right after that when someone else moved in with him three days later, um, we still stayed close. [106-1, 135-143]

In spite of the heartache George endured following their breakup, he maintained his friendship with Brian.

We were social, uh, if Brian ever needed something, it was always me that he would fall back on. Um. So that's how we got together and I was there the day that he got his test results back and, uh, at a point when I knew that he was starting to get ill and yet everybody else didn't seem too aware, I said to him, "you know, if you ever need me, I'll be there." [106-1, 147-157]

George's love for Brian was enduring. Love enabled George to extend his commitment to caregive if needed in the future.

Brian had tested HIV positive 8 years prior to re-entering George's life and home.

The two years prior to Brian's return were spent out East. In spite of their geographical distance and the 8 years that transpired, George maintained a watchful eye on Brian. George was ready and willing to have Brian home when the opportunity arose.

Brian had just gotten out of the hospital and the doctors encouraged his parents to have him home. They [the doctors] didn't think he would make New Year's if he didn't come home for Christmas. Um. So I was there. I made sure I was there when he came in and wasted no time in telling him I wanted him. [106-1, 165-174]

George believed that it was "destiny" that Brian return to live with him. George had moved to his present address that October. He recalled the difficulties he encountered trying to find a roommate.

I had moved in here last October. Could not find a roommate who wanted to live here. Just could not. Three months I struggled by myself and at Brian's arrival made me realize that he was the roommate I was supposed to have, you know. It's no wonder nobody wanted to be here. He was supposed to be here. We had good space. Um. Close to hospital. I was very close to work so for the first while I could look after him myself bouncing back and forth. [106-1, 174-193]

George believes it is his destiny to have become engaged in caring for Brian.

So, it was meant to be Brian and me in this place. And it worked well, you know. But, had a lot of advantages that worked well for us. [106-1, 208-211]

George recognized his location and space were advantageous in assisting him to care for Brian. However, there were also barriers in engaging to caregive, including the uncertainty of Brian's physical requirements.

I didn't know what I was in store for, whether I'd need a wheelchair for him, you know, in the house or what. [106-1, 205-207]

George utilized his creativity to overcome the physical limitations within his home environment. To provide for Brian's hygiene care at home, he devised a system to enhance the ease of bathing Brian. Using an assortment of plumbing and mechanical devices, George learned how to improvise. As well, George quickly learned the skill of becoming proficient in caring for Brian's central line.

I'm just a guy trying to do the best that I can here. Um. I had exactly 20 minutes training on doing the home IV. I was in between a job and had a fill and one in the west, the hospital happened to be in the middle. I said, O.K. I can stop there between this job and that job. I get in there and the girl says, O.K. we're going to. I says you got 20 minutes. So we ran through it. I ran through it. And she said, "When can you come back?" I said, "I can't. This is

it babe. Bye." And with that did home IV's for the next month. [106-1, 637-651]

George managed Brian's care with little assistance by others for the first month. However, with his demanding work schedule he recognized that he alone could not maintain Brian's care. Brian's parents were called upon to assist.

Uh, so his parents would come in and take one day int the beginning. well, one day when they went to the doctor, when they were in, he said something that they considered rude. And said, what, you're going to be rude, we're not staying. And they left. And never said boo to me for 10 days. Just never came back, you know, for the day so that I could go to work. [106-1, 783-793]

Although George was left without the support of Brian's parents, he was not deterred. His awareness and use of community resources enabled him to maintain Brian at home while he continued to work.

I finally got [help] in here so that I could spend more time focusing at work. And the volunteers would just keep him company, make him lunch, breakfast, whatever. I mean, he had no problems with incontinence or anything else. Um. He didn't require help except he needed someone to cook for him. [106-1, 773-782]

George's resourcefulness was a factor in being able to caregive to Brian at home. A CMV infection resulted in Brian's subsequent hospitalization and demise. George recognized that he was able to fulfil his commitment to Brian through the support of others and his love for Brian.

So I got encouragement, financial support even from people I hardly knew. So it's things like that that give you the strength to keep going and I loved Brian dearly, you know. There was no way that I was going to fold before I got through this. No way. Nuh, nuh. [106-2, 1038-1042]

### Robert

Robert is an articulate, young, gay adult, who works full time in a small family run business. His day-to-day work life is one which is stressful and demanding of his time and energy.

I'm working in a family business, full time, five days a week. It's demanding, you know. There's certainly a lot of stress there. [107-1, 57-59]

As well, Robert's daily home life is also demanding. Robert lives with a roommate and his former lover Andrew (PLWA), in an older, well kept home.

Andrew and Robert have known each other for 10 years. For seven of the ten years, Andrew shared a live in relationship with Robert and was his lover. Robert was aware of Andrew's HIV seropositive status and history prior to his becoming engaged as a caregiver.

He tested positive in June of 1985. Beginning of June of 1985. He was the second person to be tested positive. And that's from a reliable source. [107-1, 97-101]

Andrew had been able to live a "good" ten years with HIV before having "full blown AIDS". For Andrew, this period of time living with symptoms was relatively short, "no more than a year".

That was a very short span. Um. His appendix blew up. Like he was relatively healthy. Like nobody, he did not look like any AIDS (PLWA), his counts were, you know, 300, 250, somewhere in that and, you know. And even at 2 he was still really good and, uh, he's maybe feeling a little more tired but he was still working full time. And, uh, he was having pains and like anybody, you know. Not just some of them with AIDS or HIV virus, you know. [107-1, 124-134]

Andrew had lost a lot of weight following the ruptured appendix, however, he recovered and resumed his independent life.

And looked like he had AIDS, but he bounced back from that. You know, his

count levels went up and he seemed to be doing O.K. and uh, took a trip out east and somehow along the lines, CMV came in, so he came back.[107-1, 172-177]

However, Andrew's circumstances have changed, from being able to work and live independently, to being unable to work and requiring a wheelchair for mobility. As well, Andrew had become increasingly concerned about his appearance and subsequently had become more home bound. Robert believed that as Andrew perceived his quality of life was affected, his downward slide in health occurred.

It was really fast but part of it I believe was Andrew could not handle what he had started to look like. That was the biggest difference. Like I couldn't get him out of the house, home. We got a wheelchair here. I couldn't get him to go in the wheelchair to go outside. He didn't want people to see him. He couldn't stand mirrors and I mean there's mirrors here in the bathroom in the wall unit and in his bedroom. [107-2, 180-195]

Robert believed that Andrew's downward spiral was quick and that somehow Andrew had given up.

Certainly there's people who live longer with full blown AIDS I guess, but he didn't want to. It was enough. He had had enough. He could have probably lived with it but his biggest concern was quality of life and there was no quality of life living with full blown AIDS. [107-2, 200-211]

Within a few short weeks of the first interview with Robert, Andrew had given up his fight with AIDS.

## **Section II- The Work of AIDS Family Caregiving**

### **The Work of AIDS Family Caregiving**

The psychosocial nature of AIDS family caregiving has been identified as work that caregivers engage in throughout the AIDS illness trajectory. Five themes have been identified to depict this work, each is further defined by categories which characterize the attributes. The five themes include: Monitoring; Letting In: Becoming a Caregiver; Protective Labour; Labouring the Emotions; and Caring Transformations. The themes and categories are delineated in Figure 1.

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Themes	Categories
Monitoring	Surveillance Vigilance Hypervigilance
Letting In: Becoming a Caregiver	Engaging the PLWA Engaging the Caregiver Mutual Engaging
Protective Labour	Psychological Integrity Physical Integrity
Labouring The Emotions	Labouring in Exile Estrangement from Family Exile from Community and Society Exile from the PLWA Exile as Consequence of Anger  Labouring the Losses Facing Loss Letting Go  Labour of Uncertainty Uncertainty within the Present Future Dimension of Uncertainty Past Dimension of Uncertainty
Caring Transformations	Self Perspectives System Perspectives

**Figure 1. The Work of AIDS Family Caregiving**

### **Monitoring**

Monitoring may be described as those caring behaviours which the family caregiver engages in to assess the health status of the PLWA. Monitoring entails the caregiver seeking out specific functional health information about the PLWA. The caregiver's historical knowledge of the functional health of the PLWA when well, is compared to their knowledge



of the PLWA's present disease/illness symptoms. Particularly, family caregivers examine the PLWAs psychological, social and physical resources for their wellness or presentation of signs of disease or illness processes. Through monitoring, the family caregiver determines what type of supportive responses or aids are perceived to be needed. Monitoring is pervasive in that it occurs prior to and throughout the caregiving experience, either through direct or indirect appraisals.

The theme of monitoring is comprised of three categories, surveillance, vigilance and hypervigilance. The type of monitoring, whether surveillance, vigilance or hypervigilance, is distinguished within the contexts of temporality as well as the caregivers' physical proximity to the PLWA. The physical opportunity to observe the PLWA helps to differentiate whether the family is in surveillance or in vigilance. The timing of the caregiver's monitoring may be such that it occurs episodically or on a regular daily basis. As well, the amount of time the caregiver invests in these behaviours, as well as the PLWA's progression through the AIDS illness trajectory, assists to define the type of monitoring.

### Surveillance

Surveillance constitutes those family caregiver monitoring behaviours when the PLWA is not living within the context of the family residence. The family maintains a guarded, watchful eye, or "surveillance" on the PLWA's health. Two family caregivers who were ex-lovers of PLWA describe how, despite their failed relationships from some years prior, they maintained an close awareness of their ex-lovers situations and health.

He was diagnosed with CMV and he had a roommate downtown and, uh, his roommate was kind of you know, just met him out of the newspaper cause he

had. When we split, he went to live with this guy named Joe. We lived together for a couple of years but he kind of got transferred with the bank. So anyways, he acquired a new roommate out of the paper. And the guy was just, well he'd done a lot of scam here. He never stole from Tim or I but he got into a whole mess of trouble, and took off and Tim kind of needed a little, a place to go. He couldn't afford a one bedroom apartment in a decent type setting unless it would be in some city housing. [107-1, 967-990]

He was healthy. He was driving his car. He was getting around doing his own thing. And, uh, so we were pretty independent living and, uh, then things stated to slide. [107-1, 328-332]

In surveillance, the PLWA may present as being well and living with AIDS. The family compares their present knowledge of the person's functional status to their historical knowledge of what comprises wellness for the PLWA.

Surveillance may be done overtly or covertly by the family caregiver, through weekly visits, telephone conversations, supper invitations or discussion with mutual acquaintances. One caregiver expressed his knowledge of the PLWA's health despite his living in another province.

We were social, uh, if he needed something, it was always me that he would fall back on. Um. So that's how we got together and I was there the day that he got his test results back and, uh, at a point when I knew that he was starting to get ill and yet everybody else didn't seem too aware, [106-1, 150-155]

As well as the geographical distance which is apparent during surveillance, a emotional distance may also be present, which affects the monitoring process. One mother whose son was living with her, maintained surveillance of her son as an ongoing activity. Although she is aware of his AIDS status, their relationship is maintained within the boundaries of his need for privacy. She feels she lacks knowledge necessary of her caring for her son. In this case seeking out health information about the functioning of her son is done

without his knowledge or his sharing.

I was on to the dentist, I was on to the secretary of the doctor's office, you know because I was so anxious, you know. What's going on, I wanted to find out. I didn't want him to go out, you know, but I want to know exactly what he was doing and what was happening to him. [101-1, 684-693]

In another instance when her son is hospitalized, she maintains her surveillance of his status through telephone contact.

So every day I phoned and the nurse in the hospital will tell you. Every single day I phoned to find out how he was. I would never let a day go, even when I wasn't going. I would always phone and I'd say, "Don't tell him I phoned but I want to know how he is." [101-1, 912-919]

Her surveillance of her son's well-being is evident when following a brief stay in a hospice, her son returns to reside with her.

And when he walked in through that door I nearly died. I thought it was somebody coming out of a torture chamber. He looked awful. He hadn't slept for 4 days. [101-1, 1044-1050]

As well, surveillance occurs when the family caregiver suspects that there may be something wrong with the person but the knowledge of their HIV status is not known. For some families, the HIV/AIDS diagnosis of the PLWA is suspected, but not openly shared or sought out. One mother stated that she suspected there was something seriously wrong with her son for more than five years. However, she never confronted her son for fear it could alienate her from him or disrupt their relationship. In this case, she observed her son's energy levels decreasing, and noted that he seemed tired all the time. As well, she was concerned when he became unable to work full time at the family business. In the months preceding his re-entry into the home, although away on holidays overseas, she maintained surveillance through her contact by telephone.

He was in New Brunswick and I would always keep in touch because I would keep, I especially would go out of my way, you know to find out. [102-1, 657-660]

I phoned him when we got back and he was very, very sick and that's when, at this particular time right now, I feel that that's when he, um, you know when it really hit him and um. Yeah. Cause he spent three weeks more or less in bed in New Brunswick, but he just said oh no, its just the flu, its's just this, its just that. You know, and what doctors he saw and what went on in New Brunswick, it was all very private, just like very private. [102-1, 623-634]

These interactions led her to suspect that her son was "very sick" and in need of aid.

Surveillance behaviours encompass concerns not only about the PLWA's physical health, but also of their physical resources. Appraisal includes how the PLWA is managing financially, and the ability to obtain the necessities for daily living.

But I, uh, I helped him more or less, you know, stay, exist. And when he was in New Brunswick, I was concerned because I knew he wasn't well enough and I just kept in touch. So at least once a week or twice a week I would phone. And I'd say, phone collect back cause he was staying with someone [102-1, 692-697]

And when I met Dean, actually when I met him was I gave him an estimate for his patio so that's the first day that I met him and as soon as he started talking to me I knew that he was HIV. And, uh, I just came in the door and I saw that he wasn't living properly. He opened the fridge and I knew that he didn't have food as I thought I would want in my fridge. So ever since that day, I made sure he had some. [103-1, 378-388]

Surveillance may continue to define the caregivers' main effort within monitoring, or a transition into "vigilance" may occur.

### Vigilance

Vigilance can be differentiated from surveillance, in that there the caregiver has a shared knowledge of the PLWA's illness. The AIDS diagnosis has been medically established

and is known by both the PLWA and the caregiver. As well, the PLWA resides with the family caregiver. Vigilance can be described as those appraisal behaviours which the family caregiver partakes in on a daily basis to assess the PLWA's health status. The family caregiver is knowledgeable about the manifestations of AIDS in the PLWA and of the AIDS illness trajectory. They have a historical perspective of how the PLWA has manifested the illness and changes in the PLWA's presentation. In vigilance the structure of the caregiving relationship has changed and as well, the PLWA may have progressed along the AIDS illness trajectory.

Dean's not feeling well today, so, um, he had to go to bed early. Otherwise, it's an everyday thing. For the past year, it's been much the same. It's been very good. But usually around the springtime it seems like something always happens. So I'm not saying that he's coming down with something because he might not be it. Let's hope not, you know. But if he is, then I just have to deal with it. [103-2, 8-22]

His health seems to be all right but I know in the past couple of weeks or so there's something different, you know, there's something wrong. Cause he's taking medication and, I always ask him, "Are you O.K.?" Let me know if you need anything (chuckle) you know, just if I'm in the kitchen or my room, just don't feel that you're going to bother me if you're knocking on my door (chuckle). It's been all right, o.k., we've caught colds and flus (laughter) as well as everybody else that I know. But he hasn't really been sick sick sick where I had to bring him out or. [100, 199-221]

Like a couple of weeks back he started some kind of new medication, I don't know what it was. I knew he had started something different just by his habits you know. His coughing increased. Uh? "Did you start something or did you catch a cold?" [100, 623-635]

But just by his, his daily routine and activities and stuff, I know he's not sick, sick, sick, you know and I know he'll still be here for a couple of years yet. He's got to see me go, come home with my change, (chuckle) and then he'll go and then he'll get sick (laughter)[100, 832-839]

He just one morning he was sick in the bathroom. And he hadn't been sick in a long time. Like he was healthy, like I say. Like he wasn't sick at all. [107-

2, 457-460]

Vigilance is also evident in the caregiver's appraisal of the PLWA's self care. Several family caregivers took watchful actions regarding the PLWA's management of medical therapies.

One caregiver related concerns regarding the PLWA's central line site, another their ability to safely manage their medication.

Anyway, um, on one of his Tuesday trips into the doctor, uh, I asked his parents to make sure they looked at this site. Didn't look right. I saw it every day. I knew what wasn't right. They said it was fine. Was not fine. Uh., Bill went in for a transfusion. He was transfusion dependent, the following week and so while he was in there I paged the nurse and I said, you know, have you been up to see Bill. Yeah, nn,nn,nn, I said, "Well, what do you think of his site?" She said, "didn't look at it". I said, "well, didn't the nurses say anything to you about it?" She said, "no". I said, "don't they look at this?" And she said "I guess not".[106-1, 659-675]

Vigilance results in the caregiver seeking out nursing or medical assessment and treatment of the PLWA. Vigilance is a characteristic of the ongoing nature of the work of caregiving.

### Hypervigilance

Hypervigilance may be described as those caregiver appraisal behaviours which are intensive in their effort to keep informed of the PLWA's status. This type of vigilance may occur when the diagnosis of AIDS has not been confirmed medically. In hypervigilance, the caregiver has a heightened awareness of the PLWA's functional status, possibly due to the timing and occurrence of illness events in the AIDS illness trajectory. As well, this heightening of awareness and intensity in the monitoring processes may be affected by the lived uncertainty and period of waiting for the confirmation of the test results. Perhaps it is also affected by the anxiety of the PLWA as well as the caregiver.

Hypervigilance was observed in one family caregiver, Lizzie. Her attentiveness to the

physical changes her friend Tommy was undergoing, and attending to his medical work up and treatment, demonstrated an intensity beyond that of vigilance.

And I took a holiday day to go with him to the hospital and I know the Doctor, so I phoned the office and just pleaded could I go into the OR with him. [104-2, 1209-1213]

Lizzie has been scrutinizing the changes in her friend Tommy. Her fears for Tommy are bound by both of their anxiety.

So I haven't told you any of that but, um, I think he's, he's on the verge of AIDS. Like last week he had two biopsies and I was with him in the operating room and, um, his results, he'll get his results tomorrow. I'm sure they're Kaposes. He's got a horrible, horrible lesion in the roof of his mouth. I mean he's absolutely terrified and so am I. [104-2, 40-53]

Lizzie is terrified of Tommy's physical changes which are heralding in the AIDS diagnosis.

As his illness progresses Lizzie recounts one week's events and it's illness management.

He was in the hospital Thursday and Friday. Had a very high temp. And they did a CT scan. They were looking for toxoplasmosis. That was negative. He had no lesions in his brain. They did a lumbar puncture. [104-3, 31-42]

Lizzie articulates with knowledge the types of medical examinations and their results. She is acutely aware of Tommy's ongoing illness events. As Lizzie awaits the outcome of the biopsy mentioned above, her anxiety heightens. She is unable to attend the doctor's office with Tommy as "it was during the working day and there was just no way I could go. And I wanted to."

And then I was sitting all day Tuesday on pins and needles. I was just in agony. I didn't hear. I said to him, "Phone me the minute". He said, "I'll phone you from the hospital." Didn't hear from him until about 3 o'clock in the afternoon. I was thinking that they sent him directly to the Cancer Foundation. [104-3, 289-298]

Unable to physically go with Tommy, Lizzie attends by awaiting the test results. Lizzie waits

in agony and speculates on the worst possible scenario. She continues to caregive and is bound by her commitment to Tommy to support him through his illness.

And I told him that when he became ill that, this was before he was living with me, I said that he could, I would bring him into my home and that I would take care of him. And that's what will happen if he needs me. [104-2, 1187-1193]

### Letting In: Becoming a Caregiver

*Letting In* explicates the process of becoming involved as a family caregiver. *Letting In* may be described as the mechanism through which the family caregiver makes a deliberate and conscious decision to engage in the roles and functions of a family caregiver with the PLWA. The theme of *Letting In* is defined within contextual factors which involve relationship issues, as well as strategies and personal motivations for becoming a caregiver. Entering into the role of caregiver is also in part delineated within a time element. For some of the family caregivers there was time to cognitively prepare for this role. As well, the decision to become a caregiver may have followed a precipitating event encountered by the PLWA. For example, for one PLWA the precipitating event was the loss of a roommate. The PLWA's response to this event may have led to the definitive timing of the decision to engage in caregiving.

In this study, most family caregivers have had no previous caregiving experience to a PLWA. Through *Letting In*, the family caregiver defined the context of the caregiving relationship and established boundaries around his or her perceived caregiving roles and those perceived by the PLWA. As well, the PLWA also negotiated the boundaries associated with the roles and functions of that caregiving relationship. The theme of *Letting In*



encompasses the physical, emotional and cognitive work associated with the process of the PLWA's entry into the caregiver's home and life. Both the caregiver and the PLWA care recipient become engaged in this process.

*Letting In* is comprised of two categories, Engaging the PLWA and Engaging the Family Caregiver. As well, one family caregiving situation encompasses both categories and is described as Mutual Engagement. The type of *letting in* which occurs is defined by the actions taken by the caregiver and/or PLWA to establish the caregiving relationship within a home setting. In both categories, a conscious decision to "let in" the PLWA to the caregiver's life and his or her home, is grounded in the caregiver's commitment to caring.

#### Engaging the PLWA

Engagement constitutes the process by which the family caregiver pursues a person living with AIDS with the intent of becoming their caregiver. For most of these family caregivers, the decision to engage as a care provider was grounded within their compassion, based on their past or enduring love for the PLWA. This compassion or love was rooted in the caregiver's historical knowledge of the PLWA realized through a committed relationship. As well, engagement occurs in part, through the process of the family caregiver's monitoring of the PLWA. For these family caregivers, monitoring constituted the means by which they were kept apprised of the PLWA's situational needs. The caregiver took an active role in seeking out the information felt to be necessary on which to base his or her decision for care provision. Through monitoring, the caregiver has both the knowledge and a time to formulate his or her decision to become engaged.

All of these family caregivers engaged in establishing physical contact with the PLWA through which they shared their intent to provide care. The family caregiver tangibly sought the PLWA's presence, bridged the physical distance and established the caregiving connection within the midst of his or her home life.

This category describes the majority or four of the seven family caregiving situations in this study. All of these family caregivers committed to provide care to the PLWA throughout the illness trajectory. Of these, one continues to provide care, while three had sustained caregiving roles until the time of death of the PLWA.

For two family caregivers, the decision to enter into the caregiving relationship was predicated by their level of past involvement and previous commitment as that of lovers. One family caregiver, George, whose past love relationship with Brian had ended some 10 years previously, was motivated to become a caregiver because of his enduring feelings of attachment.

My relationship with Brian was the love of a lifetime. And I knew that it was never going to go away. It was comfortable for both of us. And it's like if you love something, set it free. So I did. [106-1, 110-115]

Like I said the love of a lifetime. And just the best. And, and, I think part of what I deal with on an ongoing basis is I was never quite sure whether Brian ever loved me at all. [106-1, 287-292]

George's uncertainty regarding the reciprocity of Brian's love did not diminish his own love for this man.

Although their prior relationship as lovers was over, George extends his previous feelings of commitment to Brian's present needs for assistance. George had continued to maintain a friendship and *monitor* Brian's health through surveillance.

We were social, uh, if Brian ever needed something, it was always me that he would fall back on. Um. So that's how we got together, and I was there the day that he got his test results back and, uh, at a point when I knew that he was starting to get ill and yet everybody else didn't seem too aware. I said to him, "You know if you ever need me, I'll be there". Um. So, he spent his last year, year and a half and went out to P.E.I. [106-1, 147-159]

Although Brian was out of town when he was hospitalized for an AIDS related illness, George was aware of the recommendations of the hospital physicians who encouraged Brian to return home. George feared that Brian would not survive, and knew of Brian's intent to return to live with his parents. It was at this point that George decided to take Brian into his care.

He had gotten out of the hospital and the doctors encouraged his parents to have him home. They didn't think he would make New Year's if he didn't come home for Christmas. Um. so, I was there. I made sure I was there when he came in and wasted no time in telling him I wanted him. [106-1, 169-176]

George had previously let Brian into his life, committing himself and never really let Brian out.

Robert also decided to enter into his caregiving relationship with his former lover and partner, Andrew. Robert and Andrew had previously lived together as lovers for seven years before their relationship had ended. Despite the three years which had passed and the intense turmoil Robert suffered following the breakdown of his "marriage" with Andrew, his love endured.

When we split up, like in any marriage I guess, friends kind of go one way with the one person and one of the spouses is left out. Well, I guess I wasn't really left out but I certainly chose not to participate in little clique groups anymore, you know, that um, especially where Andrew was involved cause I didn't want to be around him. I mean, we had split up and seeing him I would have fell to my knees I was so damn weak a that time. [107-1, 838-850]

I mean, I've literally crawled across the floor before throwing up, crying when

I've had a relationship breakdown with this guy. And, I mean, my love certainly is different when he came to live with me than when we were in a relationship. It's a different love but yet it's the same love. Like it was like we were never broken up with, just now we didn't sleep in the same bed. [107-1, 911-922]

Robert's love enabled his continued surveillance of Andrew's circumstances, despite the personal upheaval this caused him. His decision to become a caregiver was made with the awareness of the difficulties Andrew was encountering in both his health and in finding a suitable roommate.

He was diagnosed with CMV and he had a roommate downtown and uh, his roommate was kind of, you know, just met him out of the newspaper. So anyway, Andrew acquired a new roommate out of the paper. And the guy was just, well he'd done a lot of scams here. He never stole from Andrew or I, but he got into a whole mess of trouble, and took off. And Andrew kind of needed a little, a place to go. He couldn't afford a one bedroom apartment in a decent type setting unless it would be in some city housing. Which I don't know how well an AIDS (person) would fit into there to start with. What kind of abuse they'd go through living there. So, and it was just when I went to see him, I just thought, he's, he can't care (take care), I shouldn't say that, he could care for himself. [107-1, 967-990]

Robert consciously committed to sharing his accommodations with Andrew because he knew he could provide some stability in a stressful period of Andrew's life, a period marked with many losses.

February of 95 he moved in and he needed a roommate. Actually, what he needed was some stability because he had gone through two room ...three roommates. Andrew's mother had passed away and he really needed a roommate quickly. This guy took off. This other guy ended up burning him, taking off and Andrew wanted to know that he could come home and there would be somebody in the house always. Or not always but there was somebody coming home. [107-1, 1047-1065]

Robert's concern for Andrew's well being enabled him to set boundaries on the stresses he could control in Andrew's life. The impact of his decision to bring Andrew home and to

provide care was made with the knowledge of the stresses it would add to his own life.

And it was difficult for me to bring him in and certainly my group of friends, not Andrew's, oh yeah, I guess in some respects, Andrew's friends too. "What do you want to go live with him for?" you know. Like "he did this, this, and that to you after you split up", you know. Like, "I can't stand him" and "I'm never going to visit you". And uh, I don't know that it was said to Andrew, but it was certainly said behind, in conversations in other room. And my friends kind of said, "You know Robert, you should go and hey, talk with him and see him and stuff and then be his friend in the hospital, but bringing him to your house is just insane". "Your an ex-lover you know and all, like put that behind you, you don't owe this guy anything anymore." And I just couldn't do it (not bring him home). [107-1; 1074-1096]

Despite the advice of his friends, Robert carried out his commitment to Andrew and brought him "home".

Freda's commitment to engage in caring may be viewed within the context of the love relationship a mother has with her son. Freda secretly feared for Derek's health and the possibility of a diagnosis of AIDS for over five years. In the two years prior to engaging in home caregiving, her *monitoring* intensified from that of surveillance to that of vigilance.

Previous to that, uh, I would say, it was something you thought about before you went to bed and something you thought about when you woke up in the morning [102-1, 425-430]

Freda's decision to engage in caregiving is rooted in her pervasive role as a mother caring for her child's welfare. Her close ongoing monitoring of Derek's health, as well as her knowledge of her own resources, both physical and emotional, influenced her decision regarding where and when caregiving would occur. Freda had for some years assisted Derek with his self maintenance, purchasing a home for him and assisting him financially. Ultimately, Freda decided to caregive in her home when she noted Derek's inability to drive himself over for to her home for supper.

And, uh, and then when he phones he wasn't feeling good enough. I had to pick him up and I walked in, I knew that, you know, I guess this is, there's probably no cure for this. He seemed to fight everything else off but this time. So he came and stayed here. He wanted to go back and stay in the house and I said, "No." I would rather he be here instead of me driving over there everyday and looking after him, "making sure you're ok." "I would rather you come and stay here". And I said, "besides, you know there's no one there. We have the T.V.'s are here and everything and you'd have your own room and everything." So that was fine. So he came and he stayed here. [102-1, 760-780]

Although Derek initially agreed to Freda's caregiving conditions, when relatives began to ask questions regarding his status, Derek wanted to return to his own home. Negotiations occurred between them to ascertain the boundaries surrounding the context of care provision including the involvement of new family caregivers, and the provision of medical care by a physician. Eventually, Derek decided to remain in Freda's care. Derek's decision to maintain the present care arrangements were perceived by Freda within the boundaries of his need for privacy and the secrecy surrounding his AIDS diagnosis.

I think he figured, hey, that way you know, uh, the family would get to know too much about his private life. So, he figured that if he stayed here then, you know, everything would be O.K. and eh, he would try and conquer this, this time for the final time, he would try and conquer this. At that particular time, he got an abscessed tooth. And this abscessed tooth just made his face swell because, like, his system just couldn't fight off any more, you know. And, uh, he just was in, just the most agony. He just, in fact at one point I wanted to call the doctor here at home. He wouldn't. Every time I mentioned the doctor, he would just shove me away. And he knew that if he saw a doctor, then, hey, everything would probably all come out. And every day I'd say to him, "Derek, we're taking you to a doctor". "No, I don't need one, I'll go, I can do this" and he'd get angry and he'd just lash out at me. And finally I sat down with him and I said, "It doesn't really matter anymore", I said, "you're not getting better, so will you see a doctor?" "NO". [102-1, 900-919]

Freda's steadfast vigilance of Derek's status was made possible by their mother - son relationship. She appreciated the boundaries Derek established surrounding her caregiving,

however, she identified the scope of the care required was beyond her abilities. Through her vigilance, Freda negotiated with Derek to "let in" a physician and he agreed to allow medical treatment.

For one family caregiver, the decision to engage to provide care was made without a historical knowledge of the PLWA through a love relationship. This family caregiver was unique in that he chose to engage because of his strong compassion toward others who are in need. Prior to entering into the caregiving situation, the caregiver was unaware that the PLWA had been selected to become the next recipient of care provided through a caregiving group in the community.

The intended care was to be provided by the group of community caregivers to which the caregiver belonged. The family caregiver coincidentally became engaged by performing some work for the PLWA.

I knew of him, like, but I didn't know he was him cause our group, we were getting ready to deal with Dean and we have to prepare ourselves. The ones that if there are five people in the group that's going to take care of this person, then we have to see, uh, does he seizure, does he have this, does he have that and so we have to learn to deal with the person like that. And, uh, when I, when he started talking, I just started thinking about this person that we were getting ready to deal with and then it just happened that it's Dean.  
[103-1, 405-419]

At that initial meeting four years prior, Jeremy decided that Dean's living situation was wanting and made the commitment to become engaged in caregiving.

And uh, I just came in the door and I saw that he wasn't living properly. He opened the fridge and I knew that he didn't have food as I thought I would want in my fridge. So, ever since that day, I made sure he had some. And it was about a year and a half later that I moved up. He put up his house for sale and I put up my house for sale, whichever house sold first, then the first would have to move in with the other. [103-1, 383-394]

The decision to engage as a family caregiver was not entered without some deliberation and planning by both Dean and Jeremy. Jeremy's commitment to caregiving necessitated their negotiation of the home context for the caregiving and as a result, his subsequent move to Dean's home.

Jeremy has been involved as a gay caregiver for other PLWAs for five years, but he had never before ventured into the role as the sole caregiver. His motivation for caring for others is a simple one. "I, I like to be wanted, you know, like I need, I need that." [103-1, 444-445] Although his motivation for caregiving was simple, there was complexity in its impact. Jeremy became perplexed by the reaction of his gay friends.

They, I saw who my friends are by moving in here. There was another step in my life. I lost a lot of friends or people that I thought were my friends. And if I had 20, I'm lucky if I have 5 left. So, you know, like when you're emotional and you like people and all of a sudden these people do this to you, you know, it makes you wonder, you know, its, "like what kind of people did I really know?", you know. What kind of people are they? [103-1, 508-519]

I need him too but they don't see that [103-1, 702]

Jeremy's commitment to caregiving has survived despite the personal loss he has encountered. The loss of support from his gay friends is endured by a need to care which is deeply connected to his personal history of suffering.

And I think that's why I do what I'm doing, I think I've said this before, I cannot stand people suffering and suffering is, there are a lot of ways you can suffer, you know, but this pain caring heals. And it heals a lot of things. And if I show Dean, or any other person that I care, I think that heals. [103-1, 1586-1591]

And by feeling like that black sheep I guess, he's doing a lot for me too because I'm needed. Otherwise, I'd be alone. I have a friend. [103-1, 1620-1624]

Having himself suffered, Jeremy continued to caregive because of its healing properties. For



Jeremy, suffering the stigma of being gay is healed by caring.

For most caregiver's, the decision to seek out the PLWA was deliberate and based on the ongoing surveillance described in the first category. When the caregiver's awareness of the PLWA's needs became apparent, the decision to engage in the caregiving relationship occurred despite their knowledge of the difficulties this might bring. As well, the caregivers motivation to become engaged was grounded within their historical knowledge and love for the PLWA.

### Engaging the Caregiver

Engaging the caregiver constitutes those letting in behaviours which occur when the PLWA approaches and engages the individual who then becomes his primary family caregiver. A conscious decision by the PLWA is made to deliberately seek out the caregiver prior to becoming a resident within the caregiver's home. Unlike *engaging the PLWA*, engaging the caregiver does not occur through a process of monitoring. The caregiver's living situation is one the PLWA is familiar with, either through kinship or by acquaintance. As well, the caregiver is apprised by the PLWA of the information they feel may help the caregiver decide to engage in this process. The amount of information sharing is at the PLWA's discretion. However, once engaged, the caregiver begins the process of *monitoring*.

In this study, the decision to engage the caregiver seemed contingent on the PLWA's need for residence and the timely availability of it. The PLWA initiated the physical contact with the caregiver through which they shared this need. As a result, the caregivers may have had little time to cognitively make their decision to engage and to consciously prepare for the

role.

These family caregivers retained control of the opportunity to chose how to face this role. Choosing to accept the PLWA into their home may have been influenced by feelings of obligation because of friendship or familial ties. The obligation to provide assistance and service to "one's own" (as in a mother - son relationship) or to "someone in need" (as in a friendship) when experiencing difficulties, may have both a moral and cultural context. As a result, this feeling of obligation may have motivated the caregiver to engage in and provide assistance. As well, the motivation to engage may be influenced by the characteristics of the previous relationship held with the PLWA. If the prior relationship with the PLWA was unstrained historically, then there may be more willingness by the caregiver to engage. Thus the motivation underlying the caregiver's commitment to engage may differ from the compassionate motivation underlying *Engaging of the PLWA*. As well, the nature of the commitment to caring which is noted in *Engaging the PLWA* may be inherently different. The family caregiver has committed to providing residence or shelter to the PLWA and may assist in the managing of financial strain. However, as the caregiver did not engage the PLWA, the onus to negotiate other aspects of the caregiving relationship is with the PLWA.

In this study, the family caregiver was engaged by the PLWA as contextual factors influenced their ability to live independently. Engaging the caregiver represents two of the family caregiving in this study. One PLWA actively sought out care from his mother and another from an acquaintance. For both of these PLWA's, the need for conjoint housing evolved while dealing with changes in their physical health and financial status.

Margaret has been Harry's roommate about a year. Although acquaintances for eight

years, Margaret was unaware of Harry having AIDS, a disclosure he made upfront and prior to Margaret's decision to accept Harry as a roommate and become engaged as caregiver.

I had a roommate that had moved out of here, I guess July last year. I wasn't going to get another roommate, I was tired of a roommate over here. And I guess deep down inside he didn't know if he was going to stay in his own apartment or. Cause he had broken up with someone himself. And one night he come over and I was getting ready to out. And I says particularly, I says, "I don't know, I've had like five experiences with all kind of roommates, but I'll let you know" I says, "in a couple of days". I says, "I don't really know if I can afford to rent here myself" I says. He said, "Well, let me know", he says, "I'm looking for a different place". And he comes in a couple of days later and I says, "Yeah, you can come and live. We just kind of talked, this is what you've got, you've got it already, (chuckle) you know. He says, "Well there's something, a few things I should tell you". It kind of shocked me because he didn't, it never dawned on me that he might be sick. [100, 126-167]

Harry had approached Margaret regarding a living arrangement which would be mutually beneficial, as both had recently ended live-in relationships. Their living arrangement has evolved into one where Harry now identifies Margaret as his primary family caregiver. Margaret views the decision to accept Harry into her home as one which is mutually beneficial. At present, she is living on social assistance and having Harry as a roommate has lessened her financial strain.

Margaret ponders whether her decision to accept to engage has had an impact on her life physically or emotionally. Margaret feels there has not been much impact on her present life as Harry is independent in his ability to manage his own care.

Yes and no. No, because it's I think we kind of needed each other because we're a lot similar and, I guess, a lot different. [100, 768-770]

Their shared connection is that they both are coping with the HIV virus. Their differences lie in contextual factors surrounding their personal needs.

Margaret has consciously considered her role as caregiver when Harry might need to rely on her more.

I've prepared in my mind but not in my heart. Cause I, I keep wondering, like "what if", O.K. "What if", you know, you always, there's always that "if" part. O.K. If you get sick then I know where that's going to lead, if you get sick because I've seen it so many times already. Will I be able to handle that, you know? It's like if he does get too sick to the point where I know he's not coming back, gonna come back here, then it's going to be like, O.K., this has been your home and my home for a long time and, you know, can I go back to that home type thing, you know? [100, 798-819]

Her uncertainty of the future reflects concerns for the management of Harry's needs as well as her own.

Margaret recognized that it is within Harry's prerogative to chose to disclose the information she may require as his caregiver. She conceded however that his "privacy" is an issue which affects her caregiving.

That's the only, that's the only thing that's really, that really bothers me sometimes. I know he's, he's sick but really he might not be telling me, like maybe, how sick he might be, you know. [100, 823-828]

Inspite of this deficiency, she makes it her business to keep abreast of information which may be beneficial to Harry's care.

And when it comes to some cures about all the stuff, I'll let him know. Like, it might be, it might not be my business, but I would like to know, you know. [100, 616-619]

Margaret demonstrates her concern for Harry's well-being and continues to negotiate the caregiver role.

Negotiation of the caregiver role is a central issue for Isabelle and Jerald, a mother and son. Isabelle as a parent must re-integrate Jerald her son into her home and her life.

Uh, he came in July. It was let's see, he came up from the Fringe Festival

because he's in the theatre. [101-1, 73-75]

There was insufficient time to consider the decision to engage, as Jerald's return heralded his re-entry.

Well, as I told you, like when he came in, he was fine and everything was really, was good. No problems or, you know. Uh, he did have outbursts of anger and I was very sensitive. I was looking after my mom too. She was 93 so I had two people that were, needed my attention. [101-1, 51-58]

Isabelle was already committed as a caregiver to her 93 year old mother who resided with her. Prior to Jerald's return, she was satisfied with her life and her caregiving abilities. Jerald's return prompted her to question her proficiency in this capacity.

And, like I personally, I think I keep a clean house but according to him, everything's wrong. Nothing's right. Uh. Mom didn't do anything right, she was 93 for God's sake. She put up what she could. She had a little problem with toilets and, you know, she'd jump and maybe she didn't get there, you know. I'd go and look after it. Maybe I didn't get time to maybe wash around the toilet and that. He'd walk in, He'd blow his top. And I didn't like him saying this to mom because mom and I had been living on our own, like since my daughter got married, and we were quite happy and he come in. Then he came in and he wanted to be in charge. He wanted to take over, take over everything. [101-1, 76-100]

Jerald's "coming in" illustrates Isabelle's perspective regarding her freedom to choose to accept to engage in the role of his caregiver. It appears she feels little control of the process of engaging as his caregiver.

I felt that, um, he had control, he was controlling everything. Uh, I was, I didn't feel free in my own home. I felt like the visitor. Because no matter what I went to do, it was wrong. [102-1, 68-76]

Isabelle's ability to engage as Jerald's caregiver appears impeded by his attempts to "control" his caregiver and the caregiving environment. As well, the anger and negativity she senses promote an hostile caregiving environment.

Uh, Jerald got angry with me, like, uh, like he was ornery and I'd shout which I shouldn't have but I've never, never done this before. From the day he came to my house up to last November, I don't think there was a day went by he didn't have me in tears. [101-1, 62-68]

Isabelle cognitively acknowledges Jerald's need for control of care as governed by the physical losses he is experiencing. However, the negativity has a impact which is heartfelt.

Uh. I didn't realize that but somebody brought it to my notice. He had lost control of his own body. He's got no control over his body any more. So he's looking for somebody to control. So that was me. I didn't realize it at the time. I think I did but I was fighting it. [101-1, 98-111]

Isabelle's "fighting" with Jerald, appears to be a central issue in the communication to regarding their negotiation of the each others roles following his re-entry. After Isabelle's mother's death, both negotiate a need for a "break" during one episode of hospitalization .

I said, "You're going to Betty's". He said, "Yes". "Mom", he says, "I think you need a break. You need a rest." I said, "you know Jerald, I have been looking after people like all my life." And he says, "O.K., and then you look after me". "So" he says, I think he said. I didn't mean it to come out that way. Like what I was trying to say to him. It didn't bother me looking after people but he took it up the wrong way, do you understand? And what I was trying to say "well, I don't mind looking after you Jerald, but you cannot be, ab, abusive to me". [101-1, 786-768-789]

Isabelle defined the emotional limits surrounding her caregiving, when she became uncertain of her ability to endure the strain of this caregiving relationship. Although she was committed to caring, she cannot "care" under the present circumstances. Somehow, they have been unable to successfully negotiate the caregiving boundaries.

For both of these family caregivers, the PLWA's identification of a need, active seeking, and deliberate pursuit, motivated the caregiver's decision to engage. When the caregiver decided to engage in the caregiving relationship, it was the responsibility of the PLWA to initially negotiate the boundaries of the relationship. Where unsuccessful in

sustaining a harmonious relationship, the caregiver, despite her kinship ties, may have opted out of the relationship.

### Mutual Engaging

One family caregiving situation was unique in its process of engaging. The process of mutual engaging occurred when the both the PLWA and the family caregiver concurrently engaged in establishing the caregiving connection. Both engaged in ensuring the physical occurrence of the contact needed to initiate the process. Both consciously decided whether they engaged the other.

In this process, the PLWA and the family caregiver had no previous historical knowledge of each other. Their lack of previous history allowed both to engage without the constraints of feeling obligated. Both simultaneously sought to engage because of a mutual need for caring in their lives. Their personal history however, influenced the present void felt in their lives, which they hoped the other might fulfil. As well, their past has helped shape the present decision to mutually engage. There is complexity in negotiating of the roles and functions of the caregiving relationship, as it is mediated by this personal history.

Lizzie, the family caregiver was approached through a colleague in the community who had identified a need for establishing a friendship with a PLWA.

I was called actually by Peter, you know Peter? I've done some volunteer work with his organization. He called me first. Anyway, I'm {ethnicity} and I was called and asked if I would meet a young man who is {of the same ethnicity} and who has, who is HIV positive. Doesn't have AIDS. Not yet I believe, and, um, he wanted a contact in the community and I said absolutely. So this was in um, December. I met him at the hospital with the nurse and we didn't, and then he had been in a car accident. He was on bed rest somewhere at his parent's home, and we didn't get together again until the end of January.

And Then, since then, we've had a very, very unusual and intense relationship. [104-1, 79-103]

Lizzie had been experiencing a void in her life with the move of her adult children from her home. Tommy, the PLWA, although he has family of origin, chose to look elsewhere for care. The intensity Lizzie refers to is illustrated by the events which transpired in the six months following their meeting. Her life quickly changed since choosing to engage as a friend six months previously.

A whirlwind. He's now living at my house. Oh, God. Um. I think I've become too involved with him in that, I really, I really don't know how to say this cause it's going to sound really weird. Because it's a friendship. I get too involved with people, you know, like I can't sort of, I have, I have boundary issues. You know that old boundary raised. I have them in every part of my life. Um, I don't, I don't, it's difficult for me to say no. It's difficult for me to, um, if somebody needs me, it's difficult for me to say no. And this person has been, has just come into my life. He's, he's just a very unusual boy and, um. he's just become like one of my kids. [104-1, 143-167]

Being unable to say "no" influenced Lizzie's decision to let Tommy into her home and life. Her inability to turn away someone in need has a solid historical foundation. As a single mother, she has devoted her adult life to professional caregiving while raising her two children. As well, she has previously provided "sanctuary" to a friend when "he was coming out in his homosexuality". Lizzie acknowledged personality traits and her history, past and present as factors in her decision to engage.

I couldn't say no. "Can I just come and stay for the weekend," he said. Could I just. I'm just looking at this face and I'm thinking, of course you can. I have this big house. And how can I say no? How can I say no to somebody who needs a bed to sleep in when I've got four bedrooms upstairs on the third floor. I mean I feel too guilty. [104-3, 397-409]

Lizzie felt guilty as she possessed the means to provide assistance to someone in need, both physically and psychosocially. Her past experience in offering sanctuary was "fine because it



was a totally egalitarian relationship". However, in this relationship, her guilt is mitigated by tangible differences its quality.

But in this case its not egalitarian at all. It's, it's, um, it is very much almost a mother-child relationship. [104-1, 426-429]

Lizzie vacillates between enjoying Tommy's presence and her motherly concern for ensuring his best interests.

I mean I love having him around and, but it's become, he's got to get out. I mean he's got to get out on his own. He's got an apartment and he seems reluctant to leave. He needs to be taken care of. And, um, he's just, he found the right person. And I, just today, I was saying to him on the phone, you know start thinking. But on the other hand, I don't want him to feel that I'm kicking him out. I don't want him to feel rejected. I'm feeling, I don't want to hurt him in any way. But I think that for his own independence and self esteem that it would be better for him in his own apartment. So, it's just become very complicated from that point of view. [104-1, 177-203]

The complications Lizzie perceives are affected by her knowledge of Tommy's past and present history, factors which led to Tommy's mutual engaging.

Oh, gosh, his parents, his family. They don't really understand him but then I don't understand him either and they've lived with him and know him much more that I do. Very complex. Very complicated. Very manipulative. Very spoiled. Very egocentric. Needs to be the centre of attention. Very charming. Very adorable. Just loving. I mean, you would just fall in love with him the minute you see him. Um, and his mother, I mean he just told her about a month ago. [104-1, 437-450]

Tommy's need to be understood was thwarted by behaviours which appear to estrange him from establishing connectedness, with both his family and Lizzie. For Lizzie, there is a need to distance herself from feelings associated with a mother child relationship and its' responsibilities.

But as say, this situation, even though I am as deeply involved with this child as I could be with anybody, there's that distance. There's still that knowledge that this is not my child. And I will sorrow when he dies. I mean I love him

as part of my heart, but he's not my child. I keep saying that to myself. And that maybe doesn't help me, I don't know. I mean he's somebody else's child but he's not mine. [104-3, 1488-1500]

### Protective Labour

*Protective labour* is an ongoing process in which the family caregiver engages in specific activities that are aimed at maintaining, continuing and repairing the PLWA's world so that they can live in it as well as possible. The family caregiver seeks to promote the PLWA's psychological and physical integrity through their monitoring of the PLWA's status and environment. Using their knowledge of the PLWA, the family caregiver seeks to recognize and limit those events or activities which they perceive as threats of harm to the PLWA's integrity. In recognizing these threats, the family caregiver attempts to ward off forms of disruption and establish or maintain safe, protective care boundaries surrounding the PLWA. At times, actions taken to protect the PLWA may be detrimental to the caregiver's own physical or psychological integrity. When conditions permit and if recognized, the caregiver may also take actions to also protect his or her own integrity.

Protective labours demonstrated the caregiver's depth and breadth of caring. The caregiver's actions presume "moral" caring and aim to address threats of harm by others. The caregiver's internalized values and beliefs were the moral boundaries which guided his or her protective caring. Caregivers believed in controlling life decisions, the quality of life, expectations to be treated with respect and dignity, and supporting the individual in times of trouble. This belief system was then actualized with the PLWA, the caregiving relationship, and with others. Caregivers managed their own behaviours and those of others to protect the

PLWA's integrity based on these values and beliefs. As well, caregivers assisted the PLWA to manage his own life, so that his integrity could be maintained.

The theme of protective labour is comprised of two categories, *Protecting Psychological Integrity* and *Protecting Physical Integrity*. Caregiver strategies included protecting the PLWA's independence, preventing harm, conserving resources, promoting quality of life, negotiating care needs, promoting well-being, and managing stress. These activities also represent the work of advocating for or protecting the PLWA's best interests. Some consequences of protective care are discussed within *Labouring the Emotions* which details the responses of anger, frustration, and hurt. Only those caregiver interventions which contextually reflect protective work are discussed here. As well, some of the effects on the caregiver as a consequence of protective care are discussed.

### Psychological Integrity

Protecting psychological integrity is comprised of the activities the caregiver engaged in to maintain the PLWA's positive feelings toward self. Protecting the PLWA's psychological integrity included caregiver actions to preserve personhood, promote quality of life, and respect the PLWA's expressed wishes. As well, protection also included the caregiver's actions to affect the actions of others.

Maintaining personhood denotes preservation of the PLWA's dignity, independence, respect, and value as a human being. For one caregiver, this involved focusing on what the PLWA could do and de-emphasizing his limitations. For example, Jeremy ensured Dean's feeling of being able to maintain care of his household and environment.

So if I see that he's not well, then I'll tell him to clean the carpeting and I'll do the rest or he'll sweep and I'll vacuum or I sweep and he vacuums but otherwise he'd rather do it himself because he likes that control of being able to do something. [103-2, 158-164]

Like he wanted, he'll come down and cut the grass. So, then I lose a lot of plants when he does that, but I want him to (go outdoors). Like, I don't want him to feel like don't come outside, you know, because I want him to feel very comfortable and by making the garden look very nice to him, it's heaven, you know. [103-1, 982-988]

Having recognized Dean's decreasing abilities and shrinking environment, Jeremy sought to maintain his independence, despite the costs. As well, Jeremy recognized a need to balance his interventions to maintain Dean's independence.

And sometimes you just have to learn to stand back, be there if he needs you, but don't push your help on him, because sometimes he doesn't like that. [103-2, 150-153]

Caregivers also preserved the PLWA's feelings of self-worth through their use of empathy. Two caregivers expressed the importance of empathy in AIDS caregiving. Caregivers expressed empathy as a consequence of caring about the PLWA which maintained dignity and respect. For example, Jeremy tried to envision what it would be like to live as Dean.

And uh, like I look at things as what about if it was myself? How would I feel if I couldn't go to the store anymore, if I couldn't go to the bar anymore, if I couldn't drive here, afraid to walk down to the corner. How would I feel, you know, by living his life? And to me, it's like a jail only this is a pretty one. [103-1, 245-252]

Being able to put himself into Dean's shoes gave Jeremy the outlook from which he managed his caregiving. In contrast, another caregiver felt an empathic approach to caregiving was lacking during her son's hospice care. For example, Isabelle sensed her son's appearance and his care demonstrated a lack of sensitivity by other caregivers.

Like he knows that he couldn't come back to me that time after Christmas, cause he was treating me so badly and everything else. And then out of the blue he's there one day crying and he looked to me like he had been tortured. You, never, if you had a saw him, he was pretty sloppy. I nearly died when I saw him. He hadn't slept for 3 days, you know. And, if a person is ill like that, um, they're sick, very sick and if they had one person to come along and say "O.K." and sit down and "I'll make you a nice hot cup of tea" and "We'll make sure nobody's going to bang over you head" and that. It would've made all the difference in the world. [101-3, 433-450]

Isabelle's distress was felt empathically and she felt that same empathic approach by other caregivers was needed.

Protecting the PLWA's personhood also included managing the responses of others. Strategies employed by caregivers were maintaining secrecy, controlling the environment and acting as an advocate. Maintaining secrecy of their caregiving and the PLWA's seropositive status was protective of the PLWA, but had a detrimental effect on the caregiver which contributed to his or her *Labouring in Exile*. As well, one caregiver related maintaining secrets or not fully disclosing information about others, to protect the feelings of the PLWA. For example, Jeremy resorted to keeping silent about friends who inquired about Dean. He had become disheartened by Dean's friends behaviours.

A lot of his people that used to come over before I came, before I was around, they would ask me, how is Dean? And it's like, well, Dean is doing well and uh, they would go, "Oh, I've been meaning to go and see him or give him a call." And I said, "Well you should." And I felt good by coming home and saying "Dean, I met somebody that knows you and he said that he was going to give you a call or come by for coffee." And I could see that, he said, "Who", you know, "Good", like he got excited. But then a week went by, another week went by and two months go by. This person never called. Then he sees me again, "Oh, yeah, I've been meaning to go" and I says, "Whatever. If you want to go, go. Call." And then this goes on and on and on. And then it gets to a point that is, they come up to me and say, "Well, how is he doing." Like I don't think he really cares. It doesn't make no difference if he's alive or dead to you. Because if it meant anything, if he's ill and you know he's ill, and if you think he's dying, why don't you go and visit

him before he does happen to. And I stopped telling Dean that I saw so-and-so because he doesn't need that. [103-1, 835-867]

Jeremy chose to not tell Dean about his friends inquiries as their inability to act on their intentions was perceived as a lack of caring and a let down for Dean. Jeremy felt that sharing this information was harmful to maintaining Dean's feelings of self worth.

Several caregivers worked to control environmental factors which threatened the PLWA's self-respect and dignity. For example, Jeremy ensured that Dean's home environment was respectful of his dignity and feeling of being accepted.

Sometimes he can go on talking for hours and hours and hours. Yet that's very hard for me, it was hard for me to listen to that. And I sat there and I sat and I listened and I listened and, and it was like putting on that tape recorder and playing it over and over and over and over again, thousands of times. But that's why I'm here. And if you come to visit me, and you're aware that this might happen and you put him down, I'll show you where the door is. So, I think that's what being a good, uh, caregiver.

So, I've had to kick a lot of people out of the house, because they don't respect. [103-1, 668-669]

Jeremy preserved Dean's dignity by patiently bearing the repetitive nature of his conversation and evicting those who could not. Other caregivers ensured the PLWA would be treated with dignity and respect when seeking medical care. For example, Isabelle's past knowledge of other's responses toward her son motivated her to seek out an advocate to accompany Jerald to the hospital.

I knew he was very, very sick, you know. And then I said to Peter, "He's very sick." I said, "Please Peter, don't let him go back by himself." You know, he's not going to go back by himself. Peter said, "No" he says, "I will, I will arrange for that." So things didn't get, things didn't settle down with us. He was still angry. [101-1, 457-464]

Peter, a nurse, was effective in negotiating Jerald's hospital admission while maintaining

respect for his personhood.

And when they went back to the hospital that time, they, they admitted him. But as soon as he went in, they said, "Oh, Mr. Smith, no more questions of your name, your address, your birth." I mean it's on the computer. When a person is sick, they don't need all these questions being asked. [101-1, 499-508]

Isabelle sought Peter to protect Jerald from the exhaustive process of repeating information which could already be known. Isabelle felt unable to act as Jerald's protector. However, she ensured that Peter who was well versed as an advocate, could.

All of the caregivers spoke of the importance of protecting the PLWA's quality of life. Numerous caregiving strategies were employed to maintain, promote or preserve the PLWA's quality of life. The importance of managing or reducing stress and the promotion of well-being was identified by several caregiver. For example, Lizzie encouraged Tommy to think positively.

Um, but you know, he's talking very negatively and this and that. And I said, "Oh God, you know, try to be positive. You know how important that is." But he said, "That's easy for you to say." I said, "I know." I mean, I know that, easy for me to say to somebody who is dying, think positive.[104-2, 680-689]

Caregivers recognized the effects of negative thinking and stress on the PLWA's health and encouraged actions to manage it. For example, Lizzie recognized detrimental amounts of stress in Tommy's life and encouraged the use of meditation and music.

Because my friend has so much stress in his life. He has so much family stress. Today he's at the lawyer with his mother taking care of this and that and the other so he has, he has all the family sort of financial stuff he's sort of helping them deal with plus himself, plus his own illness, plus, plus, plus. And he's just totally stressed out. And he knows that he shouldn't be. He know that it's not healthy. And I'm trying to urge him to do some meditating, to try some visualization. I don't. I just know so little about it but, not enough to help him with it, but you know, oh, no I can't. I'm too nervous, I'm too, you know, I don't have time to do yoga. I don't have time for anything. [104-

2, 909-927]

We have all kinds of wonderful music at home, that really spiritual, new wave stuff, you know. We have all this fabulous wonderful stuff. Um. But Tommy's very, very cerebral. So that's (out). And he has to be in control. I mean, he's very much a control freak. So, I mean, those kind of people don't, they don't give in easily to this kind of philosophy, you know. Give up their, they don't give up themselves easily to this kind of stuff. But he needs it. He needs something. [104-2, 942-956]

The significance of stress was also recognized in the life of the caregiver. For example, Jeremy spoke of the effects of living as with Dean's dementia.

A lot of people with HIV, they just sit there and they think and think and think and then they just go crazy, you know. I've gone through that experience with Dean, and thank God, that things worked out because otherwise I don't think I could take another year of that. And I, maybe I could, I can't say that. You know I took it for a year so maybe I could take it for another year, I don't know. But I suffered, I went down to about 160 pounds. Oh God, it was, I don't know what it was. I ate well. But it was just stress. I was going through stress and emotionally I was. And I don't know why sometimes tears come to my eyes. O.K. It's like my life right now is O.K. you know. But the stress of, I would leave here and I'd always make sure I'd let him know where I was at. There's always a phone number to reach me. And as soon as I get there, it's like, "Jeremy, come home, they're here, they're here. They're taking me away." And to me, it was like, stress of knowing what he was going through cause I knew there was nobody here, you know. It could have been the cable van or some van in front, but he thought it was somebody else. And not being able to finish my coffee with a friend or my family member that I went to visit, it's like, no, I have to leave. And they don't understand. [103-2, 278-317]

Jeremy recognized the taxing effects of AIDS dementia on Dean, as well as himself.

Three caregiver's identified the use of alternative therapy to promote well-being. For example, Jeremy discussed the positive effects of cannabis on Dean's mentation and appetite.

Uh, I don't know if I should say this now but he uses marijuana. And I find that when he doesn't smoke his joint, that he is different. He understands that when I can't get it, he understands that. But, uh, when he doesn't have, he pushes for me to get it for him. Which is fine, you know. Um, and if it makes him feel better then I see no reason why not. And like right now there's none,



so I see the effect that has. Like he doesn't eat as well. He gets, he feels sick more often. [103-2, 323-336]

And to me I don't see nothing wrong with it (marijuana). I mean, there is something wrong with it because I can get caught, you know. Like finding it to me is hard. Going to places to get it, to me, scares me lots. Like, oh God, will I get caught? Am I going to go to jail? [103-2, 372-379]

Jeremy weighed the benefits of Dean's using cannabis against the risks to his own safety. In spite of these risks, several caregivers ensured the PLWA's use of this plant.

Most caregivers spoke of preserving the PLWA's quality of life by respecting and attempting to fulfil their "expressed wishes." Wishes expressed included privacy, advanced care directives, the right to chose death, and dying at home. The caregiver functioned as an advocate to ensure these requests occurred. For example, Jeremy appreciated the significance of his advocacy role in guaranteeing Dean's advanced care directives.

I have a living will that I take with me if I have to take him to the hospital. Uh, because that's his wish. He was seizing a lot, thought he was dying. Um. They did not do anything against his will because if they did he would never forgive me. And if I did that to him, I would not be able to live with him. That I beli..., I am here to see that his wishes happen, you know. And if that's his wish, then he has it all in writing, that's what Dean wants. Dean cannot talk right now. I can, you know. I'm his friend, you know. I'm Dean's right arm and he knows it, you know. He knows it. [103-2, 920-935]

Several other caregiver's sought to respect the PLWA's request for confidentiality or secrecy of their status. For example, Freda recognized her son's "wish" for privacy and as well would have granted him any others.

So I sort of tried to follow through on his wishes and because I knew then that he wanted and he kept his life so private sort of thing that I knew he wanted that. He could have anything he wanted. We, we never, you know, said no, you can't have this or you can't have that. We fo..., tried to follow through what he wanted to till, you know (his death). [102-1, 1540-1549]

The most profound wish Freda honoured was Derek's request to die at home.

At that point when they did tell him, hey, you know, you don't have long to live. He decided, he turned to me and he said, "Mom, I don't want to die in a hospital, I want to die at home." And, uh, I was hoping he'd say that. So that's actually how he, I mean, there was no way I would have let him go anywhere or any place anyway. And I knew at this point, after being in the hospital overnight, that he was in there overnight. And after seeing the treatment he had, I, I would, I wouldn't care what it cost or anything but I would have specialists or whatever it was that would come right to the house here. And he wanted it that way, uh, he said he didn't want to die in the hospital, he wanted to be at home. And, uh, and I was glad that he asked, you know. And I didn't care if it was, if it took night and day or whatever. And once I knew I couldn't handle it, I knew that all the family would be there to help and they were. They were there, you know. [102-1, 1002-1018]

Freda had hoped Derek would choose to die at home. She felt the hospital environment did not fit with her expectations of the care Derek had needed. Freda's resolve to ensure Derek's request was substantial.

He said he didn't want to die in the hospital and when he said that to me, that was the, uh, like asking me, uh, for maybe the only thing in his lifetime that he asked me that I knew that I was going to, hey, do that for him and if it took, you know, my last breath, yeah, my last, you know, breath myself, that I was going to do that for him. [102-2, 105-117]

Freda was determined to ensure Derek's request at any cost. Her determination was based on ensuring the quality of Derek's life.

Emotionally, the energy that he wouldn't have had if he had been in a place where he felt, schedules are all sort of routinized and whatever is available is, you know, as opposed to having control, some sense of control about it's occurring. Like with you (meaning herself), you were able to meet whatever needs he had. That way if he wanted lunch at 2 in the afternoon as opposed to 11:30 in the morning. He had food beside him all the time. I mean, there was jello there, there was, uh, fruit salad. He loved fruits and he always did all his life. And there wasn't any fruit. My husband drove across the city to buy honeydews, cantaloupe, watermelon and all those things [102-2, 1019-1037]

Freda's decision to carry out Derek's request was not without consequence to her own health.

I never slept, I don't think, for 3 months. I really don't remember sleeping more than four hours at a time in the 3 months. For, I would say, almost 3 months, O.K. And I don't know. I just, uh, it didn't matter, you know what I mean? I just wanted him to be comfortable and, uh, when I, when he was sleepy I couldn't relax. I was doing things. In fact I would do things in the house and stuff like that, just to get my mind off of something else. But he wanted me to be with him, you know. Like some days, oh, like mom, leave me alone, you know, sort of thing. And then the next time, it would be, he would, he would just grab my hand and make me sit down. He just wanted his mom to be with.[102-2, 359-381]

Freda's decision to caregive at home required her investment of time and self. At times, this investment threatened her own integrity and her family felt the need to intervene.

So finally my oldest son from Calgary said, "This is it now." You know. "Hey, you're hurting, not only hurting, you know, yourself by not going to the doctor, you're hurting everybody else." [102-1, 927-944]

For several other caregivers their most difficult decision to maintain the PLWA's quality of life was their knowledge that the PLWA expressed a right to die philosophy. For example, Jeremy struggled morally with his knowledge that Dean may decide to chose his own fate.

And I know that, uh, the day might come when he realizes that he doesn't want to live anymore. He believes in quality time. And he's mentioned things to me that I don't like to hear. I don't want to know. If that's what you have in mind, that's fine. He's not suicidal, he's not that. But he could not see himself in a hospital. And he cannot see himself in the bed, on a bed for months and months. He can't do that. So if he does have any plans that's something I don't want to know. [103-2, 880-896]

In contrast, another caregiver did not struggle with the PLWA's belief in a right to die.

However, George struggled with being too late to help Brian execute the idea.

Um, if he had been in better health and chosen his own day, I was quite prepared to help him pick his own day if that was the route that he had chosen. When he finally figured that would be a good idea, and was all ready, he was already in the hospital. And I could no longer help him. That was very hard for me. [106-2, 474-480]

Once Brian was hospitalized, George's quality of life also changed.

Brian had just gone into the hospital, I was there to feed him three times a day. I got up in the morning, I met the breakfast cart, I fed Brian, I went to work. I left work at lunch, I went to the hospital, I fed Brian, and I went back to work. I did not eat. After work I went back to the hospital to feed Brian. I still did not eat, you know. I lost 14 pounds which I never do. It's just killing me to spend this much time there as I feel I need to or want to. [106-2, 1819-1829]

Although death was feared as a lonely, painful process which the caregiver wished to protect the PLWA from, living life as an AIDS caregiver could be equally as painful.

For one caregiver "quality of life" was something which was desired but not attained.

For example, Robert voiced his perspective of Andrew's life with full blown AIDS.

And there was no quality of life living with full blown AIDS.[107-2, 210]

Robert felt Andrew deteriorated rapidly once his quality of life diminished.

It was really fast but part of it I believe was Andrew could not handle what he had started to look like. Like I couldn't get him out of the house, home. We got a wheelchair here. I couldn't get him to go in the wheelchair to go outside. He didn't want people to see him. He couldn't stand mirrors. Certainly there's people who live longer with full blown AIDS I guess but he didn't want to. It was enough. He had had enough. He could have probably lived with it longer but his biggest concern was quality of life. [107-2, 180-204]

As well, living with AIDS affected Robert's quality of life.

And, uh, for the most part, it seems my life is really busy and I want to spend as much time with Andrew as possible. But yet, he needs so many other things, he needs so much done. That there were, that the amount of time I spend with him isn't really great. It was, I'm doing things with him, like if I wasn't trying to cook, or do the dishes or do his laundry, my laundry, keep the bathroom clean, um, change buckets for him every time he's been sick which could be, you know, every 5 minutes anyways, you know, like he'll just lie back down and he'll get sick again. You know, you don't want, who wants to get, I mean, I know he could get sick in another pail but you know, you can run infect.... another chance of infection or something and you just want to get it out of the room cause maybe he'll just settle down if it's not there. No, it's just, who wants to sit in a room with puke. [107-1,341-369]

For both the PLWA and the caregiver, maintaining quality of life was a significant aspect of AIDS caregiving.

### Physical Integrity

The caregiver's approaches to maintaining the PLWA's physical integrity was not a specific research question addressed within this study. However, physical protection constituted part of the caregiver's day-to-day management of the PLWA. Only those caregiver actions which demonstrate protection of the PLWA's physical health or environment from an advocacy perspective are examined.

Several family caregivers related protecting the PLWA from receiving less than sufficient medical care. For example, one mother ensured her son received diagnostic testing.

And I had to fight like, you know, the whole world to get Derek in there to have that MRI done and once that was all done and, uh, and that was the final blow. [102-1, 1089-1093]

Another caregiver negotiated with several health care providers to ensure examination of the PLWA's central line site for infection.

Anyways, um, on one of Brian's Tuesday trips into the doctor, uh, I asked his parents to make sure they looked at his site (Groshong Catheter site). Didn't look right. I saw it every day. I knew what wasn't right. Doctor said it was fine. Was not fine. Uh, Brian went in for a transfusion, so while he was in there, I paged the HIV nurse and I said you know, "Have you been up to see Brian?" "Yeah, nnn, nnn, nnn." I said, "Well what do you think of his site?" She said, "Didn't look at it." I said, "Well, didn't the nurses say anything to you about it?" She said, "No." I said, "Don't they look at this?" And she said, "I guess not." I said, "Are you nuts?" you know. Like when you've got a person who's got that sort of an IV and they're there, wouldn't you automatically just check that site and make sure that it's O.K.? Apparently not you know. So they decided, oh yes, it is indeed infected when they finally looked at it. [106-1, 665-696]

Advocating to ensure the PLWA's physical care was effective and safely maintained was also done within the home. The singular importance of the PLWA's safety was stressed above all else.

And, uh, that is the key thing with the volunteers, you know. They'd look around, nice place. There is nothing more important in this house than Brian, you know. If you have to knock the TV on the floor to stop him from falling, he is the most important feature in this house, you know. Nothing comes before Brian. Nothing. O.K. (chuckle) Yeah. [106-1, 899-909]

Caregivers reported their diligent use of hygiene precautions to promote the PLWA's physical comfort and safety. For example, George spoke proudly of his actions to prevent infection in Brian.

And he got more infection by being in the hospital than by being here. I mean, this was an infection-free household. I mean, bleached down his bathroom every morning. If he so much as did anything on the sheets on his bed, pffft, change them. Dishes were sterilized every single time they were washed. Like scalding water. Had to use rubber gloves. There weren't nothing in this house more important than that boy. [106-1, 886-895]

For Freda, protecting Derek from possible infection also involved protecting his sense of self.

And like I mean I was washing sheets every day. In fact, hey, I lost all my fingernails. All from Javex. All of them. And I'm down to this is the last one to come back. So that's, I did, I had lost them all and, uh, because I was using like pure Javex. Stupid. I was putting my hands right in pure Javex. Didn't even like, I was numb. I was so sick putting gloves on constantly and that was one thing that, in a sense, um, I felt very uncomfortable around Derek with gloves on. And I, you know, I didn't want, cause I didn't want to make him feel uncomfortable but finally I mentioned it to the doctor and the doctor said to Derek, "Do you mind if your mom wears gloves?" And he said, "No, I don't care." "It's O.K. mom, you can", he said. So then I felt, you know, better, at ease sort of thing but I would go through three and four jugs of Javex a week. [102-2, 1942-1978]

Wearing gloves was perceived as a barrier which could put distance between Freda and

Derek. Rather than put any barriers between herself and Derek, Freda bore the effects of the Javex.

For one caregiver, maintaining physical safety also meant protecting the PLWA from harming himself. For example, Jeremy balanced Dean's need for independence against actions that could be life threatening.

Uh, like this, I know what pills he takes but I, that is something that I really don't want to know about. Peter deals with that. When he needs to order his pills and I know that he's not there, all there, (mentally oriented) then, yes, I'll order his pills. Peter had to do his pills for a year cause Dean overdosed on us and I think that's why he got sick with the seizures. So we had to take his pills away and we had to keep them under lock and key, cause we thought he was trying to commit suicide. I don't think so. He just, just was getting mixed up, you know, he didn't know if it was morning, he didn't know if it was afternoon. We took something away from him. [103-2, 1654-1674]

Although Jeremy took away some of Dean's autonomy, he protected him when his confusion could have led to disastrous consequences and a fatal error. As well, Jeremy took actions to protect Dean's physical assets in their environment. For example, Jeremy prevented others from taking advantage of Dean's acts of graciousness in his illness.

What kind of people are they? Taking advantage of the sick. When I first met Dean, uh, let's say you would come to visit Dean, and you knew it was for your own benefit because he would say, oh thank you for coming and uh, and then you would comment on a knick-knack, "Well, that's a really nice dish." "Here take it, take it home." And people would come back. And more and more. And every time I'd come back to visit Dean, I would like, "what happened to that, you know, that thing you had there?" "Oh. I gave it to so-and-so." And his house was bare. And I said, Dean, this has to stop. [103-1, 519-538]

Protecting physical integrity encompassed those actions caregiver's used to maintain the PLWA's physical health and environment. Protecting psychological integrity encompassed those caregiving behaviours which sought to preserve personhood and quality of

life. One caregiver comparatively reflected on the meaning of protecting the PLWA.

I have a nephew that's autistic. How hard is it for my sister? She went through a, a good 2 years of not taking him out in public because she was embarrassed. Oh, she didn't like people looking at him, like he was a freak. She was protecting him. And I think that's what I do with Dean at the moment. [103-2, 1521-1529]

### Labouring the Emotions

*Labouring the emotions* describes the dynamic emotional reverberations of the work of family caregivers. Emotional labour is an outcome of the caring aspects of the family caregivers' efforts. It is shaped by the sense of connectedness the caregiver has with the PLWA. This theme describes the expressive consequences rather than the instrumental or objective work associated with caregiving. Labouring the emotions is integral work associated with ongoing caregiving throughout the AIDS illness trajectory. It describes the enduring impact perceived by the caregiver, which is associated directly or indirectly with his or her caring for the PLWA. This labour entails the family caregiver's emotional responses to the caregiving situation as a result of engaging to caregive, the monitoring of the PLWA and the protective work associated with caring. The theme of labouring the emotions is defined within temporal, affective, relational, and contextual characteristics.

Labouring the emotions relates the caregiver's expressive labour which is both felt and managed. The caregiver uses time, cognitive skill, presence, and emotional energy to make sense of the experience. The temporal dimension of labouring the emotions combines the past, present, and future consequences of the caregiving experience. The past can act to reinforce positive emotional feelings or to remind the caregiver of the difficulties encountered



which may have negatively affected his or her emotional energy reserves. The present provides an opportunity for the caregiver to immerse in the work of labouring the emotions and to reflect on prospects for the future. As well, the present dimension situates the caregiver within the AIDS illness trajectory and the emotional labour associated with the current presenting problems of the PLWA's illness. The future dimension of labouring the emotions is defined by the caregiver's uncertainty surrounding the AIDS illness trajectory for the PLWA. As well caregivers are often uncertain of their own anticipated responses to the PLWA's status.

The essence of labouring the emotions is that it is heart-rending work undertaken by the caregiver. The emotional component of care, like the physical component, is labour in the sense of hard work. In substance, labouring is evoked when the caregiver acknowledges his or her heart's feelings. The caregiver attests to his or her heart's emotions. It entails the intangible emotional work the caregiver does to manage feelings and ascribe meaning to events which are a consequence of caring for the PLWA.

This emotional work is actualized by the caregiver's experience of feelings and through a sense of his or her connectedness with the PLWA. The relational characteristic of connectedness implies more than the caregiver "just being there" in a geographical context, although this is inherent in the relationship. Connectedness is a mutually felt experience of caring which is developed throughout the caregiving process. Through connectedness, the caregiver's heart realizes the emotional impact of its caring efforts.

The relational dimension includes the responses of others outside of the caregiving situation which influence the heart's feelings. Contextual factors distinguish the social or life

situations and exert boundaries which may influence the caregiver's emotional labour. For example, the contextual influences of work, the availability of support, and the responses of the extended family, were identified as contributing to and compounding the work of labouring the emotions. As well, the ability of the family caregiver to use existing resources influences this labour. These contextual factors increased the demands on the caregiver's time, presence, and energy, and could greatly tax his or her emotional responses.

*Labouring the Emotions* is comprised of three categories: labouring in exile, labouring of losses, and the labour of uncertainty. Each of these three categories comprise a substantive source or domain of labouring. Although each domain is described independent of the others, they may not be mutually exclusive. All three domains may occur concurrently to synergistically contribute to the labouring of emotions. For example, the labour of uncertainty may be simultaneously experienced while the caregiver is labouring in exile and labouring the losses. The domain of labouring which occurs is defined by the caregiver's perceived emotions and the outcomes associated with the caregiving experience. Inherent to all the categories, is the caregiver's emotional work associated with attaching meaning and the managing of feelings attributed to the caregiving experience.

### Labouring in Exile

The category of labouring in exile is the caregiver's sense of feeling separated or forced away from those resources which may otherwise have been used to help manage the emotional consequences of AIDS caregiving. Caregivers may feel forced away from their home, or isolated from their family or community, as a consequence of AIDS caregiving. As

well, contextual restraints which affect his or her working through feelings associated with the process of caregiving may be imposed. For example, one factor may be the secrecy surrounding AIDS caregiving. This forces the caregiver to manage his or her feelings without some of the usual avenues of societal support offered to families caring for a chronically ill member. Exile denotes the family caregiver's sense of being all alone in his or her emotional work and its attendant feelings. Attaching meaning and managing perceived feelings encountered as an AIDS caregiving consequence, are singularly accomplished by the caregiver. The emotional outcomes of labouring in exile are experienced by the caregiver as feelings of hurt, anxiety, anger, fear, frustration, and isolation. As well, because of these feelings, these outcomes themselves may act to further isolate the caregiver.

Labouring in exile may occur because of managing the contextual restraints imposed by families and society. In some of the families, there was a need to maintain secrecy associated with AIDS and its caregiving. Imposed secrecy may stifle the caregiver's communication with the PLWA, the family, and/or in social circles. Additionally, some families perceived there was stigma in caregiving to a PLWA. These forces contributed to the caregivers being isolated. Feelings of isolation and distancing from family, friends, and society occurred when the secrecy and stigma influenced the caregiver's feelings. The caregiver was then subject to labour in a socially isolated context while experiencing the emotional strains or stresses of caregiving work.

For most caregivers, the availability of support from at least one of the expected sources such as family, friends, coworkers, or a social group, was not readily accessible. Five of the family caregiver's expressed feelings of isolation from their families or friends

when they engaged in caregiving. Of the remaining two family caregivers, one related being supported by her family. The other caregiver did not specifically relate feelings of exile as a consequence of caregiving, but realized exile as a personal circumstance in her transition to becoming transgendered.

Labouring in exile is multi-faceted in its characterization. It is comprised of several different kinds of estrangements. Each of these are interdependent and affected by the others. For clarity, labouring in exile has been contextually grouped by the source of estrangement. This section will describe exile as comprised of the estrangement from family and or friends; estrangement from community and or society; and estrangements as a consequence of anger. These are presented with supporting data as a set of causes, contexts, conditions and interactions that account for labouring in exile.

### Estrangement from Family

This category describes the exile felt by caregivers as a consequence of their interactions with family and their respective responses. The contextual issues surrounding the estrangement of support from family and friends are diverse. For Robert, his estrangement was self initiated. Although Robert had a good relationship with his family, he never told his family of his engagement as an AIDS caregiver.

And my family did not know what was going on. They didn't even know that Andrew was living here. My parents or my brother and sister, or know that Andrew was, had AIDS even. Nobody knew. I told my family when Andrew decided to die. [107-2, 1419-1424]

Robert had decided that to maintain secrecy was the best course of action because of his concern for his family. His past history of a relationship with Andrew may have influenced

his choice to not inform his family and to access their support. Robert recognized he was emotionally spent in his labour with Andrew and didn't have the time to spend with his mother.

How do you tell your mom that your ex is dying, your ex-lover and friend is dying of AIDS? You know, try to make her believe for one that you don't carry the virus. To reassure her because you don't, you don't have any time to spend with her to make sure she's O.K. with this. You know, at this time. Because you're spending all your time with Andrew. That was my concern. How can I reassure my mother? Cause I have no time to spend with her, you know, so I'll just wait. [107-2, 1451-1468]

Robert decided to wait until Andrew was dying in the hospital to inform his family of his caregiving. The decision to share was pragmatically made when Robert recognized that he would not be able to be reached at his home in case of an emergency.

I started sleeping at the hospital and I told my brother and sister. Didn't tell my mom and dad. I told my brother and sister just in case something happened, where to find me. Cause I wasn't phoning home and checking messages. Just so people knew that, if there was an emergency, where to contact me. So that was a little difficult, trying, you know, partici..., like every Sunday is a family dinner, but you don't miss it. So to go there and, "What have you been doing?" "Oh, nothing", you know. You're lying again and you think after coming out to your family there won't be any more lies. [107-2, 1426-1446]

Robert refrained from sharing his AIDS caregiving involvement with his parents as he was concerned for the difficulties that would ensue. However, the wait was not without its difficulties. When his parents became aware of Andrew's death, the difficulties Robert was trying to avert were realized.

So, she (Robert's mother) ran into actually Andrew's parents, or dad read his obituary after he passed away. My mother actually caught it (Andrew's obituary) before she went to work so she phoned my brother and sister, all crying and this and that. And like, "yeah, we knew". Like "Robert phoned us last, the night Andrew died", and that I'd phoned and told them. So it just set off a whole can of worms which I just wasn't ready to deal with. [107-2,

1470-1488]

Robert limited the opportunity for receiving support from his family, because he knew that his family's responses to his caregiving would require both his time and emotional energy. He recognized that all his time and energy were required for caring for Andrew.

As well, Robert had difficulty accepting a friend's perspective of Andrew's physical status. In essence, Robert exiled himself from the response received.

A friend was telling me, he's in the latter stages of death. His body this. His body that. And everyone thinks they know so much. Like, you know, it's like leave him alone. Like I think you may think he's dying and I don't want to think he's dying. I don't want to think anything except how he's feeling. He's feeling the shits you know, so that's where we're at today. You know, don't go and tell me he's dying. He's just feeling the shits. He's having a bad day. You know like people have bad days, especially when you have AIDS. [107-1, 505-520]

Robert did not want to hear the friend's assessment of Andrew's present status as it forced him to come to terms with the reality of Andrew's illness. For Robert, the ability to maintain his caregiving was limited to the internal sense of support gained from "doing" for Andrew.

But I don't think I leaned on anybody. I mean, at that time, what gets you through is just Andrew. I mean, sitting there with him himself. You know, even if he doesn't need something, you gotta do something. [107-2, 808-813]

Robert chose to labour emotionally while maintaining a self-imposed exile from his family and at times his friends.

Two caregivers expressed that their families disapproved of their caregiving. For these caregivers, their family's inability to support them in their caregiving efforts contributed to their feelings of exile. For example, Lizzie's access to her family's support while working through her feelings as caregiver, was limited by several factors. Her family's negative response to her caregiving relationship with Tommy was a consequence of history.

When Tommy entered Lizzie's life, he had engaged her and everyone in her family through deception.

He came into our lives and he lied. He told this unbelievable, excuse me, (tears), he told this story about who he was. And slowly it just started to unravel. I believed everything. And then, after, I was on the verge of a nervous, a breakdown, felt I was. [104-2, 2037-2043]

I have a psychiatrist that I see off and on and I'm seeing him now, cause I need some help here. And I've said to him, what, you know, am I crazy? [104-1, 779-783]

When the truth surrounding Tommy became known, both Lizzie and her family were distressed and overwhelmed. Lizzie's sister with whom she shares her home, responded by attempting to banish Tommy from their midst.

When this whole thing with him came out, she (Lizzie's sister) said, "I do not want him in the house when you're not there." So I found a place for him to stay which was next door, but he would say to me and he would be over at my house every day and every evening. "Can I just sleep on the floor. I'll just sleep on the floor. Sleep in a corner." Uh, I said, "O.K." He wore me down. [104-2, 2471-2485]

Conflicts occurred between Lizzie's family and Tommy as a consequence of her engagement as a caregiver. With pressure from both her family and Tommy, Lizzie's resolve wore down. When Tommy reentered Lizzie's home, she was confronted by her sister with being exiled from her own home.

She said, "We have to sell the house. I can't live like this any more." Blah, blah, blah. She was always dangling this over my head, that we have to sell the house. Then I came to a point where I thought, it's only a house, even though I love my house. I love it. I said. O.K., you can sell the house. [104-2, 2504-2514]

Lizzie was forced to choose between losing the support of her sister or being banished from their home, because of her caregiving to Tommy. When presented with this choice, she

chose to follow her heart. As a consequence of this choice, she suffered, alienated from her family and friends.

Anyway, when he revealed himself, my family has just never forgiven that. And they don't trust him. And they feel that he's just manipulating me, which he is. That he's continuing to lie to me, which he is. I don't tell them anything anymore. [104-2, 2118-2124]

The ripple effect, the reverberations in my family, I have two sisters, in my family have been enormous. Enormous! I'm, I'm almost estranged from all my friends because he's just totally demanding on my time. [104-1, 510-516]

Lizzie identifies feeling forced away or estranged from her family and friends because of Tommy's demands on her time. However, it is also her family's discomfort with Tommy's presence which limits their accessibility to support Lizzie.

What has been the, what has been the, uh, I don't know what the word is, the thing that's keeping my family away. I don't know. You can see why people with AIDS are so fearful of other people finding out, because my sister. Oh, it's so complicated. [104-2, 1888-1893]

The complications Lizzie alludes to are historically based. Her disclosures detail the contextual history which has exiled her family from her.

It's just, it's just very complicated but in terms of, terms of his illness, I'm uh, and I guess I'm feeling isolated. Like I spoke to my son last night and I just want to talk to him about this (the caregiving) and his girlfriend doesn't want to have anything to do with this person. And they can never come, the two of them for dinner and my son's not all that comfortable with him. My other son was there last night, it's like I'm balancing, I'm juggling. So he's (Tommy) away tonight, so my sister and I will have dinner tonight. And um, I'm just feeling sort of sick inside. Like my heart is. [104-2, 111-121]

Lizzie's heart felt sickness is in response to feeling isolated from her family. She juggles accessing her family's support, which precludes their ability to support her while she endeavours to support Tommy.

So the boys (her sons and their cousin) are in town and, but my friend



(Tommy) is not invited for dinner. Now I feel badly about that but they don't want him there. They want me without him. They don't want him. And I said to him, "Would you go if you were invited?" and he said, "No." And he said, "I wasn't even invited. I didn't have that option." And I said, "You understand." And I feel sad, you know, I feel I don't want to hurt him. But I need to be with my family too. [104-1, 1043-1058]

In choosing to access her family's presence and not feel isolated, Lizzie contends with her need to not hurt Tommy.

Isabelle's labour is also one in exile from her family. Although she has family living in the city, she feels alone in her caregiving efforts. Her son has been the force which is exiling her from the help she perceives she needs.

And I phoned Jerald's doctor to get help. I said I have to get help or I'll lose my mind. I spoke to the doctor and I told him the position, what was happening, you know. And I said, I could go through my house walking on egg shells. If somebody phones me, I'm afraid to answer because I'm, not maybe speaking properly to them. My friends would come in and he'll literally knock them down to get out of the way. The food is not good and I can't, I need help. I need someone to come and help me. [101-1, 120-137]

Isabelle fears for her mental state and seeks outside help. Her fear of Jerald's behaviour has exiled her from her friends. As well, her family feels unable to support her in sustaining this caregiving effort under these conditions.

My daughter phoned and he was very, very rude to her. My daughter phoned and asked, "What's going on there mom?" I said, Jerald is in one of his tantrums." "Oh", she says, "mom get him out of the house", she says, "even if you get the police to get him out because" she says, "you're going to have a heart attack." She says, "get him out of there." But I can't do that. I couldn't phone the police and say get him out, you know. [101-1, 612-627]

Isabelle continued to caregive because of her ability to seek out those resources which offered a liberation from exile.

One caregiver expressed feeling a lack of support in his caregiving from the PLWA's

family. George felt disconcerted by Brian's parents control of decisions during his hospitalization, in light of the distance of their relationship.

They (Brian's parents) had already distanced themselves from him, you know, whatever their family relationship was, I mean Brian had been well distanced for many, many years. [106-1, 1260-1264]  
 And on his living will, it was his parents and I. Only need two out of three. His parents should have had no right quite frankly. They didn't want him. Yeah, they were hoping for a miracle and I was it. And they were quite relieved that I was willing to do this. [106-1, 708-715]

Brian's parents may have been relieved that George would care for Brian. However, their relief did not translate to the support George felt he needed.

They (Brian's parents) were also the type of people, "If you need anything, let us know." "If you need anything," um, and I'd say, "Well, you know, I just find it hard staying on top of everything around the house, like housework, cooking, da da da da da." Well, his mother says, "You have to learn to make things up the night before so that you can just put it in the oven the next day." I have time for this? I really have time to do that. I don't have time to do when I get home from work, what makes you think I have time the night before when doing his IV or trying to get him into the bathtub. Uh. And anytime I, if I said I needed a break, "Well, you can go to work." That was my break. Eight hours a day at work, 16 hours a day caregiver. That was my whole life. So, his parents are not big in my books.[106-1, 807-832]

In this example, the distance which was present in the PLWA's relationship with his family, also extended to his caregiver. In effect, both the PLWA and the caregiver were exiled from the family's support.

One predominant contextual factor that affected caregiver's feeling of isolation was secrecy. Secrecy acted as a force which distanced the PLWA, the caregiver, the family, and friends. Distancing occurred when the caregiver was unable to openly communicate about AIDS caregiving with others. Caregivers felt morally bound from openly communicating to maintain the PLWA's secrecy. For one family caregiver, knowledge of the PLWA's

seropositive status was maintained a secret from extended family and encompassed her AIDS caregiving efforts.

Like I know even the family members would come and say, "What's wrong with Derek?" And you know, "He's not right, he's not fit" you know. And they all had their suspicious thoughts of course that something was wrong. And, uh, and I'm sure between them they discussed, you know, their thoughts but it wasn't something that anybody just come out and said, "Well, hey, you know, there's something definitely wrong" and that's how well Derek kept the secret away from, that he was sick. And even his friends that he had known for 5, 6, 7, 8 years did not even know that he was sick and were completely surprised when they heard that he was so sick that, you know. They just didn't, they couldn't believe it because they had you know, been with him a lot of times and he never ever, ever told them he was sick or anything, you know. [102-1, 1254-1280]

And it was very hard because grandpa, we tried to keep, you know, as much away from him as we could and he wanted to know why like Derek wasn't coming up to have meals and all that. But Derek was at that point was getting so he couldn't eat by himself and that. Uh, and, uh, that was the very, that was very hard at that particular time. And so Derek said, "Well I don't want grandpa and everybody to know how I feel I want to go back home." [102-1, 869-876]

Secrecy functioned to protect Derek and Freda from the possible negative responses of his family and friends. However, it contributed to their social isolation, reduced their availability of social support, and their ability to ask for help. As well, interfamily communication was also affected.

He (Freda's husband) finds it very hard to talk about Derek. He very rarely will bring up Derek. I'm the only one that talks about Derek really. Nobody else in the family will. [102-2, 1332-1336]

The secrecy surrounding Derek's life, left Freda with uncertainty.

I don't know how he did it, I don't know how a person can live almost like two separate lives, that he lived. I just, I don't know. [102-1, 1245-1248]

For Freda, Derek's secrecy was one which exiled them from potentially available support.

Two gay caregivers spoke of maintaining secrecy of their knowledge of other family members who were HIV seropositive. For both of these caregivers, this knowledge was taxing.

I have a relative who tested positive that does not deal with it. Um. And that's tough. That's the toughest one. It's a nephew. And I'm the only one that knows. And ultimately, everybody gets to know. And I don't envy my position when that happens. Yea. So that's a nightmare I'm not looking forward to. Um. And I don't go for the test, so I could be just as precarious as everyone else. I personally don't feel there's any great advantage to knowing. I'm quite hap..., well right now I could increase my happy. [106-1, 243-260]

George's knowledge of his nephew's HIV positive status, reinforced his position of maintaining secrecy and not to seek HIV testing.

I know that when it comes down to the crunch, I'm going to bet the, why didn't you tell us? You know. It's not my business to tell. It's his business to tell. Um. And besides they don't want to be going through this hell you know. I know that ultimately this is going to come out. Do I want his mother going through that? No. My mother? No. Nuh, Nuh. Would I add stress like that to other people's lives? [106-2, 1425-1439]

George maintained secrecy of his nephew's status to protect his nephew's right to disclosure and to protect his family.

Another caregiver maintained secret the knowledge of her brother's recent seropositive status. Margaret had experienced the reactions of her family to her HIV positive status and was concerned about her family's anticipated response to her brother disclosing both his gay and HIV status.

Just the, I guess, the reaction of my brothers would be really. I don't know. I don't know if they'd be um, hard to deal with this or, they were prejudiced with the fact that I was gay so. I guess not knowing that my younger brother was will really shock them. A lot of deep secrets are going to come out. [100-3, 389-394]

But I think he, he's wanting to have the whole family know about it right

away instead of when it's too late. Which is kind of good in a sense, you know. [100-3, 410-415]

Margaret's past experience with disclosing her gay identity and HIV positive status to her family influenced her concerns for her brother. She is hopeful that his early and complete disclosure to the family will have some positive advantages. Margaret recognized that if her brother maintained the secrecy of his HIV status it may delay the usefulness of her family's support. For these caregivers, secrecy served as a form of exile to distance the intrafamily communication and possible opportunities for support.

### Exile from Community and Society

This category describes the exile felt by caregivers as a consequence of the responses of community, society, and the health care system. Several family caregivers related that they felt exiled because of the stigma surrounding their homosexuality. For one family caregiver, the capacity of the gay community to respond compassionately to his caregiving efforts contributed to his feeling of exile. As a member of the gay community, Jeremy expected understanding of his AIDS caregiving.

But one thing I did not expect was I thought if any people would understand somebody with AIDS, would be a gay person. And I found out the gay community is very cold towards understanding about AIDS. I thought if anyone would understand or be compassionate, they could, don't treat him bad because I'm treated that way. [103-1, 1365-1374]

Jeremy detected his community's lack of compassion in the treatment of PLWA's and felt unsustained in his efforts. As well, because of his caregiving, he felt judged with the same lack of understanding and compassion directed towards a PLWA.

It's like, there's a chance that people will start thinking that you might be HIV

because, you know, guilt by association. [103-1, 1422-1425]

And then, that's where, now it's not just the heterosexuals I have to deal with, now it's my own community. [103-1, 1488-1491]

As well as his "own community," Jeremy felt the need to hide his sexual orientation from his neighbours and the heterosexual community.

So that's why, you know you have a 6' fence and you know, you adapt to live inside of these wall, you know your lifestyle. And then as soon as you walk out the door, it's like you take a big breath and you hold it in. And it's like, no, now you have to pretend you're somebody else. Being 35 years old and still doing it, that is hard for people, you know. [103-1, 356-364]

Jeremy expressed his experience as being exiled from his gay community and society, as a result of both his homosexuality and his AIDS caregiving.

For one family, the caregiver and care recipient were both HIV positive. Their feelings of exile are experienced through being gay and a PLWA. Margaret and Harry engage in the discourse on the meaning of being a gay PLWA.

Harry- It's like "coming out" all over again being a PLWA. I think it's even worse. Being a gay person, you know you have people who are you know, prejudiced I guess too, that sort of thing and everything else and. But uh, as far as being a PLWA is concerned, it's even worse because the people you thought would back you up being a gay person, who are very educated on the subject, wouldn't be this way, but they are. Just as prejudiced as everybody else.

Margaret- I say, if you spit up in the air, it's gonna land right on your head.

Harry- And so like people who were supportive maybe outside of the community and stuff like this will not be supportive, you know, like won't be seen with you. Because then people will think, oh, talking to that one, he must be too. [100-3, 3257-3272]

For another gay family caregiver, there was a need to maintain secrecy regarding his homosexuality and his status as an AIDS caregiver at his place of employment. Robert feared that this knowledge could exile him in his work life.

Here it's a little family run business. One of the girls is extremely homophobic, extremely. Um. So I wouldn't feel comfortable in that situation and it's just, you know, uh, even with the AIDS disease itself, you know, for them to know that you took care of someone, that this person was living in your home. "You've got to have it Robert", and uh, and then trying to work with them after, trying to, uh, for them to even, uh, just even to handling cases, you know, fearing that oh, you're going to put AIDS back to a patient or something like that. And then it's just pure silliness but that would be her mentality of the disease. She wouldn't even want to deal with it. So no, I didn't share it with any of them. [107-1, 2271-2292]

The stigma of AIDS and homosexuality affected Robert's ability to openly share his status as an AIDS caregiver with his coworkers. Robert secretly maintained his AIDS caregiving for fear of reprisal at work.

Secrecy surrounding AIDS was also exigent for heterosexual family caregivers, because the PLWA or family caregiver feared alienation or reprisal from others in society. For example, one caregiver was unable to seek the support of her coworkers, because of the PLWA's fear for his confidentiality. As well, the caregiver's perceptions of societal support, either through past experiences or within his or her present social situation, affected feelings of exile. For example, one mother related the aftermath of her son's disclosure of his HIV status while frequenting his favourite drinking establishment.

Jerald got to know a waitress up there and she said to him one day, she said, "Don't you work?" And he says, "No, I've been ill." Now to me, he should have said no more. Should have stopped right then and there. But she then said to him, "Well, what do you have?" He says, "I'm HIV positive." "I have AIDS" just like that. O.K. The next day, he went up for a beer and he was back very fast. Came back and went up to his room and I didn't see him all day Saturday, all day Sunday. Just came down, went to the toilet, went to the kitchen, to the bathroom and went back again. Monday he came to me and said, sat on the couch and he says, "Mom, something happened." And I said, "What happened?" And he started to cry and I said, "Jerald, what happened? Tell me." He says, "The fellow" he says "that owns the bar" he says, "put me out." "What"? So then he told the whole story and I said, "What the heck did you tell them you have HIV positive," you know. "Shouldn't have said

anything." [101-1, 210-250]

Jerald's expulsion from his favourite drinking establishment was perceived by Isabelle as a form of exile. Isabelle perceived this response and reinforced to Jerald their need to maintain the secrecy of his AIDS illness from society or suffer the consequence of reprisal by society. Isabelle and her family felt the stigma of society toward Jerald and sought to redress this grievance.

The family was already upset. My son-in-law was furious. My daughter said to me, "I'm going to write to John Doe, (newspaper columnist) I going to phone John Doe." And I said, "No, I'm phoning him". And the next day John Doe had it in the paper. But John Doe didn't side with Jerald. And as I said to John Doe, you know, I said, "You could have it in your own family." "Oh, no, no, no", he said. I said, "You don't know." [101-1, 260-265, 290-295]

Despite this nonconfirming response, Isabelle's faith in society was renewed when other responses received were supportive of Jerald.

So in any case, there was quite a few (responses to the story), even one of, a councillor and all, heard about it and they phoned and they wanted Jerald to take action against them. And we said no. We didn't want anything like that. All we wanted to do is let people know the AIDS patients are people discriminated against. We weren't doing it for monetary gain or anything like that. [101-1, 306-317]

However, Isabelle notes the toll of society's reprisal taken on Jerald.

But from that day on, he started going down again emotionally. Really bad, really bad and his anger fits were coming more often. And uh, then he was, he's been in and out of the hospital, you know. [101-1, 331-337]

Responses such as the above by society towards the PLWA and the caregiver, encouraged both to maintain secrecy of their status or be exiled. The discrimination and stigma felt as a consequence of AIDS was poignantly summarized by one family caregiver.

So, but I can see why people with AIDS are so terrified by the people finding out, because it's like leprosy. [104-2, 1960-1963]



Interaction with the health care system also contributed to some caregiver's feelings of exile. At times, some of the family caregivers felt fortunate in their interaction with the health care system and satisfied with specific care providers. Frequently mentioned were Dorothy, a HIV nurse clinician, and Peter, a nurse with expertise in AIDS caregiving who provided home care in the community. For example, having met Peter has helped both Isabelle and her family in dealing with Jerald's anger and other needs.

So I met Peter, and it's turned out very helpful. Peter had a meeting with my two daughters and me and we talked about what the disease was like, what would happen, so on. And um, I asked Peter, like could he take seizures and that. And Peter said., "Oh yes, he could. And if he ever does," he says, "Don't get alarmed, just lay him down" he said "on the floor." He says, "Hold him." And to tell me that, that's how he took seizure. [101-1, 181-192]

However, at other times and/or for other family caregivers, the health care system was perceived to be deficient in meeting expectations for care. Frustration was one emotion cited by family caregivers and the PLWA when the health care system was unable to provide the resources or care perceived to be required.

And Brian had a Groshong catheter in his chest rather than in an arm, something that St. George's in Halifax, they've been successful with. And some of the nuttiest time I went with, would be talking to someone in nursing on the phone and I'm explaining, "nnn,nnn, and Groshung catheter in his chest." "Are you sure?" You know. "It's not in his arm?" I think I know the difference between a chest and an arm. Like, come on, please, you know. Um. That frustrated me a little bit, um, the home IV program frustrated me. If you had any problems with your pump and you phone them to ask them about it, they didn't have a clue. It just seemed like the system was not going to help. The system was not prepared, um. So it came to the point where I was always prepared to muddle through because I didn't feel supported by the right people. [106-2, 571-598] [106-2, 617-622]

George felt frustrated and alone in his management of Brian's central line. As a consequence, he became exiled from the health care system which he felt lacked in

supporting him with the expected expertise.

Frustration with the health care system was also experienced by another caregiver.

Freda was frustrated in her efforts to obtain the medical services she perceived her son Derek required.

And we were getting like the run around here and there and everything and I waited and like I was just very frustrated at that point. And finally when they phoned and said, well, it will be 2 or 3 weeks or whatever, I just said, that isn't good enough for me. I want it done now and I don't care what it takes. If I have to hire an ambulance and go to the States or whatever, I wanted it done as soon as possible. I wanted to do what I could to my best ability. And yet I think down deep I knew that within me there probably wasn't anything that could be done other than just make him comfortable. [102-2, 141-158]

Several family caregivers expressed their concerns regarding the health care system's treatment of their loved ones. For example, Freda was aghast with the hospital's care of her son.

So finally we got Derek to go and he had his blood tests done and that and, uh, he was taken from there. I took him into the hospital which was, was a scene all by itself. And uh, I don't know if you want any information on that at all. But it was just the most horrible thing ever, to ever happen to me in my life. [102-1, 984-992]

Freda expressed further distress regarding Derek's subsequent hospitalization and the doctor's advice that Derek personally disclose his AIDS status and his near death to his family.

And that was one thing that I don't know if I really accept that, like the doctor just came right out to him and, while he was in the hospital on one of the bad occasions of going there, and said to him, "Now you're dying and you have to tell your parents, like your mother, that you are dying and I'm not going to tell them, you are." And I think Derek found that very hard. It would have been so much easier for the doctor to say, you know Derek has only 2 weeks or 2 months or whatever. But that was very hard on him to tell each one of his family. [102-2, 182-197]

Freda had difficulty accepting this advice and felt Derek deteriorated and distanced himself with each disclosure.

And I think in a sense he shut out all his friends and all his relatives other than, uh, his immediate family. And I think that was why, because he was so drained already. [102-2, 235-239]

In essence Derek became exiled from his friends and extended family as it drained his energy to disclose his status.

Similarly, another mother related concerns regarding the noncaring approach to her son when seeking hospital care.

He was vomiting and he was vomiting and he was vomiting. And he was dehydrated. And he went off to the hospital. And I didn't realize at the time that I should have went with him. And I should have phoned someone to come and go with him. But he went to the hospital, he was, pretty weak and went in and he said to them you know, I need, he knows the medication that he wants that will help him, you know. We've gone to the Children's Hospital when a child is over there, a little kid when she's got cancer, she can tell you exactly the medications that she's on and what they're giving her. So he tried to tell them, like this is what he needed. He knew he was dehydrated from his vomiting, but no, they insisted that he would have to sit down and give all the information that they al., they already had all this, you know. And then a young fellow came along and he says he was an intern. And he told the intern what he wanted you know and the intern says, "Hey, you're not at McDonald's that you can go in and order a milkshake". And Jerald says, "Well" he says, "I would have got the milkshake a lot faster than I'm getting medication that I need right here." So the next thing, they came back, the intern, and gave him exactly what he had, he had asked for. So after starting it or something, they told him they were going to put him in the hall. He says, "You're not putting me in any hall." And the nurse says, "Well, we have a patient out here with terminal cancer that needs that room." This is in the emergency. Now I might be getting confused because so much has happened, you know. Uh. He said, so the nurse came in, he says, "I'm not going in any hall." He says, "I'll go home first." And the nurse just come in and she said, "Well you better sign this." And she pulled the IV out of his arm. It wasn't even finished. [101-1, 353-415]

And Jerald wrote to the paper and said he's sure that the Premier if he'd went to the hospital, wouldn't have been shoved in the hall. And he said "They

hadn't even a blanket for me." They told me the reason they didn't have a blanket for him because there was no funding to get blankets for them. [101-1, 425-437]

Isabelle described Jerald's inhumane treatment as an ordeal which lacked in respect and dignity. As a consequence, Isabelle requested that Peter accompany Jerald on subsequent trips to the hospital to act as his advocate. As well, Jerald also had a month long stay at a hospice which was felt to be less than satisfactory.

So then he went to [a hospice] and that was a disaster. Complete disaster at [the hospice]. Now, I think right now, he's quite happy at home. He came home last week Monday. When he came, he phoned me. He said, "Mom, I'm coming home." And when he walked in through that door I nearly died. I thought it was somebody coming out of a torture chamber. He looked awful. He hadn't slept for 4 days. [101-1, 1040-1051]

For these caregivers, their first hand experiences and those experienced second hand through information shared by the PLWA, left them with a negative impression of care offered within the health care system. These experiences acted to reinforce the caregiver's need to protect the PLWA and to provide caregiving in the home. In this sense, the caregiver became isolated or exiled from those health care resources which are usually perceived to be supportive in times of illness.

### Exile from the PLWA

The caregiver's ability to maintain a sense of connectedness with the PLWA was affected by the ability to communicate in an open, honest fashion. Several family caregivers reported breakdowns in being able to communicate openly with the PLWA. For example, one family caregiver feared telling the PLWA of her participation in this study. Lizzie feared Tommy's response to her involvement in this study because of his concern for maintaining

confidentiality.

I haven't told him that I've met with you because I know he's going to be really, really worried. And I will tell him. Maybe not now, just wait and see what happens tomorrow. But I should have told him. I just kept forgetting about it, um, because he's so worried about confidentiality. [104-2, 957-965]

Tommy's knowledge of Lizzie's participation in this study was initially maintained as a secret, for fear that it may disrupt the trust she had built with him. As well, Lizzie also feared confronting Tommy with issues surrounding their daily living.

But I'm on the verge, although I'm sure I won't do it, cause every time I've confronted him he ends up in the hospital, attempting suicide, he bleeds, vomited all over my living room floor. [104-2, 2256-2261]  
Oh, we have been to the wars and back, and the next time I confronted him, I can't remember what happened, whatever the issue was. He walked in the house and he said, "Lizzie I pooped my pants, I vomited blood, call the ambulance." He collapsed at the top of my stairs. Scared the shit out of me. Um, I'm afraid of him, I'm afraid of what he's capable of doing. [104-2, 2680-2691]

Lizzie's feared that confronting Tommy had led to his reprisal with severe physical and emotional responses. In effect, Lizzie was exiled by her family's distancing and also by Tommy's illness related exacerbations.

Three of the family caregivers expressed feeling stifled in their capacity to communicate AIDS related physical changes and concerns with the PLWA. The caregivers felt inhibited by privacy and denial, in their ability to discuss these concerns.

He was terribly private. You never knew what was going on in that kid's head. Um. We never talked about his illness. We would sit here very quietly and watch TV for days on end. He said that he was comfortable about talking about anything. I wasn't. I wasn't comfortable about the whole idea of letting him go at all. [106-2, 442-458]

But when someone isn't dealing with it as he wasn't, you don't deal with it either. [106-1, 237-239]

He's got something here. He's certainly got a lesion here (pointing), sort of on the right side of the face. I said, "Oh, what's this?" "Oh, it's an ingrown hair." And I said to him, I said, "It looks like the same things on the other side of your face." And he said, "Don't do that to me." He said, "I'm in such a panic." He said, "Please don't point those things out to me." I said, "Oh, God, I'm so sorry." [104-2, 596-606]

If a person doesn't let you know, well, you can't, you can't help them if they don't, if they don't let you know how they feel, or what's going on. Cause you don't know what's going on with them. [101-2, 857-862]

When the caregiver was denied opportunities to openly communicate his or her fears with the PLWA, the effect was that of distancing. For these caregivers, denial of the opportunity to communicate functioned as a form of exile from the PLWA.

#### Exile as a consequence of anger

One of the most pervasive emotional responses reported by caregivers was that of anger. Anger was identified as a dominant influence which affected caregiver feelings. Caregivers reported the presence of anger influenced their emotional labour throughout the caregiving trajectory. As well, anger was identified among the PLWA, the caregiver and the caregiver's family. Caregivers were subject to their own anger, the anger of the PLWA and the anger of family.

Anger acted as a destructive force which strained and emotionally distanced the caregiving relationship. Caregivers bore the brunt of their own anger as well as that of the PLWA and family. Feelings of anger were directed at the PLWA by the caregiver and or from the PLWA toward the caregiver. As well, the caregiver identified feeling angry at family.

The PLWA's anger was identified as a consequence of the loss of control over the

AIDS illness. This anger permeated their relationships with the caregiver and others. The aftermath of the PLWA's anger affected not only the caregiver's relationship with the PLWA, but also his respective family. The caregiver's feelings of hurt and resentment as a consequence of anger, led to emotional distancing and estrangement. The PLWA's anger resulted in decreasing the caregiver's feelings of connectedness and the ability to sustain caregiving. As well, anger was a response to the caregivers feelings of hurt and loss. As a result, anger engendered protective feelings and actions by two caregiver's family toward the caregiver. These actions further contributed to distancing and isolation within the caregiving relationship. Combined, the effects of anger contributed to the caregiver's feelings of exile.

For one caregiver, help was sought to deal with the anger and to decrease her sense of isolation. Isabelle, sought someone knowledgeable about AIDS to help her and her family learn how to deal with her son's anger. Since Jerald's return to live with her, his anger had affected their daily living.

He was so angry at everybody. He was angry to his toenails. You couldn't talk to him, you know. Couldn't you know. I got to the stage I couldn't have anybody into the house because I didn't know how he was going to respond. I mean, I had some ladies come in, come in through here and he was coming into the kitchen, and he just about knocked them down. He was the most obnoxious thing. And as I've said many, many, times, as my son I loved him, but as a human being I hated him. I say the whole trouble was, I have never, before this all happened, I, you know never, I had no one to call. I had no one to call. That's it. But then after that, then I had Peter. [101-2, 512-536]

Peter, a nurse and caregiver in the community, was the "outlet" Isabelle needed to help vent Jerald's anger and decrease her feelings of isolation. Jerald's anger was pervasive and threatened to also distance caregiving relationships both within and outside of his family.

And the day that Peter came with Linda, Jerald insulted them like you'd never believe. He was just rude. But afterwards, when they had gone, he came down

and cried and apologized. Said he didn't want to feel he was on parade. I said, "Jerald, those people" I said, "are not coming to see you, they are coming to see me." "Because", I said, "when you get sick" I said, "I, they are the only people that I will be able to call to come and help." [101-3, 19-33]

Prior to Peter becoming involved in helping Isabelle, she felt alone in managing her feelings and Jerald's unrelenting anger.

Oh, he was really very, very angry. And like that again, you see, the only one he could take it up with was me, but it was very difficult. Very, very difficult. Uh, when a person is sick, well sure we have those times that we're angry. And uh, we all get angry at the world, you know, but your anger doesn't remain there for say, a week, a month on end. It's got to let up sometimes. And uh, apparently anger is part of the course, you know, with this disease but I don't know what we can do, what I can do to help him. Just that he knows that the house is here. [101-2, 761-777]

Having lived with Jerald's anger for some time before receiving help, Isabelle felt managed by it's impact.

It was bad. It was really bad, I found that I was snapping at everybody. Uh, maybe I was at fault, I don't know but, you know, I was so, so tense. [101-2, 109-112]

I've been told by lots of people that I have a heart of gold, you know and yet he would come along and hurt me and then say, "oh well, you know, you always hurt the one you love" and "don't take it personally". But that's all very fine until it's happening to you. You're living in it. [101-2, 657-665]

The enduring nature of Jerald's anger had severe effects on Isabelle's caregiving. One consequence expressed by Isabelle was the feeling of hurt.

But what really hurt me is when he would get angry, he would look at me with so much hate in his face and in his eyes. His friends even said, Mrs. Smith, why is he treating you like a dog?" The pastor in the church came up and he said, "He's treating you like a dog," he says, "Why is he doing this?" [101-2, 393-403]

Isabelle felt incapable to continue caregiving under the unrelenting condition of anger. Living with Jerald's anger became intolerable and affected her commitment to caregive.



So frankly, it finally got to the stage that I wasn't going to accept that and told him to get the hell out. I couldn't take it anymore. So then he turned around crying and told me how sorry he was, you know. But in the meantime, I was, I thought I was going crazy. [101-2, 413-420]

That's it, L. I said. "You're out." I said, I can't take this any more. I've done the best I can for you and I can't do it any more." I said, "You'd better find somewhere to go." "And you shut up, shut up, shut up you bitch," he shouted to me. [101-2, 590-596]

Isabelle decided the only way to survive Jerald's anger was to distance herself both mentally and physically from him, and it.

I won't let him hurt me. I won't let him control me. Uh, that's the way it's going to be. [101-3, 56-58]

So I told Peter that I wasn't going to see Jerald. I said I wasn't going to see him because, I said, there's no point in it, you know, he's, he's rude to me when I go. [101-1, 49-53]

As well, Isabelle's family felt the need to protect her from Jerald's anger. They too distanced her from his anger.

And um, my son Joseph took Jerald aside and sat him down. He said, "Enough is enough" he said. "You're not doing this to mom any more." "I didn't know" Joseph says, "You were doing this to my mom." He says, "No more." Jerald says, "I want to be alone." Joseph says, "You are alone. Nobody comes to see you." He says, "What can you expect" he says, "If this is the way you go on with people" he says, "What do you expect them to do? They're not going to come and see you" he says, "When you're abusive like that." He says, "No more. No more Jerald." And he says, "You're not phoning my mom any more." He says, "She's had it with you." So Joseph came home. The first thing he did was got my phone number changed. And uh, then I think maybe that hurt Jerald a little because I think he'd been trying to phone me. [101-1, 881-910]

Anger was the mitigating force which exiled both Isabelle and her family from Jerald. The hurt suffered as a consequence of anger distanced Jerald from Isabelle and others.

Another caregiver reported feeling distanced by resentment experienced as a

consequence of her own and the PLWA's anger. Lizzie for example, felt managed by Tommy's resentment and his substantial demands on her presence.

He resents it. He resent's my, he's very, very possessive. And he's just, so angry, you know. "I'm not going to come with you any more. You're always talking to people." I said, "well". He just resents my, my having any life that doesn't involve him and, you know he's very isolated. He has no friends that I know of. [104-2, 411-420]

Tommy lacked other resources besides those of friendship. Money was another resource which contributed to his isolation. Ongoing debt became one issue which contributed to Lizzie's feelings of resentment toward Tommy.

I know, I lent him money. He owes me \$1200.00. He promised me, this was in March, O.K., he's promised me that on August 1st I'm going to get my money, but I'm not. Because something else is going to happen. [104-2, 2118-2130]

So I feel resentful because here he is, here he has been. Oh, he did pay me for July's rent now he did. But not to me, but he paid, or was it June, I can't remember. He knows that I'm a single parent. Nobody helps me. Um. I could use a couple of hundred bucks. That would be nice. I mean, I'm buying all the groceries. I'm paying all the utilities. Um I don't know if he has any money or not. I don't know. We don't talk about his money situation. [104-3. 817-829]

It's unconditional (her acceptance) but its' providing me with a little bit of resentment. I'm feeling a little bit resentful and, I mean, he owes me money. Tomorrow's August 1st, O.K. [104-3, 712-716]

As well, Tommy's indifference to her personal sacrifices affected Lizzie's resentment and anger.

I was just so pissed off with him. I mean, here I am at 1 o'clock in the morning, I have to get up for work the next day. And he's only fantasizing that the private duty nurse is going to be there. And uh, I told him how much that had hurt my feelings. And he said, "Well, I was just so doped up." He said, "I didn't know what I was saying." And I think, yea, you did. [104-3, 448-460]

Lizzie "works" at managing her emotions and recognizing their impact. She is aware that her

anger extends beyond the PLWA to her family.

And you know what Sonia, as I'm talking to you, I'm for the first time, feeling angry. Like I've never said the word angry in the last 6 months. I'm feeling angry at my sisters. I really am. How dare they? [104-2, 2021-2027]

As well, Lizzie is aware of feeling the impact of her AIDS caregiving.

Um, and a word came to me today as to how I'm feeling. I'm feeling isolated. I'm feeling that this person who is in my life is isolating me from other peop..., like I feel just isolated. I can't explain it any other way. [104-2, 15-21]

In this sense AIDS, has isolated or exiled not only Lizzie, but also Tommy from those resources which could assist them to manage their responses to the illness.

### Labouring the Losses

Labouring the losses constitutes the emotional work of family caregivers as a consequence of the tangible and intangible losses incurred throughout their AIDS caregiving. Loss denotes that something is being taken away from the caregiver, or that he or she is being deprived of something they ought to have. The labouring of losses entails developing awareness, attaching meaning, and managing the feelings associated with the loss. Loss is suffered within a temporal context and is laboured over the entire illness trajectory. Consequently, caregivers may sustain multiple losses and feel these additive effects. Losses pervade all aspects of the caregivers' lives affecting their primary relationships, work, recreational activities, hobbies, and their noncaregiving hours. The constancy of caregiving activity and demands may initially obfuscate the recognition of loss. However, over time caregivers become aware of loss, and its meaning for them. Caregivers manage their feelings of uncertainty, anger, guilt, anguish, and sadness as consequences of these losses.

Intangible losses constitute the caregiver's loss of social circles, personal freedom, interpersonal relationships, time for caring for oneself, and watching the loss of the PLWA's personhood or physical self. Tangible loss constitutes those economic losses such as a job, finances, or home. As well, for one half of the caregivers (three) this labour of losses included the physical loss of the PLWA through death. At the conclusion of the study, five of the seven family caregivers had survived the loss of their loved one.

Labouring the losses is comprised of two subcategories, *Facing Loss* and *Letting Go*. Together they portray the caregiver's struggles associated with loss and dying. The type of labour which occurs is primarily distinguished by the temporality of the loss (actual or anticipated death of the PLWA), and the caregivers movement toward resolving the loss. Each category is discussed in terms of its process, context, and consequences. Labouring the losses is managed within the context of labouring in exile and as well, is affected by the labour of uncertainty.

### Facing Loss

Facing loss describes the ongoing work of caregivers in developing awareness of, and attaching meaning to, anticipated and incurred losses as consequences of their caregiving. The process of facing the loss requires that the caregiver reflect on the tangible and intangible losses associated with their caregiving. Caregivers faced substantive losses pertaining to relationships, personal freedom, and use of time. The range of losses experienced included their relationships with the PLWA, family, and friends; their quality of life; a "pre-AIDS" lifestyle; and financial status. The most profound, enduring loss suffered

was facing the possible death of their loved one, the PLWA. The process of facing loss requires that the caregiver confront the reality of the eventuality of the PLWA's death. As well, it involves the development of an awareness of loss in his or her life since AIDS caregiving began.

Making a commitment to caregive marked the beginning of facing the loss. For one caregiver, facing the loss represented coming to terms with his uncertainty to engage in the role as caregiver.

I knew Dean a lot, a year, almost two years before I moved in here you know. And to me it was, I was facing, it was like getting into a cage with a lion, you know. Like I didn't know. I was scared of him. Prejudice has nothing to do with that, I'm not explaining it properly. It was, what I'm trying to say is that it was a challenge, it was a big challenge for me and I'm very glad I did it because it made me a better man. It made me understand. [103-2, 1162-1174]

Facing his uncertainty to commit to caregiving provided Jeremy with a sense of personal satisfaction and understanding. However, his commitment to caregive also resulted in social and economic losses.

And uh, the person that I was working for, he was going to fire me if I did not quit. I did have to quit cause I just couldn't go on any more with my back, but he was ready to fire me because he was getting complaints from the other workers that they didn't want to work with me. It wasn't that I'm not a good worker, you know, and it wasn't, it was just cause they knew I lived with somebody that was HIV and they were afraid to work with me cause they were going to catch it. [103-1, 281-293]

For some caregivers, the intense demands and strain associated with caregiving restricted their personal freedom, time, and energy for other activities. The loss of personal freedom translated into not being able to spend time with friends, to take trips, and or to work overtime. For example, Robert's social functioning became restricted as Andrew's care needs intensified.

So we were pretty independent living and, uh, then things started to slide. So I would miss functions, socials, you know, for instance family socials, or get together with friends in the neighbourhood. Um, I was wanting to take a French course with my roommate, and I didn't enrol with him because Andrew needed my care. [107-1, 331-340]

Robert felt the need to put his own personal life on hold and postpone pursuing his personal goals while caregiving to Andrew. In contrast, another caregiver felt that his life was not held back by his caregiving. For example, Jeremy was aware that his feelings of protectiveness toward Dean affected his loss of time for himself.

I could say that I put my life on hold but when I really look at it, I really didn't. Because sometimes I look at Dean, yeah, sometimes he stops me from going to Mexico for a couple of weeks. But he really doesn't stop me from going because he doesn't. I think what's happened to me is I'm overprotective. Uh, he's not mine, but he's my responsibility and if something happens and I'm not here, that's something that, again, is like I shouldn't have done that, I should have stayed at home. So that's one of the reasons why I don't go. I do need a break though. [103-1, 1690-1705]

For the three caregivers who worked, the strain of caregiving affected their ability to work at their full time jobs. Caregivers reported their loss of ability to concentrate on work while thinking of the PLWA's needs. For example, George expressed his loss of focus and eventual loss of employment.

I was very close to work so for the first while I could look after him myself by bouncing back and forth. Um. And although I couldn't stay very focused at work and my boss finally laid me off, um, which made finances even worse. [106-1, 191-197]

Of these caregivers, one ranked the importance of his status as caregiver as the priority in his life. For example, Robert faced his anger at a colleague at work who suggested that "work" was his priority without knowing the substantive details of his life.

I was really upset by him, especially the point when he said to me, you know, your number one priority is work. And I mean, here's Andrew lying in the

hospital bed and right now, my, yes, right at this point in time my number one priority at this hour is being here, but when I leave from here it's not the number one priority in my life. [107-1,232-234]

The increased demands on Robert's time because of his caregiving efforts resulted in changes his lifestyle, including his ability to socialize at work.

Whereas before when Andrew was healthy or before Andrew had lived with me, you know, I'd sit around after work, you know, drink a cup of coffee or go soc..go get a bite to eat or, you know, just be more relaxed. I wouldn't be rushing out the door, or even going out every day for lunch, I mean I don't do that now. [107-2, 2296-2304]

Several caregivers experienced a loss of personal freedom as a loss of control over their daily lives and circumstances. Time with and away from the PLWA no longer seemed under their control and they felt the PLWA's needs affected their use of time. For example, Robert felt his time away from Andrew was preoccupied by his thoughts of needing to be with him.

Didn't want to leave him. When I did leave, I thought about him all the time, you know, wherever you go. Why would I want to sit here? You should be sitting with your friend. You ain't going to be able to do that much longer. And so I was aware of that. It's probably why I didn't want to leave him because I knew that it was, you know, he was, we only had him for a short time. Like time was, it was coming to an end and very soon. [107-2, 769-786]

As well, the sense of time as an uncertainty was an apparent factor which affected loss of control. For example, Jeremy chose to remain at home because of his uncertain fear that Dean may die alone.

And I think that's what keeps me at home when he's not well. I don't want him to die alone. I've been here for, I've been here this long and that moment I want him to feel as good as possible and if it means me laying next to him, me holding his hand, I will, I want to be there for him. When my time comes, I might not have that. [103-2, 1131-1141]

Within the intensity and demands of the caregiving experience while working, caregivers had

difficulty taking time for themselves. For example, Robert felt guilty taking time for himself.

I found myself stealing an hour for myself when I'd be downtown, you know, off work early and, rather than coming home and, uh, relieving the person who was here. I'd steal an hour for myself. Tell myself don't feel bad about it. And after he dies, don't feel bad about it either because you, this is a conscious decision you're making. This is what you feel you need. [107-1, 301-312]

As the illness progressed, several caregivers related changes in the quality of their time spent with the PLWA, both at home and during hospitalization. The time spent doing caring things for the PLWA increased with the severity of the illness and the quality decreased. Two caregivers spoke of their time spent caregiving in the hospital prior to the PLWA's death (one spent three weeks and the other six). For both of these caregivers, their energy and time was consumed by their commitment to care.

Brian had just gone into the hospital, I was there to feed him three times a day. I got up in the morning, I met the breakfast cart, I fed Brian, I went to work. I left work at lunch, I went to the hospital, I fed Brian, and I went back to work. I did not eat. After work I went back to the hospital to feed Brian. I still did not eat, you know. I lost 14 pounds which I never do. It's just killing me to spend this much time there as I feel I need to or want to. [106-2, 1819-1829]

I would go to work. I'd come back to the hospital on my lunch hour and spend my lunch there. And then go back to work. And uh, go from work right back. Maybe if I, if I come home, it was to have a shower. Um, I wouldn't really eat here. I'd grab maybe something and eat it while I was driving. I slept there for 17 days. [107-2, 725-732]

As well, caregivers at home felt the time spent doing things for the PLWA was intensive.

For example, Robert's time was "busy," trying to maintain a clean, comfortable environment for Andrew.

And uh, for the most part, it seemed my life was really busy and I wanted to spend as much time with Andrew as possible. But yet, he needed so many other things, he needed so much done. That there were, that the amount of



time I spent with him wasn't really great. It was, I was doing things with him, like if I wasn't trying to cook, or do the dishes or do his laundry, my laundry, keep the bathroom clean, um, change the buckets for him every time he'd been sick which could be, you know, every 5 minutes anyways you know, like he'd just lie back down and he'd get sick again. You know, you don't want, who wants to get, I mean, I know he could get sick in another pail but you know you can run the risk of infection or something and you just want to get it out of the room cause maybe he'll just settle down if it's not there. No, it's just, who wants to sit in a room with puke. [107-2, 340-369]

Even when the PLWA did not require their caregiving attention, the caregiver found it hard to take time for him or her self. For example, Robert had difficulty taking time to relax.

After Andrew was sleeping, my dishes would be done and the bathroom done, I'd probably sit down and read the paper and just, it was almost like a job, like I had to sit down and read the paper but it was a way to force myself to relax. [107-2, 381-387]

The loss of personal time and freedom was significant as caregivers' day-to-day lives became more home- or hospital-bound. As well, the caregiver's previously established lifestyle became restricted when activities such as working overtime, or taking a vacation were not endeavoured because of his or her uncertainty of the PLWA's status and or the loss of resources to do so. Lizzie, for example, was unable to take holidays as she laboured the uncertainty of Tommy's illness and her loss of the financial means to do so.

Several caregivers reported social losses entailing friendship and family support as consequences of their caregiving. Some of these losses were discussed within Labouring in Exile. For example, Jeremy felt the loss of friendships when he engaged as Dean's caregiver.

They, I saw who my friends are by moving in here. There was another step in my life. I lost a lot of friends or people that I thought were friends. And if I had 20, I'm lucky if I have 5 left. [103-1, 508-513]

Recognizing the significance or nature of the loss was at times made difficult for the by the constant activity and needs of the PLWA when ill. For example, Robert related the

loss of friendships was not perceptible until after Andrew died.

It wasn't till after he was gone and all those requirements you know that the evenings are all of a sudden available, you realize, you know, where all your time and energy was. And hey, where are all my friends now? You know, because you've been out of their life for quite a bit of time too. I mean, my circle of friends was not part of Andrew's support network. [107-2, 825-834]

Developing an awareness of or recognizing the loss was not always something the caregiver wished or chose to face. Anticipating the death of the PLWA was a difficult yet integral part of facing the losses for several caregivers. Some spoke with uncertainty of their future and the PLWA's. Others were more certain that death was an anticipated outcome they did not want to face. For example, Jeremy did not want to realize life without Dean.

It's like I have not been emotional like this, (tears) but I'm talking about death that I don't want to realize. I, it's coming right out in front of my face right now. I'm talking about what is going to happen. Um, like he talks about that he's dying. Oh God that's one thing that really..., I had to tell him to stop doing that. He was talking about dying, dying and it's like, "Dean you have to stop that," because I have a better chance of dying before he does.

Anticipating Dean's death was not something Jeremy felt comfortable doing. For Jeremy, the hardest part of caregiving was facing the uncertain yet probable loss of Dean to death.

The worst thing is knowing that you're living with somebody that might not wake up one day and I mean, that's, that can happen to me too. With Dean, it's a different thing you know. I think I lost a lot of friends which I didn't. I lost, I went from enjoying my life of, before I moved in here, which was a different lifestyle, to a responsible, responsive lifestyle. I did have responsibilities at the other house but they were different you know. Dean is a child, I'm a man, you know. And um, who wants to live with somebody that, you know, they might not wake up in the morning. That he'll never say good-bye to you. I still can't take death very well. [103-2, 946-963]

Jeremy equated the prospect of losing Dean to that of losing a child, his child. The many other losses he had sustained were not comparable to anticipating Dean's death.

Anticipating the loss of the PLWA was compounded by many factors including witnessing

the physical and mental suffering of the PLWA and the sensitivity of others when dealing with death. For example, Freda felt the deleterious effects of Derek's disclosure of his AIDS status.

That was, I think, the hardest part of, of the dying was him telling because it, you see, it drained him more and more every time. [102-2, 221-224]

Another caregiver was affected by the PLWA's loss of memory and physical pain. For example, George felt tormented by Brian's requests to go home, which he alone knew.

I'd see Brian at the hospital. "I want to go home. I want to go home. Why can't I go home?" And I would tell him, "Your parents are keeping you here. I want you at home. There's nothing I can do about it. They have decided to keep you here. It's not the doctors, it's your parents." Um. And after we went through a session like that, like 30 seconds later, Dorothy (the HIV nurse) walked in the room and I was just in tears because he kept saying he wanted to come home. And I said tell Dorothy what you just told me. He couldn't remember. [106-2, 492-510]

George's torment was compounded by his loss of control to effect decisions for Brian. When Brian's suffering became unbearable for George, he faced helping Brian to let go and die.

And I went up to see him and he was really rough. They were giving him a lot of morphine and, uh, he was sort of moaning and I said to him, you know, it's not worth trying to make your birthday. This just, no, it's not worth it. I just want you to take all the energy that you can muster and you call the universe and you tell them that you're ready and to come. And as I spoke to him the pitch of his moans got, it changed. Uh, they were louder, it was like, are you hearing me? Are you trying to tell me something? What is it? And I made sure that, that I started from day one the last words I ever said to Brian when I left him was to remember how much I loved him. [106-2, 1945-1964]

George's love for Brian helped him face his loss.

The context in which the news of the death of the PLWA occurs also affects the management of loss. For one caregiver, the insensitivity of others was an apparent factor which affected his feelings of facing the loss. For example, Robert received the unexpected

news of Andrew's death over the telephone.

You know I found that Andrew passed away over the telephone by the switchboard operator at the hospital. And I never said nothing. When I walked in, I just told the nurse, you know, she said, oh it wasn't me and then the nurse was so upset that I knew but that's how it happened. She wanted me to say so, like lay a complaint with the hospital and I just said, maybe it's better that I don't know the face who told me, you know. It's a blank face. [107-2, 567-579]

Hearing the news of Andrew's demise, Robert was not able to face his feelings of his loss at the time.

And I mean, I was standing at work. I, alls I was actually doing was calling Andrew's room. To talk to the caregiver and tell him I was going to go home and grab a shirt, and she (the telephone operator) said to me, "Are you family?" And I thought why are they asking for the family before they connect the room. I said, "Yeah." And she said, "Well, Andrew passed away this afternoon." Like, "Oh he did?" She said "Yes he did." O.K. And I just kind of left work all shocked. [107-2, 597-609]

As well, Robert's capacity to manage his feelings of loss were complicated by the cumulative losses connected with Andrew's family.

We had just lost Andrew's mom a year ago, and we lost Andrew a year later and now it's his dad. And uh, even now if find it, I never phoned his dad in a couple of weeks. And I'm almost scared to phone him. I'm scared to go see this man sick. Like I don't, I'm scared that he's dying too. [107-2, 1594-1598]

Robert feared he would soon again face the loss of yet another loved one. He had just begun to face the meaning of his loss of Andrew.

Anticipating the death and loss of the PLWA was for many caregiver's the most emotionally difficult and painful aspect of the interview.

### Letting go

Letting go constitutes the process by which caregivers come to terms with the

acceptance of their losses and are able to let go of their past. Letting go is experienced temporally and affected by the *labour of exile*. For some caregivers, letting go of their prior losses occurred gradually. For example, the process of *facing loss* helped the caregiver's gradually let go of usual activities such as recreation or socializing with others. As well, letting go was incurred as part of his or her ongoing caregiving effort and many realized loss through the process of labouring in exile. The death of the PLWA required the caregiver to let go of his or her past relationship, make sense of, and accept the loss.

For the three caregiver's who experienced the death of the PLWA, letting go entailed working through the loss and centered on finding acceptance. For example, for one mother the process of letting go occurred over time and involved going through her son's personal effects.

In fact, when I think when I was really able to let go is when I finally went through a lot of his stuff that I had, we had just packed up and put in boxes and, um, I have an antique collection upstairs, but, anyway, I started going through all his stuff and sorting all his stuff and uh, going through that and day by day, I would do like a box. And uh, I think I learned a lot by that knowing that hey, I, the little things that he did and I even read letters of his of how he was so helpful to people. And I think that's more or less what does help me, you know get over that. [102-2, 1209-1223]

Working through the loss required the caregiver recognize the meaning of the loss for him or her self. For example, Robert reflected on Andrew's importance in his life.

But how can I go to work, like I've lost my best friend? Somebody who, I didn't even have to talk to, they'd know what I was thinking. Like there's nobody else on the face of the earth that I know, that knows me like this person. And suddenly they're gone now and all these lifelong experiences that I've made with this person, memories. To be able to sit down and talk with that person the way you did is not possible any more. To get those answers from him and laughs and every little thing is not there. And why don't I feel more devastated? Dorothy seems to feel that I felt a lot of it before Andrew passed away on a day-to-day basis. You don't even realize that you're already

doing this. [107-2, 2205-2225]

For Robert, the ability to take time off work for compassionate leave was not a sanctioned option. He struggled to work through his feelings of pain, guilt and acceptance.

So when he died, I was almost disappointed that I didn't really feel like this big separation like when we broke up. For about three or four day, maybe someone who loses a partner, you might experience that, it's like an internal pain. And like, it must be in your heart, because it sure darn feels like it. And you can literally feel over the course of a couple of days, it's going away. Like it's getting less. It takes about, I don't know, took my four days for it to go anyways. And I know Andrew went through it too. [107-2,930-948]

The physical pain of losing Andrew was let go quickly as Robert had previously faced loss with Andrew.

As the caregiver worked through the process of letting go, attention and energy shifted from the deceased to him or herself and his/her own needs. For example, the focus of Robert's time and attention shifted from caring for Andrew to caring for himself.

But when Andrew passed away, all's I wanted to do was come home, be alone. And just sit on the couch and go to sleep. Get up and have coffee in my house. I'd been away from here for almost 3 weeks. I just wanted to sit here and have coffee. I would have been sorry that Andrew wasn't with me now to have coffee with him. But he wasn't even a thought at that moment. It was, it was just me now. I just wanted some time for me at home. [107-2, 1495-1505]

Similarly, George realized the intensity of his caregiving efforts had left him feeling emotionally and physically drained.

And get my energy back. I know it's slipped this year, it's like because I'm, getting older. Or because my health is failing. Oh, I'm just burned out cause it's been a hell of a year. [106-2, 1784-1789]

The caregiver's ability to *let go* varied in its intensity of difficulty and duration. The process of letting go was made difficult by the loss of youth of the PLWA. For example, George was Brian's senior by several years.

And tough to let somebody so young go. Hell, if they could have given him another 10 years if I was dead the next day, take me. [106-2, 861-864]

George felt the tragedy of Brian's death. He relived the experience and faced letting go.

And they said that he didn't have any anger, he was quite accepting and ready. Um. Of course we weren't. Never are. Even when we say we are, we're not. We're not. We will do our very best to keep alive for whose sake? Our own. Which is too bad, you know. He was ready to go. Um, if he had been in better health and chosen his own day, I was quite prepared to help him pick his own day, if that was the route that he had chose. When he finally figured that would be a good idea, and was all ready, he was already in the hospital. And I could no longer help him. That was very hard on me. [106-2, 462-481]

For several of the caregivers, letting go of their loved one was affected by their readiness to accept the reality of death, without having had an opportunity to grieve.

### Labour of Uncertainty

Labour of uncertainty describes the caregiver's pervasive sense of feeling unsure of the present, future, and past illness events or outcomes connected with his or her AIDS caregiving. The labour of uncertainty is a constant, derived throughout the caregiving experience, as the caregiver attempts to make sense of the sustained illness events and outcomes. The caregiver's emotional labour is comprised of generating meaning and managing his or her feelings associated with the unpredictable nature and pervasiveness of the AIDS illness, symptoms, and care. The emotional outcomes of the caregiver's labour of uncertainty are experienced as feelings of lack of control, anxiety, worry, and fear.

Uncertainty was expressed as a consequence of caregiving in the present, the future, and/or the past. In the present, caregivers experience uncertainty when awaiting test results,

and or anticipating the meaning of the PLWA's illness responses. As the caregiver *monitors* the PLWA, he or she may experience uncertainty related to the disease progression, treatment issues, and emotional responses. The duration of the illness and the specific nature of the symptoms that evolve as the illness progresses, can not be used by caregivers to predict the future course of the illness. As well, the caregiver's past ability to manage AIDS caregiving is not predictive of their future ability. The caregiver's existing knowledge of the PLWA's day-to-day illness symptoms is also continually changing and contributes to his or her feelings of uncertainty. Caregivers labour in future uncertainty when anticipating their ability to manage the illness outcomes or the death of the PLWA. Uncertainty is also a product of past reflection on care outcomes. The caregiver labours uncertainty in the present, anticipates the future and relives the past.

Caregiver's feelings of uncertainty vary in intensity, timing, and content, but are never completely allayed. As the caregiver engages in monitoring the PLWA, the uncertainty of AIDS is experienced as moving into and receding from conscious awareness. Uncertainty is experienced in distressing peaks of intensity and relatively tolerable background levels between the peaks. The PLWA does not need to demonstrate new symptoms for caregivers to labour the uncertainty of AIDS. Caregivers are aware that AIDS can jeopardize the PLWA's health with little or no warning. This knowledge of possible AIDS-losses is of concern to caregivers. Uncertainty in this respect is a constant, even when the PLWA's disease symptoms are under control.

The labour of uncertainty is inextricably bound with the *labour of losses*. As well, uncertainty is experienced by the caregiver within his or her *labouring in exile* and its



management. This section describes only the set of causes, contexts, conditions and interactions that comprise the labour of uaphor of a "roller coaster."

It is a roller coaster. Especially when they have their good days and you're so up and the next day, ten things can go wrong. [106-1, 2109-2111]

It's been an unbelievable roller coaster ride but there's been lots of joy and lots of fun and, you know, just like I feel, you know, I'm in a web. In a web of a very, very skilful spider. [104-2, 2821-2826]

For these caregivers the contrast of the good and the bad days, with their ups and downs, resembled the uncertainty of the PLWA's illness responses. As well, one caregiver extended the metaphor to a spider's web. For Lizzie, this illness was encompassing and entangling. Lizzie's metaphor of the spider-web, related to her relationship with Tommy and her AIDS caregiving relationship. It demonstrated a sense of an unexpected, yet certain fate.

For some PLWAs and their families, uncertainty had a dual nature. On the one hand, the uncertain course of the disease gave the caregiver hope that the PLWA's continued survival would allow them to benefit from treatment. For example, Freda recognized Derek's deteriorating health status, however, she maintained hope that he would benefit from medical treatment.

So at this point he couldn't walk straight or anything anymore. He had lost, you know, I mean, it had, you know regressed more and more all the time. Every day. I would see from not being able to talk or I mean, gradually every day. Then all of a sudden one day, it would all, it just seemed like it was like a miracle hey, you know. Yeah. It was better and you know, so he finally decided to uh, let the doctor come in to see him. [102-1, 932-944]

On the other hand, the uncertainty of the PLWA's day-to-day disease management extracted an enormous emotional toll. For example, Lizzie identified feeling anxious while awaiting Tommy's biopsy results. Lizzie's uncertainty was heightened by the period of waiting for the

results and was marked by agony.

And then I was sitting all day Tuesday on pins and needles. I was just in agony, I didn't hear. I said to him, "Phone me the minute." He said, "I'll phone you from the hospital." Didn't hear from him until about 3 o'clock in the afternoon. I was thinking that they sent him directly to the Cancer Foundation. Finally, he phoned me at 3 o'clock and I said, "Oh my God, I've been waiting all day to hear from you." He didn't get any result and then he and his mother went shopping. I was sitting here. (chuckle) I was so angry. And I thought, well I thought, well who am I angry at, you know. I mean, I got myself into a snit and I shouldn't be angry with him but. [104-3, 289-313]

Another caregiver laboured with uncertainty during a holiday away from her son. Isabelle worried about Jerald's ability to manage alone.

Do I have to go home? What's going to happen? You know. So, I didn't really enjoy my holiday at all but I thought all the time, every time, all the time I was there. I felt nauseated. You know, I'm feeling nauseated. I didn't want to eat or anything. I just didn't want to be there. I wanted to be away. Like I felt as though there was a whole heavy load on top of me. So, O.K. when we get back he was fine. [101-2, 466-477]

As well, one caregiver also identified being uncertain of the day-to-day resources he needed when he engaged in caregiving.

I didn't know what I was in store for, whether I'd need a wheelchair for him, you know, in the house of what. [106-1, 204-207]

George engaged in caregiving even though he was not certain of Brian's care needs or of the equipment he would require to provide care.

The present dimension of uncertainty also included the constancy of caregiver's contextual worries. Caregivers expressed uncertainty in maintaining their caregiving relationships, their inability to predict the PLWA's responses, and their own HIV status. For example, Lizzie worried about the effects of her caregiving relationship on Tommy, his family, and her own family.

I'm worried for him and I'm worried for me. I'm worried for the relationships in my life and I'm, worried if I'm giving up too much. If I'm, if giving up is the right word, but if I'm, do I have my priorities straight? I don't know, I don't know. [104-2, 137-143]

Two caregivers expressed a combination of feeling uncertainty within certainty. For example, Lizzie was uncertain of Tommy's intention to move, yet was certain that money prevented it.

I don't know. I just don't know. I said to him today, "When are you planning on moving?" Do you have (a plan)? "Yeah, I'm going to talk to my mother about it today." I don't think he is. He has an apartment that he hasn't moved into yet. All his stuff is in storage right now. So, it's just a matter of getting the money together and making this move. But he never has the money. So this is just a continuous sort of thing now. [104-1, 840-858]

As well, Lizzie's historical knowledge of Tommy's past responses affected her ongoing feeling of uncertainty. She feared what could happen if she asked Tommy to leave, based on her past experience.

I said you can't live here any more." I said, I'm not kicking you out of my house." I said, "I'm not kicking you out of my life." I said, "You just can't sleep here any more." I said, "My sister knows." I said, "You have to understand the complexities of my life." He just went nuts. He said, "O.K." He packed his knapsack. He said, "Don't worry about me anymore. You will never see me again." I went running down the street after him crying. I said, "Where are you going? Please don't do this." He said, "Don't worry. You don't have to worry about this." And then he phoned me at 8 o'clock in the evening. I said, "Where are you?" I said, "Tell me where you are. I'll come get you." He sounded drowsy. He had taken something. I could hear street noises behind. I said, "Have you taken anything?" He said, "It doesn't matter, I'm just going to lie down under a tree and you're never, I'll be out of your hair. You don't have to worry." I said, "Where are you, tell me where you are. I'll come and get you." He wouldn't tell me so he cut off the line. I phoned Dorothy (HIV nurse) back and I said, "I don't know what to do." I was so terrified. Um, and as I'm on the phone with her, the doorbell rings, it's him. [104-2, 2547-2587]

Lizzie's uncertainty was compounded by her knowledge of Tommy's past suicide attempt. She worried about approaching him to leave and or asking for the money he owed her.

I was lying in bed and I was thinking, "What's next, you know? What's going to happen now that's going to prevent me from getting my money on August 1st." I need the money, you know. I said to him, "I can't go on holidays if I don't get my money back from you." I don't think he has a conscience. [104-2, 2135-2143]

Mixed uncertainty was also experienced by Isabelle. She feared encountering her son's pervasive anger. Isabelle's historical knowledge of Jerald's anger was a constant in her role as caregiver.

Like he was sitting on the couch and I'd be, do something, cause I was waiting for him to pounce and say this is wrong, that's wrong, that's wrong. Everything in the kitchen's wrong. Like, he, he was running everything. And it was hard. I was, it was like walking on egg shells. And I, when I'd get up in the morning, I was, he'd come down and I'd be looking at him to see what kind of a mood he was in. When I went out anywhere and I came home, I'd be looking up at the window to see whether he was up and out because it was always tense. [101-2, 89-102]

The certainty of Jerald's anger was indisputable, yet Isabelle was uncertain of her necessary exposure to it. As well as living with Jerald's anger, Isabelle dealt with not knowing how to help him manage it.

If a person doesn't let you know, well, you can't you can't help them if they don't, if they don't let you know how they feel, or what's going on. Cause you don't know what's going on with them. [101-2, 857-862]

Two gay caregivers lived with the uncertain knowledge that they too may become HIV positive. One caregiver dealt with his uncertainty by choosing not to become knowledgeable of his status and avoiding testing. The other, although presently HIV negative, worried that he could still become positive in the future. In this case, Jeremy suffered uncertainty as a member of the "worried well."

But I still think that I'm going to get it though. It's something that it's always been my, you know, so. I've had lovers from the past that are HIV. Uh, there's a long period in between since we broke up that they could have got it

then after, you know. But it's still, it's still there, you know. It's still that ghost in the closet. [103-2, 1352-1361]

As a consequence of his uncertainty, Jeremy underwent testing on a regular basis.

I go and get checked every 6 months because I need to. But, uh, if I go get checked, I have to go get checked soon, if he tells me that I'm HIV, I don't know. I don't know how I'm going to face that. Just cause I'm dealing with it now, that doesn't mean that I'm going to be able to deal with it myself. [103-2, 1382-1390]

For Jeremy, the knowledge of his seronegative status is not enough to dispel his uncertain knowledge of his future status. As well, being able to deal with AIDS in someone else, does not ensure that Jeremy can "deal" with AIDS in himself.

#### Future Dimension of Uncertainty

The nature of AIDS as a chronic disease of multiple and complex changes created an uncertain future. It was impossible for the caregiver to predict the illness trajectory, care needs, or the responses of the PLWA based on his or her historical knowledge. Caregivers were also uncertain about their future and the consequences of their caregiving. Anticipating the future progression of the illness and the care required was expressed by caregivers as feelings of lack of control, worry, and/or fear. For example, Lizzie worried about her life as well as Tommy's.

Yeah, I'm struggling along and I'm worrying about the future. Just worrying about, you know, my ultimate involvement. [104-3, 393-397]

Uncertainty regarding the PLWA's well-being and the effects of AIDS led to the caregiver's fear of the future for self and his or her ability to manage. For example, Lizzie anticipated the effects of AIDS on her life. Even though Tommy was not ill, uncertainty was

a recurrent theme within the temporal context of her caregiving.

So I can't imagine what's going to happen to my life, I know this sounds selfish but, can't imagine what's going to happen when he really becomes ill. He's not right now. He's terrified. He's very frightened. And I've said to him, "What are you going to do?" So, I'm in the position of feeling a little anxious about the ultimate, oh, the ultimate, um progression, outcome. [104-1, 219-224, 272-275]

You can't imagine when it really starts and the awfulness and the illness really starts. It's just going to be. And I'm feeling really selfish about that and I'm feeling, oh, I'm feeling selfish because I'm, I don't know, it just sort of seems the next couple of years of my life, sort of, excuse me, (crying) in and out of emergency rooms and waiting and, you know. [104-3, 137-147]

Lizzie anticipated a lack of control in her future as an AIDS caregiver, with fear and the prospect of time spent waiting and watching Tommy's deterioration. Her uncertainty increased as she received the results of his biopsy.

I'm just feeling very frightened about tomorrow. I'm just feeling really frightened like what next. And I guess AIDS. He said to me, "It was Kaposes. That means I have AIDS." But I said, 'Yes, I know.' And he said, "I'm really frightened." And I said, "So am I." I don't know if that's the right thing to say. I said, "I love you and I'm frightened too." And I don't know if it was the right thing to say but it was from my heart. [104-2, 647-663]

It's really hard. It's really hard because I just love him. He's like one of my children. He's my boy, he's my child. He's part of my heart and um, uh, I don't know. It's um, oh God, I mean I just, I'm so worried about tomorrow because I just don't know what, how they're going to treat him, or like he's just terrified of chemotherapy. [104-2, 1246-1255]

Lizzie's love and her knowledge of Tommy's fears affected her own fear of his possible treatment with chemotherapy. She was uncertain of whether her response to Tommy was "right", but it was heartfelt.

Several caregivers anticipated the future death of the PLWA as the ultimate progression of the disease.

I mean, as I said, I don't think, however this ends, I can't even imagine that he would die. He knows, I don't know, it's just going to be just terrible. But I mean he's not ill right now so. [104-1, 1152-1158]

Will I be able to handle that, you know. It's like if he does get too sick to the point where I know he's not coming back, gonna come back here, then it's going to be like, O.K. this has been your home and my home for a long time and, you know, can I go back to that home type thing, you know. That's the only, that's the only thing that's really that really bothers me sometimes. I know he's, he's sick, but really he might not be telling me like maybe show sick he might be, you know. [100-1, 812-827]

Anticipating their future life without the PLWA was one certainty that caregivers did not want to imagine. One caregiver spoke of uncertainty in her response to the PLWA's wish to discuss his funeral.

So we had this ridiculous conversation and I said, "I don't know if those conversations, I guess they're O.K. to have," but I said, "Let's not talk about that kind of stuff right now." I said, "Let's try and talk about positive steps." But then maybe I'm denying him because of my own, but I'm not afraid of talking about death or dying. You know I had many powerful conversations with people. Um, But I just, and I don't know if my inability, not inability, I'm not unable, but my reluctance to talk about it, it's more predicated on let's talk positive stuff. Let's not talk about funerals and death right now. Let's talk about treatment and, and, uh, some living, not dying. Right? But I don't know if that's right. I don't know if that's my denying. I don't know. [104-2, 1285-1310]

Lizzie was uncertain of whether she should help Tommy anticipate death or promote his hope for treatment.

### Past Dimension of Uncertainty

The past dimension of uncertainty represents the caregiver's reflection on the meaning and outcomes of their caregiving work. One caregiver doubted the benefit of a past action which affected her current caregiving situation. For example, Isabelle questioned and relived

her decision of giving the hospital her son's phone number.

So I gave him Steve's number and I don't know if I did right or not, you know. Now I think back, I think I did things that was wrong. [101-1, 860-863]

In retrospect, Isabelle recognized her uncertainty of how to best manage Jerald's care.

For two other caregivers, uncertainty was a outcome of their need to make sense of the death of the PLWA. For example, George was left with the feeling of regret and wondered if he had done enough to keep Brian alive.

It's too bad a lot of things turned out the way they turned out. Um. In his life, um, I spend my time wondering if I should have done things differently. You know you do. You know. Um. Did you do enough? But that's only because I didn't want to let go, you know. Is there anything that I could have done that would have kept him around longer. That extra four days to make his 31st birthday that he wanted to make. [106-2, 850-860]

Another caregiver, Freda wondered if Derek's quality of life was affected by her love and caregiving.

And I do think his life, and I don't know if I'm satisfied in my own thoughts and if I am that's good because I'm important, not anybody else. I feel that his life was extended longer because I did feed him good and I did care for him and he had the love, you know, the security. [102-2, 1006-1013]

As well, George wondered about care decisions that kept Brian alive and questioned the cost of continuing supportive treatment.

You never know what is right or wrong about anything. Was I right to feed him you know? Um. He was ready to go. No one was ready to let him and as long as there was any thread of life in him, health care was going to spend dollars to keep him alive. Why? He's going to die anyway. But we spent like \$50,000, \$60,000 dollars trying to keep him alive when he was ready to go. You want health care cuts, as odd as it sounds, that's a waste to do so. [106-1, 2234-2247]

In light of Brian's readiness to die, George was left to question the effort of maintaining life at all costs.



The caregivers' struggles with the uncertainty of caregiving in the present, anticipating the future, and reliving the past were made tolerable by hope. One caregiver eloquently shared this hope.

And I think, I hope, I hope that underlying all of this is true affection and true caring. Well I just hope that. I hope. [104-3, 980-983]

Hope offers a sense of control in the uncertainty of AIDS caregiving.

### Caring Transformation

Caring transformation is both a discovery process and an outcome of the AIDS family caregiving experience. Caring transformation is embedded in the details of ordinary, everyday life experiences of the AIDS family caregivers. Caring transformation expanded consciousness, giving a different form or appearance to the caregiver's life as a consequence of the caregiving experience. As a process, caring transformation is discovery where caregiving enables the caregiver to construe and validate the meaning of his or her experiences. The process of making sense is a derivative and interpretive one, arising from the context of caregiving and the caregiver's world view. As a consequence, transformation occurs within the social context of AIDS caregiving to reformulate the caregiver's sense of self. The order of things and the rhythm of their lives changed irrevocably. In essence, the caregiver changed throughout the discovery of the lessons learned from AIDS caregiving.

Caring transformation is educative as it brings about what is an unknown faculty of the caregiver and entails emergence of a new self. It often takes the form of expanded consciousness, and in this sense a family caregiver is educated by his or her caregiving and is profoundly transformed. To be educated, a caregiver does not have to know much or be

technically informed about the disease of AIDS. However, he or she does have to be exposed to the transformative events of an engaged and vulnerable human life. Caregivers become more articulate about matters of the heart. They learn to hear with their hearts, not just their minds. An important dimension of the caregiver's transformation is his or her insight or sensibility. As caregivers educate their hearts, they may spend time contemplating certain events never fully grasping their meaning, but becoming more intimate with their mysteries. Gradually they may be woven into ways of thinking and living as the basic themes of their own mythology and philosophy. The transformation which occurs, affects and is affected by his or her caregiving.

Transformation is comprised of two categories, *Discovering Self Perspectives* and *Discovering System Perspectives*. The categories are defined by the properties and attributes of their transformative knowledge.

### Discovering Self Perspectives

Discovering self perspective describes the caregiver's expanded consciousness of how AIDS caregiving transformed his or her personal life meaning. Caregivers reflected on the process and outcomes of caregiving and construed meaning perspectives in their lives. In the process of discovery, caregivers asked questions of themselves to discover a new reality. Through discovery, changes were made in the ways caregivers defined themselves and the meaning of their experiences. Knowledge of self as a caregiver was both painful and satisfying, and entailed self-doubt and self-discovery. Caregivers discovered awareness of self which transformed perspectives on time, health, life and the relationship with the

PLWA. In the process of discovery, caregivers found inner strength to cope with the daily demands of caring for the PLWA. They found hope in their spiritual beliefs, changes in their lifestyle, forgiveness for past resentments, and taking an active role in the PLWA's life. Their ability to give of themselves in committed, compassionate caring under these conditions was voiced as a transformative experience.

### Caregiving: A Gift of Human Love

Caregiving was seen to be the most important gift of human love, kindness and compassion the caregiver could provide. Several caregivers reflected on their caregiving experiences as opportunities and challenges, which were growth producing and enhanced their understanding of their self. For example, Jeremy considered himself to have become a better person.

It was, what I'm trying to say is that it was a challenge, it was a big challenge for me and I'm very glad I did it because it made me a better man. It made me understand. [103-2, 1168-1174]

Jeremy discovered inner strength to deal with the realities of caregiving in the present and all its implications for the future. As well, the process of caregiving served as a frame for caregivers to experience themselves in a new way. For example, Jeremy's engagement as a caregiver led to a change in his gay lifestyle.

I was living a single life, young party and yes my life did change. But it changed to the better. I, I'm doing a thing that I enjoy. [103-2, 606-610]

And in a way I'm glad that I'm not working cause if I was working I wouldn't be able to do this, you know. But as long as I can, yes, I will. [103-2, 1190-1194]

Caregiving provided Jeremy with a new sense of fulfilment in life. As well, it provided Jeremy with the opportunity to learn to overcome his fears and lack of knowledge of AIDS.

But I've, I look at myself as going on the ladder. And as long as I keep going up instead of down, I'm learning something. [103-2, 405-408]

I'm just growing, growing old learning. [103-1, 697-698]

Jeremy felt caregiving provided him with the an opportunity to learn and grow. A positive redefinition of self emerged that included a new awareness of self as capable, competent, and committed. Caregivers spoke of these elements as being positive and essential to sustained caregiving.

Many caregivers reflected on their personal relationship with PLWA. In the context of caregiving, most care providers referred to the PLWA as their "child". This transformed perspective of the PLWA denoted the caregiver's sense of the PLWA's vulnerability, need for protection, and changes in role expectations.

He was kind of like my child, you know. [106-1, 1148-1149]

He was my New Year's baby. I was a new mom with a baby that wasn't going to get any better. [106-1, 1606-1608]

The daily context of caring for the PLWA which included cooking, cleaning, bathing and toileting, transformed the caregiver's perception of the adult PLWA to a child like state. As well, the caregiver's sense of responsibility of caring for his or her sick "child" engendered an urgency to actualize the time together, and transformed the caregiver's perception of time.

#### Changes In the Perception of Time, Priorities, and Mortality

Time became a precious commodity for both the PLWA and the caregiver. For many caregivers, their conscious awareness of time influenced their daily living. Personal goals were delayed and the PLWA's care needs took priority. As caregivers' perception of time transformed, a sense of mortality affected their caregiving.

It's probably why I didn't want to leave him because I knew that it was, you

know, he was, we only had him for a short time. Like time was, it was coming to an end and very soon. [107-2, 778-782]

Many caregivers identified the importance of living life in the present without regret. For example, Jeremy spoke of the need to "do it".

If Dean, if you pass away, I will not look back and say, I feel really guilty that I did this or that he wanted this and I didn't get him this, because I can't live, I can't live with my conscience like that, you know. Like you want to do it, do it, don't feel sorry that you didn't do it. you know. If you can do it, do it. [103-1, 1478-1487]

With the realization of life's fragility, caregivers' attention shifted focus from their desires to the desire of the PLWA. For example, Robert shifted his focus from what he ought to have to what Andrew wanted.

This isn't about what I should have, this is what Andrew wants. He's ready to die now. And that is the process of life, you know. Just be grateful you have known him for so many, so long and so many good times with him. [107-1, 886-898]

For other caregivers, death as a process of life transformed the caregiver's sense of his or her mortality. For example, George compared the youthfulness of Brian's loss with own life and the life span of others.

Take me, I'm ready to go. Yeah. Makes me, makes me look at mortality differently. Now I can look at someone who's, you know, 78 and passed away and it's like, he had a good long life, you know. Um. Brian did not. I don't feel bad about the old people any more. Feel bad for the young. Real bad. [106-2, 868-876]

Surviving Brian's loss transformed George's sense of his readiness to die. For Margaret, surviving her own HIV diagnosis made her aware of a change in her outlook on death.

People just test HIV positive and automatically think, oh my God, I'm going to die. Well, yeah. We're going to die, of course. Now it doesn't really bother me. It used to for a long time, it bothered me. Oh my God, my T4 count is going down and down and down. I'm going to die. [100-3, 3045-3053]

Surviving loss transformed the caregiver's understanding of the importance of the PLWA and valuing of the time shared in their lives. Three caregivers spoke of time shared with the PLWA as precious gift to be grateful for. For example, Freda expressed an awareness of a turning point where she encountered a new reality of time with Derek.

I think we all have to accept the fact that he, at that point, there wasn't anything that we could do any more. And, uh, then if this is, you know, this time was precious to us and with him. We would spend it the best way we could, you know. And I, and Derek, knew it too. In fact I think it was probably 3 months out of the previous 6 years or whatever that he enjoyed the most out of his whole life. As far as, and I mean he said, you know, that he was so happy that his family could be with him. Be with them and them to be with him sort of thing. [102-1, 1141-1157]

The confrontation of this new reality of time compelled caregivers to reflect on their feelings for the PLWA. For example, Robert contemplated his feelings of wanting Andrew's presence and George his unrequited love for Brian.

I wouldn't say, like earlier I said that it's wrong for me, my feelings. Um, my feelings are right but they're very selfish feelings to want him here sick, I'd like him here healthy. But I'm just grateful for having him at all, like to know him as a person. [107-1, 2158-2161]

It was my feel good love so that's the important part. He didn't love me, that's O.K. I didn't lose anything by it. I gained plenty. [106-1, 302-306]

The realization of time spent with the PLWA as a gift, enabled the caregivers to recognize the personal significance of the loss of the PLWA in their lives. As well, having survived the loss, a different sense of self emerged. For example, Robert discovered a different sense of his inner strength and love.

Well, most people here should be like all devastated and, you know, not being able to carry on. I feel guilty with how well I've done in this. And, I mean, my love certainly is different when he came to live with me than when we were in a relationship. It's a different love but yet it's the same love. [107-2, 907-919]

Through bereavement, Robert discovered a new sense of self to help him deal with his loss.

A transformed sense of valuing time was also described by several caregivers as appreciating the value of each day and the ordinary aspects of living. Enjoying life's little moments, as well as not taking life for granted, were commonly expressed ideas. For example, Freda's outlook on life's events became more circumspective and unnecessary trivia was shed.

I've just sort of realized that, hey, life has to go on. And you got to let go, you know, a lot of things. So, how it has changed my life is, I'm not saying it's changed my life for the better, I would never say that. But it has made me realize that things in life not to take for granted and uh, not be overly concerned about little things that aren't important and to try to you know, enjoy the little things in life. [102-2, 1194-1202]

Well, do you know what I find is that I don't have the energy that I used to have but that's not because of Derek. I'm sure it's because I'm getting older and I think there's things in life that have more meaning to me that they used to have. Uh, some things that have more meaning and some things that have less meaning. So I really do think that, not only me, but I think the whole family has a different approach to things in their life. I know his two brothers certainly have changed in a lot of ways, you know. Uh, I think they have realized that there's more to life than, you know, getting up and going to your job and coming home and having your, you know. That there's so many things in life that have a meaning to it. And I think maybe what I've learned that, uh, is to try and uh, understand things better than I used to. And I'm sure it's because of what happened. [102-2, 1125-1150]

Freda's awareness of less energy allowed her to let go of needless worries and trivia. This resulted in Freda's and her family's closer, more intimate relationship with living.

For another caregiver, appreciating the gift of each new day was important. For example, Margaret found happiness in her daily awakening.

We wake up, I'm just lucky to wake up the next day. I'm just happy for that you know, that I'm not sick and I don't want to (take medication) even if I have to. It's like, I don't need to take that medication. It's all up here (pointing to head).[100-3, 2772-2788]

Margaret's feeling of "luck" in awakening healthy each day is understood from the context of her own uncertainty living with a positive HIV status. Subsequently, her caregiving experience had not changed her response to living life.

It hasn't really changed. It's just um, we just live our life on a, on a day-to-day basis and what happens after, we're there for each other and give each other space. [100-3, 445-449]

Margaret's attitude regarding her self as a caregiver was that it was just "living life" and not unusual or extraordinary. This perception of self as a caregiver was echoed by Jeremy. When Jeremy had initially faced his caregiving, it was like "getting into a lion's cage." His sense of challenge was now subdued.

I don't do nothing for Dean anymore, you know. It's an everyday thing to me you know with Dean. Yes, it is, it's still hard because you can see how emotional I can get but, to me, this is just my life, you know. Now if I can go and help somebody else, to me I did something good. [103-2, 1199-1206]

For Margaret and Jeremy, time spent in the "role" of caregiver was the "ordinary" or everyday context of their lived experience.

#### The Caregiving Commitment: Joys and Sorrows

All of the caregivers realized the strength of commitment by skilfully helping the PLWA survive the HIV illness and or to die peacefully. For several caregivers, the loss of the PLWA through death transcended their time spent as a caregiver, and affirmed their sense of commitment.

Yeah, it was a crazy time. It was a crazy time. God damn I miss it. Oh yeah, yeah. I've been quite happy to do it for a long time, long time. It was really, really weird. Yeah it was weird. Strange, but glad I did it. Really glad I did it. I wouldn't have wanted him to be anywhere else. [106-1, 2015-2020]

So, um, I'd do it again in a minute. Might do some things differently but I'd do it all again. For him. And if I'm still clean, and it comes down to it, with



my nephew. [106-2, 1274-1280]

In achieving their commitment with the PLWA, feelings of satisfaction realized by the caregiver realized were reflected upon. For example, Freda questioned her feelings of personal satisfaction of herself as a caregiver.

And I do think his life, and I don't know if I'm satisfied in my own thoughts and if I am, that's good because I'm important not anybody else. I feel that his life was extended longer because I did feed him good and I did care for him and he had the love, you know and security. [102-2, 1006-1013]

For other caregivers, although there was satisfaction, there was also struggle to find positive meaning in the experience of suffering. For example, for two caregivers, Lizzie and George, self doubt was evident as they questioned their future ability to again caregive in the context of AIDS.

I don't think I'll ever do this again. I think that I, I think I'm a wonderful nurse and I'm a wonderful friend and, but I think that I, as I said to you initially, it takes too much from me. [104-2, 332-337]

And I don't know, well, I know that I don't want to do it again in my current situation. It's not going to work, um, you know, whereas with Brian you know, you weren't going to take him from me without me fighting real hard. [106-2, 1073-1076]

These caregivers recognized the emotional toll of caregiving. However, they also discovered their inner strengths of determination and commitment. As well, by recognizing her personal limits, Lizzie discovered a positive perspective of self and was able to commit to do volunteering with AIDS testing counselling.

I am starting, I do some work with volunteering. I want to give something back. Yeah. I didn't give as much as I got. Certainly didn't. I certainly got lots. [104-4, 1765-1775]

George recognized his personal limit and realized the opportunity for change. For example,

George reconsidered his current living situation with his roommate, a PLWA.

And I figure it's probably a good time to get out of this situation that I'm in, because I'm starting to resent my roommate's presence already. And I would feel obligated to become caregiver and that's a hell that I refuse to go through. I would do it and hate it. Um. And I couldn't let someone else be caregiver cause then they would be in the house too, you know. Have two to deal with. So. I'm game to give it a shot (move to the lake). He can do what he wants to do, or what he has to do. And I'm not going to feel responsible. I'm not. I have a big guilt complex when it comes to doing stuff like that. I'm not going to have it this time. So I have to do this for me. I've done a lot of things for a lot of people in my time, now I'm just going to do for me. [106-2, 1747-1768]

I have a good life, you know. Um. I don't want a dark cloud over my head. I want to live life to the fullest right up till the day I die. I don't want to be like some people who, then they get on their CPP, sit and do absolutely nothing all day, day in, day out. That is very hard on people. That's the reason I want to move to the lake. I can't go through this again. [106-1, 265-282]

The lived experience as AIDS caregiver provided George with the understanding of his inability to extend a commitment in this situational context. At this point of time in his life, he was aware of his need to take time for himself.

Through their caregiving commitment, caregivers reflected upon their caregiving and feeling consequences. Questions were asked of themselves to find meaning and understand their feeling responses and or those of the PLWA. As a result, caregivers became aware of their need to gain perspective. For example, Isabelle reframed her responses toward Jerald as she reformulated her understanding of self.

Now the way I look at it, I'm looking at it now, before I was, he's my son, how dare anybody say or do anything to him. But as I told you before, I was climbing a mountain at that time, and when you're climbing a mountain you don't see anything. You just look at where you're going, eh. Now, I think to myself and you know maybe the hospital wasn't that bad. Maybe it was just him. That he was so angry at everybody and everything. That nobody could reason with him. Uh, and I can see that happening if the person is very ill, you know. [101-2, 484-498]

Isabelle reflected on her perspective of Jerald and of his anger. Understanding her perspective enabled Isabelle to learn to respond differently to both the anger and to Jerald.

I'm approaching it in a different way altogether. I think my approach is going to be different. Uh, if he does anything that bothers me, I say. "Jeremy don't do that, you're bothering me." "Oh, pardon me." He's still very angry at the moment. But I think he has, I don't think that the anger is as bad as it was. [101-2, 748-757]

But one day maybe he'll give me an opening and that'll be it. See, this I wait for now. I wait for openings to say anything. You know I don't bring it up, like, but I'll wait until he says something and then I will, I will kind of jump in and say something. Very calmly, not get mad any more, you know. Don't get mad like that any more. [101-3, 158-171]

For Isabelle, transformation occurred in her knowledge of self, changing her attitude and approach to anger.

### The Caregiving Commitment: Healing Discoveries of the Heart and the Spirit

For other caregivers, reflecting on their commitment to continue caregiving, motivated them to ask new or different questions of themselves. In the process of this soul searching, caregivers discovered love and spirituality as explanations to what helped them manage or personally sustain their caregiving experience. As well, caregivers contemplated that what had helped them, may also help sustain others in a similar circumstance. Most caregivers were aware of their love for the PLWA as enabling them to initially engage as caregiver. However, their knowledge of love's power to endure suffering was a different awareness. For example, George identified caregiving as love, accessing its power and the HIV nurse to sustain his efforts.

What helped me get through all this? (sigh) Love. Odd word, isn't it? Yeah. The fact that I loved him. Um. The fact that I had, uh, that something that I did made me aware of that love gave me another stepping stone to push from to keep going. And the HIV nurse. She's an incredible lady. [106-2, 913-920]

Other caregivers identified turning to God or religion to access the power of their beliefs to manage. For example, Freda sought God to understand meaning in her son's illness.

I don't know what helped me to get through this, it was, I would say probably spiritually. Uh, I don't know, I don't know, I can't, I'm sure God's the only person who could answer it. I think you have to have something in you life that you believe in, you know, a lot of. And, uh, my ans..., my question was, "Why"? "Why does this have to be. Why does it have to be him? and Why does this have to happen?" and all this kind of stuff. And, uh, I think I'll probably still be asking that question why. And maybe, uh, if I ever get up there I'll probably still be asking why. (chuckle) You know what I mean? Why? And I'm sure I won't be the only one asking why. [102-2, 770-802]

Although Freda did not have answers to the question asked, her ability to turn to God had helped her manage loss. In contrast, Jeremy struggled with his sense of religion as a source of solace.

I'm not religious anymore. I have my own beliefs and, uh, if I'm going to hell, I don't understand anything because religion's talked out and I don't know. And why do I have to go, like why am I going to hell, for what purpose? For caring for a child? Or for caring for a sick person? For caring for people that abuse you? You know. So I think religion is one of the worst things that people could have because they are, it's so pre..., you know, they're prejudiced. So that's why I don't have a religion. I believe there is a God. But I don't know why he makes me, why does, like why do I suffer now, you know? Like you ask yourself so many times why, you know. Maybe because you know, I'm starting, I've, I had to learn to accept it and life. You know if I, if there's anybody to suffer, O.K. make me suffer instead of a poor innocent person that might not be able to take it. [103-1, 1122-1149]

Jeremy believed that religion had caused him to endure suffering. However, through his belief in God he found healing and acceptance in his suffering.

And I think that's why I do what I'm doing is, I think I've said this before, I cannot stand people suffering and suffering is, there are a lot of ways you can suffer, you know, but this pain, caring heals. And if I show Dean or any other person that I care, I think that heals. [103-1, 1586-1594]

The powerful healing powers of caring, transformed both Deans' and Jeremy's suffering.

Some caregivers offered personal insights of their discovery which they found helpful in their caregiving. Through their expanded consciousness of their own caregiving experience, they reflected on what may help other AIDS caregivers. Caregiving necessitated a new reality of AIDS and the need for caring connections. These are now offered as their gifts which may assist other caregivers. For example, the gift of shared learning.

I guess to become more aware of what the disease was actually all about. At that time, heard a lot about it and read a lot about it but with him being here and going through all kinds of things I learned a lot more about it and I can talk easy, more easily about it with other people. [100, 933-940]

The gift of a embracing life with a positive attitude.

Be as supportive as you can with that person and know that hugging or whatever, you're not going to get anything from that because you go to know that, you know, there's somewhere out there there will be a cure. If not, then, you know, you live your life to the fullest and avoid, I guess, avoid as much stress as you can. [100, 1042-1050]

The gift of discourse through healing connections.

I think the best help is just to be able to talk, uh, and I don't necessarily mean about AIDS. It's how I talked with Bill. We can talk about the AIDS thing or we can talk about something absolutely normal. We can make a joke about AIDS. Or laugh at something that Brian has done. Uh, and then talk about everyday things. All in the same conversation, you know. You've got to be able just to let things in and out as they come out. Uh, you friends who haven't been through the experience can't understand that, you know. If we're talking about nn,nn, and da da da da and all of a sudden I say something about AIDS, there's that pregnant pause and lights, you know, like whereas, you know, with other caregivers, you know it's a part, you know. And it's O.K. to say, um, but other people don't know how to deal with it, you know. So I think that is probably the best help is to have someone that has been through it, uh, just to talk to. [106-2, 1370-1405]

The gift of honest, self expression.

B: Well, what I learned from Margaret is that, um, there's, if something is bothering you, say, it's a, say what you think, say what you feel.

A: The less stress you have to deal with the better.

B: It's like, even if people don't like what you're saying, it's your opinion and you have that right, the right to that opinion and don't hide anything, tell the truth, even if it hurts. Um, that's basically, like I used to be like that but I was never very

A: Open

B: open about it. Where Margaret was very open about it and that's what I've learned from Margaret has been, is something's bothering you say it. Do something about it.

A: Don't keep it in.

B: Don't keep it in, And um, now I teach a lot of other people that. [100-3, 2092-2119]

The gift of love, faith, hope and charity.

Just knowing that people believe in what you're doing. [106-1, 982-983]  
So I got encouragement, financial support even from people I hardly knew. So it's things like that that give you the strength to keep going and I loved Brian dearly, you know. There was no way that I was going to fold before I got through this. No way. Nuh, nuh. [106-1, 1036-1044]

The gift of supportive relationship.

Like you can't do this alone. And that goes for anybody you bring home who is ill. One person to do it. I mean, I guess it is possible but not many work. If I wasn't working full time I could have probably done it for the most part. But I did work full time so, uh, you need someone to relieve you so you can go out, even if it's to go and buy groceries for the house. Go to work. So you do need a fairly large network of people, some form of support network. And in that network you've got to have people who are brave enough. [107-2, 2560-2569]

Caregivers expanded awareness of the self discovering commitment, ability to endure, spirituality, suffering, compassion, connection, and love, as well as new properties of time and relationships. These were the answers to the question of what had helped them throughout their AIDS caregiving experiences.

### Discovering System Perspective

Discovering system perspective describes the caregiver's expanded awareness of the

moral caring within the broader social or health care system that affected their AIDS caregiving and its experience. The "moral caring" perspective of the caregiver, situated within his or her caring ethic was expected in the provision of care by others, including health professionals. In the process of discovering system perspective, caregivers illuminated their view of self to that of self or PLWA and system. Their lens of consciousness was expanded to witness the system as the PLWA may have. Caregivers reflected on the process and outcomes of interactions between the PLWA and the wider social context. These interactions became the moral caring lens through which they developed meaning in relation to the health care system. Caregivers discovered both the adequacies and inadequacies of the system to meet the PLWA's needs. As a consequence of a moral caring perspective, caregivers shared their meaning perspective through a discourse which predominantly addressed inadequacies.

Several caregivers discovered an awareness of the scarcity of resources which adversely affected the PLWA's existence.

I don't think there's enough help out there for them. So, I think there's a great need for supportive, emotional, spiritual, psychological (help). The doctors, I mean, forget it. We all know what, the doctors I guess have to keep that distance. [104-1, 367-372]

The most common identified resource was the financial means of the PLWA to sustain himself. Several caregivers spoke of the financial plight of the PLWA which motivated them to provide assistance. For example, Freda's awareness of her son's inability to work and lack of income motivated her pay his household expenses. Her personal awareness of Derek's difficulty expanded her consciousness to consider other PLWAs.

And I think you know, that's one thing. Money has a big thing to play in the

care of anyone that's sick. If they have the money and can be cared for properly, you life is going to be extended by, you know. Those in the majority of them that are very sick with that disease, they don't have the money, they don't have the support of, or the care that they should get. [102-2, 990-1013]

In this Province, we are fortunate to have social services which provide financial assistance for those who are otherwise unable to provide for themselves. However, PLWAs in this study identified difficulty meeting nutritional requirements with this level of assistance. For example, one caregiver shared his observation of the need for PLWAs to access food banks.

I'd say most of the people who are on city (social assistance) right now access the food bank. They have no choice. They don't make enough. A lot of people that are HIV positive that are provincial, there's a lot of different medical needs and like we're all on like things like 3,000 calorie diets, just to keep our weight as it is. Do you know how much 3,000 calorie a day diet costs? [100-3, 2332-2346]

As well, this moral perspective brought awareness of the bureaucratic requirements which affected the PLWA's ease of accessing social assistance. For example, one caregiver related the PLWA's ability to navigate the system's "red tape" while ill to access the resource of social assistance.

It's like there's so much information and there's so many forms and so many questions that it's like, it, what it seems to do is, it, uh, scares them (PLWA) because there's so much at the same time they freak. You know, it's like, "No, I don't want to know anything anymore," because the more they know it seems the more they freak out so. Just applying for provincial is a nightmare, you know. You have an intake worker and you have a case worker and you have a social worker, you have a financial worker, you have, there's forms to fill out. You have to get the doctors letters. You have to f..., you know, it's like, you're, you're last year's income tax, your birth certificate, your. They go like, oh my God, you know. You feel that if it's not a PLWA that's explaining these things, you feel this person, you're just a number. You know, you're just a number. [100-2, 1278-1300]

A moral imperative to assist the PLWA in a humanistic rather than mechanistic process was identified.



Caregivers reflected on the "caring" interactions of the PLWA with the health care delivery system. Through this reflection, caregivers discovered perspective within their understanding of the health care delivery system. Some caregivers discovered their personal lack of necessary knowledge to access or make use of available system resources. For example, George related his lack of knowledge of "what to say " resulted in the PLWA's hospital-based death.

Uh, but there were just things I didn't know. I didn't know that I should say to Peter, "Peter talk to his parents. Help me get him home." And I was so pissed off with them (Brian's parents) at that point I didn't want them in my house. [106-1, 2186-2192]

George lacked awareness of the power of his voice or of employing Peter's voice to realize Brian's wish for a home-based, rather than hospital-based death. As well, he discovered he lacked understanding of the system's care.

I didn't necessarily understand palliative care either. Like at the hospital, if a family member goes into a room, nursing will not come in. They will leave you alone. Oh, there was one day I went in there and George is lying there, half cleaned, naked, uncovered. And they left him that way because I was in the room. I didn't understand that. To me, that was disgraceful. And I lodged a complaint (chuckle). Like how could you treat him like this. But I didn't know that that is their policy. Know that if a family member is in there, you don't go in. I didn't understand, of course, the head of Palliative was not thrilled that I had lodged this complaint. Like why didn't you come talk to us? I didn't understand, you know. To me they were doing him horrible indignities to the person I loved most in the world. [106-1, 2201-2229]

Brian's experiential knowledge was realized after the emotional indignities suffered. Other caregivers reflecting on their own knowledge gained and recognized a need for professional guidance. For example, Lizzie suggested preparing caregivers for their role.

But, um, I, I think, and this has just come to me as we're talking that there should be counselling, education, counselling/education, whatever, for people who are entering these kind of relationships. [104-1, 1169-1174]

Ongoing interactions with professional health providers, notably nurses and physicians, yielded caregivers with perspective on care practices. Awareness of fear, lack of professional knowledge, and insensitivity of strategies to manage care were perceived. For example, Margaret felt fear within health care professionals was a barrier to caring practice.

I think the biggest thing from a health, people that are in the health care system is not to be afraid. That's I think, that's the one biggest um, bump in the system as far as health care professionals. Just don't be afraid of us, you know, because if you're afraid of us and especially with somebody (PLWA) that doesn't know anything about it, that person's going to be freaked out. [100-2, 1870-1879]

As well, practice which lacked in particular knowledge of self, and practice which did not include a family perspective was perceived as inadequate in meeting information needs. For example, Margaret identified the need for health care professionals to be effective as educators.

Uh, be a good listener, and if they have a question you can't answer, just say so. Say, I don't know the answer to this but let's work together to find out. Because they always seem to feel that they're aside and not involved in the process. It's to say, let's do it together cause then they feel like there's somebody learning for them at the same time. It's like, it's all positive reinforcement. Always, always, positive reinforcement. Don't act differently with them than you would with anybody else. I've seen caregivers that's like, (sigh) you know, oh, you poor thing, you know. And all this and it makes them feel even worse because they're being pitied. [100-2, 1563-1580]

As well, caregivers spoke of the need for health care professionals to be cognizant of the reverberations of their interactions. For example, Isabelle spoke of the indirect untoward effects on family.

"When patients come into the emergency," I said, "When they are treated badly or made to feel badly," I said, "It reflects back on the family." I said, "We come home again." So I said, "When a patient is treated badly in the emergency, remember there's a family at home and they're going to get the brunt of it. No matter what happens to them in the hospital." [101-2, 355-367]

For Isabelle, there was a need for professional care providers to have a family system perspective in managing the PLWA. Whereas, Freda identified deleterious effects on the PLWA.

One thing I will say, that the way the doctors handle a patient that they know is terminally ill means a lot to the comfort of that patient. And I don't think that Derek got the comfort from one of those doctors. But I understand now that every doctor has their uh ways, or their, within their boundaries that they can handle patients. I mean once you're a patient of one doctor, um, I guess it's up to that doctor to, you know, inform that patient of how ill that patient is or whatever, you know, within reason anyway. But uh, I think that was one thing that I don't know if I really accept that, like the doctor just came right out to him and while he was in the hospital on one of the bad occasions of going there, and said to him, now you're dying and you have to tell your parents, like your mother, that you are dying and I'm not going to tell them, you are. [102-2, 161-192]

As a consequence of their moral lens, caregivers engaged in developing political awareness and taking political action. Several caregivers volunteered time to agencies to assist with support of other AIDS caregivers, fund raised, attended workshops and retreats, and counselled families. Through the process, knowledge of resources was gained. For example, one caregiver expressed concerned awareness of the lack of a unifying strategy for AIDS.

And it's one thing that I found from going to all these other provinces, PLWA in Manitoba should be very, very, very angry because we're not getting services at all. We're probably the worst province to be living in as far as people with AIDS. Like we have no provincial AIDS strategy. We're the only province that doesn't have one. You know, as far as money is concerned for our welfare, we're the second worst. [100-2, 1103-1120]

This discovery of knowledge at times engendered anger at the awareness of what was missing or could be provided. Consequently, anger was also expressed at the system. For example, one caregiver expressed anger at a clinic which provided AIDS care.

The reputation of (a clinic) and the work that they do is just down the tubes. I'm surprised they're still open any more, you know. What have they done for people with AIDS? Tell me? Now they're switching from being a gay community clinic to just a regular community clinic. It was already hard enough to get any services for PLWAs when it's supposed to be a gay clinic. Never mind when it becomes a community clinic. So anyway a 2 week wait for an appointment. Like, PLWAs when they're sick, they're sick right now, you know. [100-3, 1904-1912]

Anger was expressed at the inflexibility in the system's response to acute care episodes and the strategy to change management of AIDS illness. Discovery transformed the caregiver's anger to action, motivating political awareness and grassroots AIDS resource development.

One caregiver's perspective of the broader system's moral imperative to care, assists to summarize *discovering system perspective*.

I never realized how st..., like I knew humanity was stupid in some ways but I never realized how stupid (chuckle). It really, really brought it into perspective. I'm going like, oh my God, we're doomed as a species cause they can't even care for each other. [100-3, 3453-3463]

## Conclusion

This chapter has presented an mini-ethnography of seven AIDS family caregivers. Qualitative data was analyzed using content analysis. The analysis revealed the five major themes of Monitoring, Letting In: Becoming a Caregiver, Protective Labours, Labouring the Emotions and Caring Transformations. Each theme is discussed with its categories.

## CHAPTER 5

### DISCUSSION OF THE FINDINGS

#### INTRODUCTION

In the concluding chapter, I discuss the findings of the study. A summary and discussion of the findings are organized under the following headings: (1) Monitoring; (2) Letting In: Becoming a Caregiver; (3) Protective Labours; (4) Labouring the Emotions; and (5) Caring Transformations. The caregiving experiences of AIDS family caregivers are examined and related to the literature. As well, the empirical literature was revisited to include several more recent studies that are reflected within the discussion of the findings. Themes and categories are explored throughout the discussion by linking them to the literature on AIDS family caregiving. Findings are related to the conceptual framework of "AIDS Family Psychosocial Health" which guided the study. Strengths and limitations of the framework in relationship to this study are identified, and a reformulation of the framework is suggested. The effectiveness of the study design and methods are also discussed. As the researcher involved in this ethnographic study, I describe the processes of reflection and reflexivity in the concluding portion of this chapter. Finally, implications for nursing practice, education and research are presented.

#### Study Findings

Analysis of the study data conducted within the qualitative paradigm resulted in the emergence of five major themes. The themes represent AIDS family caregiving from a psychosocial perspective. Of these themes, three describe processes and two describe

psychosocial outcomes of AIDS family caregiving. The initial concern of this study, the psychosocial impact of AIDS on family caregivers, provided an orienting frame of reference to the data which emerged in relation to the caregiving process. The "work" of AIDS family caregivers was discovered as a universal theme of the family's psychosocial responses. Collectively the themes represent the "work" of AIDS family caregiving.

### Monitoring

Monitoring represents the ongoing process of caring behaviours that family caregivers engage in to assess the PLWA's health status and become aware of his care needs. In essence, monitoring entails the caregivers' efforts to examine "what is going on" with the PLWA psychologically, socially and physically. Caregivers used their historical, as well as present, knowledge of the PLWA to make inferences or judgements about health on which to base their caring intervention.

Monitoring is comprised of three categories: *Surveillance*, *Vigilance*, and *Hypervigilance*. The caregiver's geographical and emotional connection with the PLWA; shared awareness of the AIDS diagnosis; and the PLWA's situation along the illness trajectory help to differentiate the type of monitoring. *Surveillance* occurs when caregiver's are distanced from the PLWA, either in their feelings of connection or shared residence. As well, it may occur covertly, without knowledge of the PLWA's AIDS diagnosis and occur early in the AIDS illness trajectory. *Vigilance* represents the caregiver's predominant mode of monitoring. It is differentiated by the caregiver's shared awareness of the AIDS diagnosis and residency, as well as the PLWA's illness progression. *Hypervigilance* represents the

caregiver's heightened intensity of monitoring efforts during acute illness episodes of the PLWA or caregiver uncertainty.

### Letting In: Becoming a Caregiver

*Letting In* explicates the process by which family caregivers become involved in AIDS caregiving. This theme encompasses the physical, emotional, and cognitive work, associated with the PLWA's entry into the caregiver's home and life. Caregivers made a conscious decision to "let in" the PLWA to his or her life and home. As most caregivers and PLWA had knowledge of each other through relationship, (either as mother, former lover, and/or friend) their historical relationship may have affected the feelings of obligation, commitment, timing, and/or compassion inherent in the decision to caregive. *Letting In* was initiated because of a change in the PLWA's life circumstance, either perceived through the caregiver's monitoring, or by the PLWA.

*Letting In* is comprised of three categories: *Engaging the Caregiver*, *Engaging the PLWA*, and *Mutual Engagement*. Physical, emotional and cognitive actions were taken by the caregiver and/or PLWA to establish the caregiving relationship within the home. Actions taken by the caregiver were described as *Engaging the PLWA* and were rooted in caregiver's feelings of compassion or enduring love for the PLWA. Engaging the PLWA described the majority or four of the seven caregivers. Of these, two were former lovers, one a mother and one had no prior relationship with the PLWA. *Engaging the Family Caregiver* occurred when the PLWA took action to connect with the family caregiver and was predicated by the PLWA's change in health or financial circumstance. As well, feelings of obligation may have affected the decision to engage as caregiver (as one caregiver was a mother and one a

friend), the type of caregiving commitment, and the caregiver's role. When both the PLWA and the caregiver engaged in the process, *Mutual Engagement* occurred. This decision was made to fulfil mutual caring needs without historical knowledge of the other or feelings of obligation. The caregiver had recently launched her adult children and felt a void in her life, and the PLWA felt a need for a cultural connection.

The findings suggest that the process of becoming a caregiver is complex. There is a need to negotiate entry and caregiver role. Control of the decision to engage, the underlying motivation, feelings of obligation, and commitment all affect the process. As well, the historical quality of the caregiver's relationship with the PLWA appears to affect the strength of commitment and the decision to engage. These findings may have implications for nurse's assessment when working with PLWAs and their family.

### Protective Labour

*Protective Labour* describes the ongoing work of the caregiver as he or she engages in maintaining, continuing, and repairing the PLWA's world so that he can live in it as well as possible. The caregiver's moral ethic of care was applied when managing their responses, as well as the responses of others. Additionally, caregivers assisted the PLWA to manage his own life, so that his psychological and/or physical integrity could be maintained. The caregiver's values and beliefs form the moral boundaries which guide his or her protective care. In essence, the caregiver acts as the PLWA's advocate to address the threat of harm by others. Caregiver's protective care action entails *monitoring* and is aimed at maintaining the PLWA's *Psychological Integrity* and/or *Physical Integrity*. Caregiver strategies include



protecting the PLWA's independence, preventing harm, conserving resources, promoting quality of life, negotiating care needs, promoting well-being, and managing stress. Feeling consequences of protective labours were expressed by caregivers as stress, frustration, conflict, and anger. As well, caregiver's physical health, particularly weight loss, was experienced.

### Psychological Integrity

*Psychological Integrity* describes the caregiver's work to preserve the PLWA's personhood. The caregiver acts to maintain dignity, independence, quality of life, respect and value, and respect of the PLWA's expressed wishes. Caregivers manage secrecy, control the caregiving environment, use empathy, and act as or seek advocates to protect the PLWA. Maintaining secrecy was protective of the PLWA, but had a detrimental effect on the caregiver which contributed to his or her feelings of isolation. Strategies to maintain, promote, and/or preserve the PLWA's well-being and quality of life included maintaining hope, positive thinking, decreasing stress, use of music, touch, and the use of alternative therapies including cannabis. As well, preserving the PLWA's quality of life involved respecting the PLWA's expressed wishes including privacy, advanced care directives, the right to chose death, and the wish to die at home. Dilemma arose when the caregiver's moral beliefs and his or her ability to meet the PLWA's expressed wishes for death at home differed. For both the PLWA and the caregiver, maintaining quality of life was a significant aspect of AIDS caregiving.

### Physical Integrity

*Physical Integrity* describes the caregiver's actions that demonstrate protection of the

PLWA's physical health or environment from an advocacy perspective. Several family caregivers related protecting the PLWA from receiving what they perceived to be less than sufficient medical care. As well, caregivers negotiated with nurses and other health care providers to ensure the care they perceived was needed would indeed be provided. One caregiver protected the PLWA from harming himself by managing the PLWA's improper use of medication.

Protective Labours are caregivers' strategies guided by the caregivers' moral worldview to ensure the PLWA's integrity. At times, strategies arose in response to managing the responses of others, including those of health care providers. Understanding the world view of the family caregiver to ensure quality care is imperative. This suggests that as professional care providers, nurses need to be aware of their actions, inactions, and caring ethic.

### Labouring the Emotions

*Labouring the emotions* explicates the substantive expressive or emotional work of family caregivers associated with attaching meaning and managing feelings attributed to the caregiving experience. Emotional labour is an integral outcome of *Monitoring*, *Letting In* and *Protective Work* and its expressive consequences. It is enduring, pervasive, and heart-rending work which occurs as consequence of the caregiver's connectedness with the PLWA. Labouring the emotions is affected by the caregiver's relationship with the PLWA and others (family, co-workers, community, and health care providers).

Three categories of *Labouring the Emotions* emerged: *Labouring in Exile*, *Labouring*

*the Losses*, and the *Labour of Uncertainty*. Each comprise a substantive source or domain of labouring and may occur concurrently to synergistically contribute to the caregiver's labour. Although each domain is described independent of the others, they may not be mutually exclusive. For example, the labour of uncertainty may be simultaneously experienced while the caregiver is labouring in exile and labouring the losses. The domain of labouring that occurs appeared to be defined by the caregiver's perceived emotions and the outcomes associated with the caregiving experience.

#### Labouring in Exile

*Labouring In Exile* is the caregiver's sense of feeling separated or forced away from those resources which may otherwise have been used to help manage the emotional consequences of AIDS caregiving. Caregivers reported feeling emotionally distanced, isolated, or estranged, from their home, family, community, and or members of the health care system. Estrangements may have been self-imposed, but usually occurred as a consequence of prejudice, insensitivity, and distancing by others. Significantly, secrecy, stigma, and anger contributed to these estrangements.

#### Secrecy

For most caregivers the need to maintain secrecy of AIDS and their caregiving, resulted in stifled communication with the PLWA, the family and or in social circles, and affected opportunities for support. Secrecy was maintained for fear of reprisal by family, coworkers, neighbours, and the community, against the PLWA and the caregiver. Although secrecy was protective, it also functioned to distance the caregiver from support which may otherwise been accessible.

### Stigma

Several heterosexual and homosexual caregivers expressed feeling stigma and being isolated by "guilt by association." Stigma was felt as a consequence of being gay and caring for someone with AIDS. Particularly, most gay caregivers perceived that the gay community was not supportive of their AIDS caregiving.

### Anger

Many caregivers reported anger as a pervasive and destructive force affecting their relationship with the PLWA, family, and health professionals. Frustration with the health care system was expressed as a consequence of being unable to provide resources or care perceived to be required. As well, anger was expressed at the insensitivity, prejudice, lack of knowledge, lack of caring and empathy, encountered in interactions with health care providers, including nurses.

As a consequence, caregivers "managed" their feelings of hurt, anxiety, anger, fear, frustration and isolation. As well, these feelings may have contributed to further isolation. Caregivers were subject to labour in a socially isolated context while suffering the emotional strains or stresses of caregiving work.

### Labouring the Losses

*Labouring the Losses* describes the emotional work of the caregiver as a consequence of the multiple and additive, tangible and intangible, losses incurred throughout AIDS caregiving. Loss denotes that something is being taken away from the caregiver, or that he or she is being deprived of something they ought to have. Most caregivers experienced losses of

personal freedom, social circles, time for self, interpersonal relationships, while witnessing loss of the PLWA's personhood and/or physical self. As well, several related economic losses of jobs, finances, and for one caregiver his home. Half of the caregivers experienced the loss of the PLWA through death.

Loss was managed within the context of the caregiver's feelings of connection with others and, as well, was affected by his or her feeling of uncertainty. Loss was distinguished by two categories: *Facing Loss* and *Letting Go*.

Caregivers developed awareness and attached meaning to anticipated and incurred loss through *Facing Loss*. Making a commitment to caregive marked the beginning of facing loss. Facing loss included additive and multiple losses, including caregiver's personal loss and that related to the PLWA. Anticipating the death and loss of the PLWA was for many caregivers, the most emotionally painful aspect of facing loss. Several caregivers came to terms with accepting their losses and let go of the past through *Letting Go*. For three of the caregivers, the death of the PLWA required them to let go of his or her past relationship, make sense of, and accept the loss. *Letting go* may have occurred gradually, as caregivers faced loss upon loss. Often, caregivers were unable to draw upon support of others, because of secrecy, stigma and feelings of social isolation.

### Labour of Uncertainty

*Labour of uncertainty* is the caregiver's pervasive sense of feeling unsure of the present, future, and past illness events or outcomes connected with his or her AIDS caregiving. Feelings of uncertainty varied in intensity, timing and content, but were never

completely allayed among the participants. Uncertainty presented as a constant and was experienced as feelings of lack of control, anxiety, worry, and fear. Caregivers expressed uncertainty in their ability to sustain their caregiving relationships, relationships with others, ability to predict the PLWA's responses, and their own HIV status. As well, some caregivers referred to the unpredictability of the day-to-day disease management and progression as "being on a roller coaster." The dual nature of uncertainty was characterized by hope alternated with emotional suffering.

*Labouring the emotions* describes the reverberations of the emotional suffering of caregivers as they dealt with the day-to-day uncertainty, losses and social isolation of their AIDS caregiving. Secrecy, stigma and anger were significant forces which affected the caregivers ability to access or receive support from family, friends, coworkers, community and health care professionals. These findings have several implications for nurses including caregiver assessment, anger management, loss and anticipatory grief counselling, value clarification, and knowledge of self as a caring practitioner.

### Caring Transformation

Caregivers became transformed in the process of their everyday life experiences of AIDS caregiving. Caregivers reflected on the process and outcomes of the caregiving and meaning perspectives in their lives. Expanded consciousness of AIDS caregiving in relation to self and the health care system occurred as caregivers asked questions of themselves to discover new realities. As a consequence, discovery of a new sense of self and the health care system emerged. Transformation is comprised of two categories, *Discovering Self*

### *Perspectives and Discovering System Perspectives.*

#### Discovering Self Perspectives

Caregivers discovered awareness of self which transformed perspectives on time, self, health, life, and the relationship with the PLWA. Knowledge of self as a caregiver was both painful and satisfying and entailed self-doubt and self-discovery. The discovery of inner strengths fortified their commitment to caregive and sustained their caregiving efforts. By realizing the strength of their commitment, caregivers became aware of the heart and spirit, discovered both joy and the sorrows of loss, and the gifts of love. They found hope in their spiritual beliefs, changes in their lifestyle, forgiveness for past resentments, and taking an active role in the PLWA's life. The ability to give of themselves in committed, compassionate caring was voiced as a transformative experience.

#### Discovering System Perspectives

Discovering system perspectives describes the caregivers' expanded awareness of the broader social or health care system affecting their AIDS caregiving and its experience. Caregivers extended their view of self to that of self or PLWA and system. Their awareness was expanded to witness the system as the PLWA may have. Awareness was achieved regarding scarcity of resources, difficulties with accessing social benefits, and the lack of caring in interactions with social and health care providers, including nurses.

The findings suggest that family caregivers are irrevocably changed as a consequence of their AIDS caregiving experience. Transformations in self and in awareness of the system affected their perspective of AIDS caregiving. Negative interactions with health care providers may influence subsequent efforts to seek support or AIDS caregive.

The *work of AIDS family caregivers* was found to be the connecting conceptual theme which related and explained the variability of the experiences of caregivers as they provided and negotiated care for the PLWA. Together, the nature of these findings suggest that the psychosocial response of AIDS family caregiving entails "hard work" or "labour." This unanticipated conceptual finding is discussed in relationship to the study's theoretical framework.

#### Findings in Relationship to the Theoretical Literature

The themes and categories that emerged from the study will be discussed, compared, and contrasted, with other published literature on AIDS family caregiving. The intention is to integrate and explain, the themes and categories developed with respect to other empirically based AIDS caregiving literature.

Gregory and Longman (1992) ascertained that with respect to AIDS, understanding of the lived experience is limited. As well, they observe that a discrepancy exists in nursing rhetoric which advocates attending to human suffering and the theoretical concept, which is largely reduced and psychologized by benign terms such as "psychological stress" (Gregory & Longman, 1992). According to Gregory and Longman (1992) the label "grief reaction" sanitizes suffering and removes it from its human experience. This perspective is particularly significant, given the findings in this study and more recent empirical literature.

More recently, studies have investigated the impact of AIDS on the caregivers from the perspective of gay lovers, friends, parents, spouses and a combination of these which represent the "family" of PLWAs. Quantitative and/or combined quantitative-qualitative



investigations have included the concepts of: caregiver burden (Folkman, Chesney, Cooke, Boccellari, & Collette, 1994), psychological distress (Bumbalo, Patsdaughter &, McShane, 1994), labour and costs of AIDS caregiving (Ward & Brown, 1994), and psychosocial needs (Reidy, Taggart & Asselin, 1994). Qualitative investigations have included the "lived experiences of AIDS caregivers" to uncover data that includes the processes of: taking care (Stetz & Brown, 1997), loss and grief (Longman, 1995; Brown & Powell-Cope, 1993), being a gay couple affected by HIV (Powell-Cope, 1995), negotiating partnerships with professional health care providers (Powell-Cope, 1994), and negotiating the AIDS journey while giving and receiving care (Bunting, 1992). The aforementioned research will be incorporated into a discussion of the findings. Significantly, the initial research reported by Brown and Powell-Cope (1991) has generated several subsequent reports utilizing the initial sample and data collected in 1987-1988.

### Monitoring

*Monitoring* as a process of AIDS caregiving was comprised of caregiving behaviours that for some caregivers occurred prior to entering the caregiving relationship. Historical, as well as, present knowledge of the PLWA, geographical and emotional connectedness, and situation along the illness trajectory helped to define the occurrence of *Surveillance*, *Vigilance* and *Hypervigilance* of monitoring behaviour. The finding of caregiver "monitoring" concurs with the work of Stetz and Brown (1997), Bunting (1992), and Brown and Powell-Cope (1991), as an important caregiving strategy used by AIDS caregivers.

Stetz and Brown (1997) conducted a nonrandomized, two-group pre-post (X2) intervention study with two cancer and two AIDS groups. This study tested an at-home

telephone intervention group. Data from this larger study were used to investigate two intervention groups of caregivers (n=26) of persons with cancer and persons with AIDS (a group of seven and a group of eight, 3 men and 12 women respectively). In-depth interviews were conducted and grounded theory served as the basis for data collections and analysis.

"Taking Care," one of the phases of a grounded theory of "The Labour of Caregiving" (unpublished observations) was described in detail and reference to "Becoming a Caregiver" was made in relationship to the larger theoretical model. Becoming a caregiver was described as the process of taking on caregiving activities and responsibility, frequently beginning at diagnosis, at recurrence or exacerbation of the disease, or when the ill person become more symptomatic. "Taking care" represents the physical and emotional efforts of the caregiver, the phase during which most of the caregiving work is done. Data were analyzed in terms of the strategies, consequences and interaction involved in the caregiving experience. Thematic strategies included: Managing the Illness, Facing and Preparing for Dying, and Managing the Environment. Themes of consequences included: Coming to Know One's Own Strength and Personal Suffering. Interactions that occurred as a result were: Responding to Family Relationship Issues and Struggling with the Health Care System. Several subthemes were identified, including Monitoring the Illness and the Response, that included watching for new symptoms, noting the recurrence of old symptoms and reporting what was observed.

Findings from the present study concur with those of Stetz and Brown (1997), AIDS family caregiving is "work" which places physical and particularly, emotional demands on the caregiver. Similarly, findings from this research reveal that family caregivers dedicate an enormous portion of their lives to caring for the PLWA and experience their own form of

suffering as they watch their loved one die.

Bunting (1992) investigated the ways that eleven family caregivers and nine PLWAs managed and received care within the context of AIDS. Unstructured interviews were conducted to generate the grounded theory of "Negotiating the Journey." Monitoring as a strategy was "a balance between being vigilant for symptoms and not letting AIDS rule one's life, the more novel and unfamiliar the symptoms, the more frequent and anxious the monitoring" (Bunting, 1992, p.95).

Findings from this present study contribute to understanding the process of *Monitoring* as an AIDS family caregiving strategy that has different dimensions than those previously described (Bunting, 1992; Powell-Cope & Brown, 1991). For many caregivers in this study, monitoring occurred prior to engaging as a caregiver. As well, the depth or extent of the monitoring effort varied not only with new symptomology, but also with caregiver "connection." Caregiver knowledge of the PLWA's T4 counts was not associated with their monitoring efforts. Monitoring occurred whether or not the PLWA shared his T4 counts with the caregiver. Monitoring is based within the caregiver's knowledge of AIDS, the PLWA's illness history, and the "caring" of the caregiver.

As caregivers may be uncertain of the meaning of the illness symptoms, informational aid and assistance is usually sought through physicians and nurses. Knowledge of the caregiver's monitoring may assist the nurse with diagnostic or prescriptive care management. As well, nurses may be able to anticipate needs for educative or counselling intervention based on the caregiver's assessment. Implications for the relationship of the caregiver with the nurse are inherent. The caregiver's role in the monitoring of the PLWA needs to be

acknowledged and valued as an integral part of the health care team.

### Letting In: Becoming a Caregiver

*Letting In: Becoming a Caregiver*, compels the caregiver to consciously establish the commitment to caregive with the provision of not only a geographically grounded "home" for the PLWA, but also one discerned by the "heart." *Letting In* is a complex conscious process existing in a web of history, social norms, interactions, and emotions to negotiate role entry and is not readily dichotomized by "obligatory" or "family ethos". Participants in this study were mothers (n=2), former lovers (n=2) and friends (n=3 not in a sexually intimate relationship with the PLWA). The structure and function of AIDS caregiving relationships is of interest (Omoto & Synder, 1995; Pearlin, Mullan, Aneshensel, Warlaw and Harrington, 1994; Takiguku, Brubaker & Hennon, 1993) in increasing understanding of caregiving assistance provided by the informal caregiver.

Pearlin et al. (1994) conducted face-to-face interviews with 487 caregivers outside the boundaries of "family" recruited from San Francisco Bay and Los Angeles. They reported that although the structural characteristics of education, age, ethnicity had some influence on the formation of caregiving relationships, they did not influence the scope of assistance provided by the caregiver. Sample characteristics revealed more than half of the sample (54%) were lover/partner, most (80%) reported a sexual preference of homosexuality, and most were white (78%) and male (86%), living with the PLWA. Scope of assistance was reported to be affected more by the interpersonal features of the caregiving relationship, particularly the closeness and intimacy it encompasses. As well, they concluded that many AIDS caregivers are drawn to the role not only by a sense of attachment to the persons they

are assisting but also out of a sense of mission of behalf of a community with which they identify. A similar sense of mission was not discovered in this present study. Cohabitation, and the provision of care by lovers/partners support Pearlin et al.'s assumption that these attachments embody many of the qualities that define primary relationships.

This study's findings of "Letting In" would seem to support the conclusions of others who describe the act of "becoming a caregiver" (Stetz & Brown, 1997; Bunting, 1992, and Powell-Cope, 1991) and characteristics of emotional intimacy (Pearlin et al, 1994). However, in contrast to Stetz and Brown (1997), this study would suggest that Letting In: Becoming a Caregiver occurs in conjunction with *monitoring* and this may reflect differences in the two studies sample characteristics. As well, the study's findings of the "conscious choice" is in contrast with Powell-Cope and Brown (1991), who related that caregivers did not consciously recall the decision to become caregiver and instead naturally assumed the role. In this present study, caregivers, whether related by blood, traditional unions of marriage or love, and or of friendship, consciously invested of themselves in a committed enduring relationship to provide AIDS caregiving. It is important for nurses to understand the these family caregiving connections, as any appreciable change in the informal family caregiving system may have severe consequences for the "formal" health care system (Omoto & Synder, 1995; Pearlin et al. 1994, Takiguku, Brubaker & Hennon, 1994).

### Protective Labour

Caregiver's protective care actions involve *monitoring* and are aimed at maintaining the PLWA's psychological and physical integrity. Acting on the PLWA's behalf, caregiver

strategies were used to promote quality of life, preserve independence, promote well-being, prevent harm, conserve resources, and negotiate care needs. Caregivers were guided in their actions by their "caring" ethic and often voiced the use of strategies to promote hope, maintain a positive attitude, and place protective boundaries around the caregiving.

The present study findings concur with Bunting's (1992) theme of reshaping the relationship which includes managing the behaviour of self and others. As well, although the sample characteristics differ, the findings are similar to those reported by Lesserman, Pickers and Evans (1994) that HIV positive volunteers can be characterized as having a fighting spirit, reframing stress, and maximizing personal growth. These caregiver attributes were noted in this population of caregivers. As well, secrecy was managed to protect the PLWA from harm or reprisal and supports the findings of Powell-Cope (1993).

The major contribution of these present findings is in the explication of protective "work" of family caregivers as they strive to maintain the PLWA's quality of life.

### Labouring the Emotions

*Labouring the Emotions* reveals that the greatest areas of caregiving work is emotional labour. Emotional labour has been described as the regulation and management of feelings (Hochschild, 1983). labour in dealings with other people's feelings (James, 1989) and nurse's labour (Phillips, 1996; James, 1992, 1989). Labour in this sense connotes that emotional labour is a sizeable and important ingredient in the work of AIDS family caregivers. Findings suggest that the intense demands associated with the role of family in AIDS caregiving are marked in their "psychosocial impact," particularly as anger, stigma,

secrecy, and loss are pervasive. Tremendous personal emotional suffering of the caregiver was associated with the stigma and secrecy and its AIDS caregiving, in the form of social isolation and distancing from family, coworkers, community and the health care system. Lippman and Frierson (1993) have suggested that all the emotional and social reactions that occur with the PLWA also occur with family and friends and thus family are often viewed as "co-infected" (Takiguku et. al. 1993). The labour and cost of AIDS family caregiving has also been investigated by Ward and Brown (1994) in respect to the economic value of family providing care in the home.

A number of investigators have posited reciprocal links between social support and stressors in caregiving (Baille, Norbeck & Barnes, 1988; Cohen & Syme, 1985). Little empirical data exists in respect to AIDS family caregivers. Stewart, Hart and Mann (1995) investigated support and coping in living with hemophilia and HIV/AIDS. Interviews and mailed questionnaires were used to investigate thirty people with hemophilia, 23 family caregivers, and 17 bereaved relatives' experiences of types of support, appraisal of support and use of social support as a strategy for coping. In all groups, many respondents reported negative interactions with people from whom they had anticipated might support them. Respondents reported insensitivity, prejudice, and avoidance from others, including friends and health care professionals. Prejudice was experienced equally from physicians, nurses, other health professionals and friends. Thus while social support is most often treated as a stress mediator or antecedent, it also can represent an outcome of stress. This present study identified family caregivers as being "exiled" from family supports as a consequence of their AIDS caregiving, and would support the findings of Stewart, Hart and Mann (1995). As

well, this study's findings suggest that similar to families of gay men, families of caregivers have the potential to be both significant sources of social support and powerful negative influences (Turner, Hays, & Coates, 1993). Lastly, that there appears to be fewer people in AIDS family caregiver's social support networks due to stigma, concurs with Atkins and Amenta (1991). Social support emerges repeatedly as a significant factor in AIDS family caregiving.

Stigmatization was discovered to have considerable negative consequences for families. Parents, friends, and ex-lovers were vulnerable to the effects of stigma, such as being isolated from friends, community, and health professionals. Family caregivers expressed emotional distress, anger, and dealing with loss without support. This study's findings support Goffman's (1963) observation of "courtesy stigma," that the relationship between stigmatized person and significant other leads the wider society in some respects to treat both individuals as one. The extension of stigma to significant others has been noted in the literature about AIDS family caregiving (Giacquinta, 1989; Geis, Fuller, & Rush, 1986). "Guilt by association" described by Powell-Cope and Brown (1992) as the stigma and discredit that significant others are obliged to share because of their close relationship to the stigmatized person, was widely reported by caregivers in this present study. Study findings are similar to Chekryn (1989) in that the PLWA may insist on secrecy and prevent family members from reaching out to their friends for support. Significance of this study's findings are that despite more than ten years, the stigma associated with AIDS and its caregiving exists. Findings would concur with aforementioned theoretical and empirical evidence. In contrast to Powell-Cope (1993) and Katz (1997, 1995) this study did not find the gay



community was supportive of other gay men who were AIDS caregivers. Katz (1997) reported that family chose to deal with illness alone because of fear of anger and stigma. However, findings from this present study would suggest that anger and stigma are forces which act to isolate caregivers from receiving support from their families. Stigma was extended to heterosexual and gay caregivers, whether HIV positive or seronegative.

As well, this present study supports the work of Sowell, Bramlett, Gueldner, Gritmacher and Martin (1991) concerning bereaved lovers. Fear of recognition as a result of the social stigma associated with AIDS, combined with the lack of customary social support systems, forced caregivers to remain hidden and alone in their grief. However, unlike the findings of Sowell et. al. (1991), it would appear that the witnessing of loss, not only the death of the PLWA, affects the caregiver. This finding concurs with that of Powell-Cope (1995) where gay caregivers are aware of their own mortality and risk of developing AIDS. Additionally, similar to the findings of the Powell-Cope (1992), losses and/or death of a partner from AIDS heightened the caregivers' awareness of their own risk for developing AIDS. The themes of *facing loss and lettings go* parallel those of Longman (1995), and the additive and multiple effects of loss described by Powell-Cope (1993).

Longman (1995) conducted interviews to investigate the bereavement experiences of six mothers whose sons died of AIDS. Grounded theory was used to discover the two basic social processes of "Connecting and Disconnecting." At the time of the interview, the period of bereavement ranged from 10 months to 4 years. Longman (1995) reported that mother's struggles related to death were intense and affected every aspect of their daily lives. Properties included fear, awareness of mortality, loss and energy. Connecting entailed

continuous effort to remain connected to the son who had died and at the same time, facing the realization that he was dead. Disconnecting was described as the process of going on with one's life and included acceptance of death and letting go. Letting go involved making sure that family and friends knew of the death of the PLWA.

*Uncertainty* associated with managing the illness and monitoring symptoms was discovered to be a significant source of caregiver stress in this study. As well, uncertainty in AIDS caregiving was discovered in relationship to loss, dying, self, and relationships, including that of the caregiver and the PLWA. These findings confirm those previously reported by Brown and Powell-Cope (1991) that uncertainty functions as the basic social process of AIDS caregiving, affecting all aspects of caregiver lives; uncertainty as a consequence of loss (Powell-Cope, 1993), uncertainty experienced as a couple living with HIV (Powell-Cope, 1995) and of uncertainty related to caregiver's increased monitoring efforts (Bunting, 1992). However, in contrast to uncertainty as the greatest area of caregiver stress (Brown and Powell-Cope, 1991), this study reports uncertainty as a component of the overall stress of caregiver's labour. In addition, caregiver's uncertainty was discovered in expression of "self" in their ability to sustain the caregiving relationship, ways of emotionally relating to the PLWA, and future fears related to coping when the illness may exacerbate. Uncertainty is an important concern for AIDS caregivers and may be similar to the uncertainty reported by family members with cancer (Oberst, Carey, McCubbin & Hughes, 1991) and those caring for the frail elderly (Morgan & Laing, 1991).

Anger as a prevalent reaction of the PLWA, family of the caregiver, and the caregiver, was a destructive force which affected ability to seek and receive support. The

study's finding of the pervasiveness and destructiveness of anger, recognizes it as an important factor contributing to the caregiver's feeling of emotional distancing from family, the PLWA and the community. These present findings are supported by those of McShane, Bumbalo, and Patsdaughter (1994). They examined the impact of AIDS on the family functioning and symptoms using the Brief Symptom Inventory (BSI) and Family Adaptation and Cohesion Scale (FACES III). As well, the Global Severity Index (GSI), a product of frequency and intensity of symptoms, was used to assess severity of symptoms. The BSI consists of 53 items to assess physical and psychological health of individual family members. Participants included 133 individuals (33 PLWA, 47 parents and 33 siblings). Families as a unit and individuals in family were reported to experience severe stress when faced with AIDS in a family member. Particularly, anger was the most severe symptom for siblings and the fourth most severe symptom for parents. They concluded that the symptoms experienced by family members and the PLWA clearly indicated a need for treatment, especially in the psychological domain.

As well, anger toward the health community is consistent with that reported by Trice (1988), and Geis and Fuller (1986). Anger toward the medical community was reported by caregivers in this present study over issues such as the lack of privacy for the PLWA, not receiving information, delay in diagnostic procedures, and insensitivity in interactions.

The findings of this study suggest that social support was an important factor in AIDS family caregiving. However, negative rather than positive effects of family, community and health care professionals contributed to the caregiver's emotional labours. The socially isolated context of AIDS family caregivers, make them a population at risk for

developing emotional as well as physical health problems.

### Caring Transformation

Caring Transformations have been described in respect to nursing education (Callin, 1996; Cohen, 1993), as a gift of healing in chronic illness and women (Lindsey, 1995); in finding meaning in caring for elderly relatives (Langer, 1995) and in transformative dreams in PLWAs (Muff, 1996). Findings of this present study would suggest AIDS family caregivers undergo caring transformation in their discovery of new realities of self and the health care system. Caregiver's reported personal growth through their recognition of caring and commitment. AIDS caregiving changed their lives and brought new awareness of self and others. Discovery of self perspectives has been mirrored in the themes of "Moving on and establishing a new world's view" (Powell-Cope, 1993), and "Coming to know one's own strengths" (Stetz and Brown, 1997) and substantiates the previous findings.

The study's findings that negative interactions with health and social care providers (including nurses) are dynamic and often conflictual and include: insensitive sharing, timing, and sequencing of information; insensitive treatment; and system barriers such as forms and waiting. These interactions were perceived as the lack of a caring presence. These present findings support the assertions by Bunting (1992) and Stetz and Brown (1997) that AIDS has highlighted the inadequacies of the American Health Care System as well as insensitivity and prejudice of Canadian health care professionals (Stewart, Hart & Mann, 1995). Additionally, anger as a consequence to these interactions motivated caregivers to become politically involved in seeking system change similar to that discussed by Powell-Cope and Brown

(1992). That little is known about the positive dynamics of successful care or professional caring as experienced by families of PLWAs concurs with the findings of Powell-Cope (1994).

Powell-Cope (1994) used indepth qualitative interviews and a questionnaire to investigate professional caring as experienced by twelve (5 females, 7 male) family caregivers of PLWA. A grounded theory approach was used to extend Swanson's theory of caring. Negotiating partnership (defined as working out care for the common good of the PLWA), was identified as the basic social process explaining interaction between caregivers and health care providers. Negotiating partnership reflects that family's desire to be acknowledged for the expertise brought to situations by virtue of their daily living with HIV infections and a PLWA.

However, in contrast to the findings of Powell Cope (1994) the caregiver's greatest need was not the professional's physical presence or accessibility. Rather, this present study's findings suggests that caregivers greatest need was "caring" in their interactions with health care providers. Caring interactions as part of AIDS family caregiving need to be further investigated.

### AIDS Caregiving as Work

Caregiving as "work" has been described by Corbin and Strauss (1988), who coined the term "illness trajectory" to denote the course of an illness, including the total organization of "work" done. The work of caregiving in other caregiving populations has been known to affect caregiver's health and quality of life and well-being (Kristjanson, 1989;

1988). In most cases, strain and burden have been described (Martinson, Chesla, & Muwaswes, 1993; Oberst, Carey, McCubbin & Hughes, 1991). As well, work emerges as a theme in AIDS family caregiving (Stetz-Brown, 1997; Bunting, 1992; and Powell-Cope, 1991). Categories and themes discovered in this research lend support to the concept of AIDS family caregiving as hard "work".

### Summary of Findings

Overall, the study findings suggest that while there are some theoretical similarities with other caregivers caring for chronically ill family members, there are distinct differences in the social context, history, and characteristics which contribute to the emotional suffering and isolation of the AIDS family caregiver. As well, the unique qualities of AIDS illness substantially influences the way that caregiving is performed. AIDS family caregiving may or may not resemble caregiving in other illness situations. Therefore, the combined approach as considering AIDS and Cancer caregivers as similar by Stetz and Brown (1997), may not be amenable to researching AIDS family caregivers. The similarities and differences are now beginning to be articulated. It is hoped that this exploratory - descriptive study of seven Canadian AIDS family caregivers will serve to draw attention to some of the gaps in the research literature and stimulate further research.

### Effectiveness of the Study Design and Methods

The use of Ethnography as the study method facilitated the descriptive portrayal of AIDS family caregivers. Little empirical literature exists in this regard. Ethnography

afforded the use of "thick description" whereby readers can assess the "fit" of the findings to their life/work contexts. While the sample size is small ( $N=7$ ), the quality and denseness of the data were substantial. The findings reflect the life experiences of the informants and describe both typical and atypical examples of these experiences (Sandelowski, 1986).

It is important to note that the informants of this study may not be fully representative of the broader targeted population of AIDS family caregivers. Informants were selected from one centre and represented those caregivers who provided care to a PLWA receiving ongoing medical care. As well, all the informants were caregivers for a gay white male PLWA. It is not known whether the family responses to AIDS caregiving may be different if the PLWA were female, or if the PLWA was not receiving medical care. As well, it is not known whether the mode of contracting AIDS (through receiving tainted blood products, or intravenous drug users) may affect the experience of family caregiving. Family caregivers who represent different ethno-social groups, (for example Aboriginal caregivers) and demographics (fathers who are caregivers) may differ in their psychosocial impact. All caregivers choosing to participate in this study remained as caregivers throughout the illness trajectory, where caregiving ranged from 6 months to 2 years. Those caregivers who do not sustain caregiving are not represented in this study.

### Conceptual Framework

#### AIDS Family Psychosocial Health

Theoretical constructs from the models of Family System Stress (Meister, 1991) and Family Social Support (Kane, 1991) were integrated to propose a synthesized, eclectic model

### of AIDS Family Psychosocial Support.

The reconstituted model proposes family social support as a process which may mediate stress appraisal in the caregiving situation. Kaner's (1991) construct of family social support suggests a process, not an outcome or resource that occurs over the life span. The process involves family interactions with others (extended family, neighbours, coworkers, and community) to lead to versatility and resourcefulness in its functioning. As well, Meister's (1991) construct of a set of family vulnerabilities that affect stress was incorporated.

Within the reconstituted model, the family's vulnerabilities were proposed as antecedent variables comprised of: 1) AIDS family caregiver characteristics (age, gender, health, education, and relationship to the PLWA); 2) AIDS family resources ( socioeconomic and environmental resource, support network, type of support, and perceived adequacy of support); and 3) PLWA illness characteristics ( symptoms, dependency, seriousness and length of illness). Together these antecedent variables were anticipated to interact and influence the family caregiver's cognitive assessment of burden. The caregiver appraisal of antecedent variables was proposed to include demand, difficulty and uncertainty. Benefits from caregiving such as the appraisal of hopefulness, and strengthening of family relationships were proposed as mediating factors that could affect the cognitive appraisal and subsequent outcome of family psychosocial health. The outcome variable of "Family Psychosocial Health" was conceptualized as emotional health (well-being) and or stress (distress).

The conceptual model was a useful guide for the study as it provided a broad



framework that was applied to guide the collection and analysis of the data. As well, it may be applied to any nursing practice setting and other illness situations where family caregiving plays a pivotal role. A variety of antecedent and mediating variables both proposed and external to the model were discovered to affect the stress of AIDS family caregivers. Stress in this context was discovered as the condition or feelings of tension within the caregiver, that occurred as a response to their caregiving.

Several of the themes observed in this study are consistent with many of the proposed variables in "AIDS Family Caregivers' Psychosocial Health" model. The themes serve to reiterate the antecedent variables outlined by the model. Specifically, social support emerged as a significant factor in caregiving. The relationships of caregivers with the broader social network of family, co-workers, neighbours, and community were affected by insensitivity, prejudice, and isolation. Virtually all informants described feelings of isolation and distancing from family, friends, and the community. It appears that negative experiences with people from whom support was anticipated may aggravate caregiver distress and make subsequent support seeking more difficult. Likewise, the social stigma attached both to the diagnosis of AIDS and the homosexual relationships, profoundly influenced the family's ability to access support. Another variable in receiving and seeking support was the perceived need to preserve secrecy and confidentiality about this stigmatized illness. Feelings of stigma may have also inhibited family caregivers from confiding in others and seeking support. Stigma and secrecy were discovered as variables which were not anticipated in this model.

Consistent with the model, the PLWA's illness characteristics did appear to affect the caregiver's appraisal. Distress or well-being varied with caregiver uncertainty, as well as

PLWA illness characteristics. However, the distress of uncertainty as a constant, with peaks and valleys was an unanticipated variable. As well, as the PLWA's symptoms of illness intensity increased, caregivers expressed increasing distress. However, caregiver distress was also related to the PLWA's anger. As well, the illness characteristically affected young male adults, who, if healthy, would have been expected to be working. As none of the PLWAs in this study worked, the family was called upon to provide tangible and intangible aid, which affected the family's appraisal of difficulty or burden.

The developmental stage of the family caregiver appears to affect appraisal, as integration of the adult PLWA into the home was suggested by caregivers to affect distress. For example, one caregiver sold his home and moved into the PLWA's home, another caregiver's son returned to live with her. The caregiver's relationship to the PLWA, whether or not biological kinship, was discovered to affect appraisal. However, education, age, gender and relationship were not discovered to increase appraisal of difficulty. In other words, although these contextual factors contributed to understanding the caregivers appraisal of the difficulty, appraisal did not seem to be predicated on any one of these factors singularly. For example, former lovers as well as mothers of the PLWA, expressed difficulty in their appraisal of caregiving.

The definition of the situation, or caregiver appraisal was articulated as how the caregiver perceived or assigned subjective meaning to their caregiving situation. For example, one caregiver regarded his caregiving as a challenge, another "every day life", and another as stressful. As well, although the appraisal may have been regarded as an opportunity or challenge, this did not seem to influence the outcome of well-being, as

caregivers identified the need for "breaks" from their caregiving. Benefits which mediated the appraisal included the caregiver's "positive thinking," maintaining hope, and taking time for oneself.

The model was limited in that it failed to adequately explicate several important variables of AIDS family caregiving as discovered in the study findings. One variable that was not articulated by the model include the ongoing nature of the caregiving work as stressful over the AIDS illness trajectory. Missing is the process of stress as it occurs over time or as McCubbin and Patterson (1982) refer to as the notion of "pile-up." In this study stress was not a singular event but an ongoing phenomena with associated hardships. Some have suggested that how an individual perceives the situation is the most significant determinant of its outcome (Takiguku, Brubabker, & Hennon, 1993). As well, the caregiver's appraisal was discovered to include other variables such as caregiver's anger, PLWA anger, and stigma which may have had a major impact on their caregiving efforts and outcome of well-being or stress. As well, the contextual variable of the nature of the caregiver's obligations outside of their caregiving, including work related demands, would appear to affect the appraisal of difficulty. A reformulated model of psychosocial health should consider these variables is suggested. Incorporating anger, stigma, secrecy, the work of caregiving, and stress as a process would strengthen the model.

### Recommendations

The findings from this study increase our understanding about the AIDS family

caregiving experience. However, because this study was exploratory, the recommendations for practice are offered with some caution. The following recommendations are offered as suggestions for nursing practice, education and research based on the understanding derived from this study. As all three areas of nursing are interdependent, these recommendations may be simultaneously applicable to each other.

#### Recommendations for Nursing Practice

- 1) This study affirmed the central role of family in the provision of home care within the community. Nurses need to expand their awareness to include a family centred approach when interacting with PLWAs and their caregivers. Nurses, working with PLWAs who enter the health care system, must incorporate a family centred focus which would include the assessment of the primary family caregiver. Assessment of the family caregivers needs to include the family's history of caregiving, caregiver health, and care concerns. Nurses involved within community based nursing practice need to ensure continuity of care providers to develop a sense of connectedness through presence and a depth of particular contextual knowledge of the family caregiver. Case management may facilitate this knowledge and connectedness, which facilitates integration of nursing services in community and tertiary care. Another step could be to strengthen family nursing expertise in the ambulatory services of hospitals. Ambulatory-based nurses could assess initial family concerns and help to identify those who would benefit from family nursing during a hospital

stay. When the PLWA is ready for discharge, the ambulatory-based nurse could refer the family back to the community or elect to follow the family within the community. Alternatively, family nurses from the community could follow their families throughout the hospitalization period. A strengthened professional collaboration between nurses from hospital units, ambulatory services, and community around family assessment and clinical intervention, provides continuity of health services (Grossman, 1995).

- 2) Caregivers could benefit from education about the system resources which could provide tangible and information aid. For example, information about programs such as respite or of palliative care. Nurses need to be aware of resources within the system, such as support groups, buddy supports, food banks, housing and financial supports.
- 3) Nurses need to identify signs of caregiver strain or stress. Loss, bereavement, anger, and stress are particularly amenable to nursing and medical intervention. Counselling and anticipatory guidance for loss and bereavement support are suggested.
- 4) Nurses are able to provide information and support to facilitate the caregiver's ability to fulfil the PLWA's wish to die at home. Teaching the caregiver what may occur in the process of dying may help prepare the caregiver to realize this wish and/or make informed decisions.
- 5) Nurses could benefit from their development of a more self-reflective practice. Self-reflective practise could engender a new reality of a caring consciousness

in their interactions with family and the PLWA.

- 6) As well, nurses need to develop particular knowledge of the cultural contexts in which AIDS care is provided.

### Recommendations for Nursing Education

- 1) Nursing curricula need to be delivered within a moral-caring paradigm or guiding philosophy. A caring ethic is central to developing caregiving interactions that are affirming, interconnected and related. Development of a moral caring paradigm within the curriculum needs to incorporate affective learning, as well as cognitive and psychomotor activities.
- 2) In addition, students need role models which demonstrate acceptance and caring behaviours toward PLWA and their family caregivers. Working side-by-side with a compassionate PLWA caregiver may provide support and model accepting behaviours. Accessing caregivers who choose to provide PLWA care would be an important factor in implementing this strategy.
- 3) Nursing curricula need to address the definition of family from a broad conceptual model such as "who the person identifies family as." The concept of non-traditional family units from gay to transgendered would assist the student in preparing for his or her future role.
- 4) As knowledge alone is inadequate in changing attitudes, students need to become aware of their own values, and how these may affect others. Value clarification, from a reflexive and reflective position needs to be addressed

within the curricula. Journaling as a reflective and reflexive process could assist the student.

- 5) Nursing Education should include the theoretical concepts of stigma, bereavement, loss, and suffering.

### Recommendations for Nursing Research

- 1) Investigations of family caregivers across and along the illness trajectory may be a supplement to understanding AIDS caregiving work and be helpful to determine the timing and delivery of nursing interventions which family caregivers may need. Longitudinal research would be of value in developing this understanding. As well, research should undertake to demonstrate the "economic" costs of AIDS family caregiving. Economic costs or burden associated with the provision of home based care could be estimated by investigating the caregiver's time spent carrying out tangible care needs including hygiene, food preparation, transportation, medication delivery and care of the PICC line, as well as the intangible care of the emotional support of the PLWA. Recognizing the family's cost associated with AIDS caregiving could assist with the planning and delivery of future community based care.
- 2) Investigation which includes the PLWA as well as the family caregiver's perspectives may provide valuable insight into assessment of family health during transitions and the flexibility of the health care system to meet their needs.

- 3) Future research efforts could be directed toward those not represented but potentially vulnerable populations, such as AIDS caregivers who mourn loss in isolation and other demographic and ethno-social groups eg. Aboriginals, people living in poverty, fathers who are caregivers. These individuals may provide valuable insights into the "work" of family and AIDS caregiving.
- 4) As well, research could seek to test the model of the "work" of AIDS family caregivers.

### Reflection and Reflexivity

Reflection throughout this journey as a neophyte researcher and life participant, led to the need for my comprehension of complex phenomena. This reflection influenced my passage. The caregiving experiences of families living with AIDS have transformed the lives of both the informants and myself. Personal meanings were derived from this venture through reflection on experiences and translated into understanding. Constructing meaning meant focusing on self-understanding within the processes of caring and work, and this included commitment, involvement, and belonging.

This experience crystallized for me my own caring philosophy of nursing. Commitment to humanism in caring requires mutual respect, dignity, and the recognition of each individual's uniqueness. I became more consciously aware of the beliefs and assumptions that I held. Caring has to be experienced to be known, is an important modality in all situations (whether nurse managed or not), and a caring philosophy needs to be embedded within our everyday life. Expressions of caring include treating others with



respect, understanding, helping, and letting the other person "become." As well, I have a greater understanding of caring as work, or labour which may not be visible. The work and caring embodied within my experience from both a personal and researcher perspective, will be addressed.

I have lived the experience of "caring" between student and faculty. Caring was expressed by the members of my thesis committee who coached, guided, and acted as partners, in my transformation as a researcher. The practical aid of Dr. Campbell was invaluable in facilitating the initiation of the study. In particular, Dr. Gregory and Dr. Kristjanson "worked" with me to facilitate my development as a neophyte researcher.

Caring was lived in the relationship, as all committee members were gracious with their gifts of expertise and time throughout the completion of this project. Time to meet with me was given beyond that expected, or required as committee members. The nature of my labour was transformed by contextual elements, as Dr. Gregory found time during his vacation to work with me at Perkins. As well, the nature of the work was transformed by the careful and constructive critique, given generously and frequently, by the committee members. Particularly, my committee supported me through the experiences of loss, with the death of my father and the losses in my personal life. My committee endeavoured to facilitate my timely progress and to assist my achievement of the continuity required for successfully completing this study. As well, they recognized my needs to balance the work of being a graduate student, nurse educator and mother. This relationship fostered my personal growth, knowledge and love of self and others.

This passage as a neophyte researcher using an ethnographic approach was one of

discovery, guided by reflexivity and reflection. Reflexivity is a process that required the researcher to actively analyze and apply the fieldwork experience to improve data collection and interpretation (Rubinstein, 1991). Fieldwork as an ethnographer entails an "iterative" process to collect, analyze and interpret the data. Initially, I discovered new cultural meanings in the nuances of family. Perspectives of family I had not previously encountered, were challenged and understood. As data collection proceeded, strategies to guide the interviews using the global broad questions were modified to allow the family to speak of what was important to them. The love, caring, and commitment of families was a testimony to the power of self to transcend adversity. Second interviews focused on themes and issues perceived from the first interview. As well, themes discovered within and between caregivers were shared to facilitate the analysis of data. As data collection and analysis were concurrent, I struggled with balancing home and work demands with interviewing more than one family simultaneously. The emotionally based nature of the interviews and my personal circumstances, contributed to delays in completing data collection, and subsequently the analysis. However, the opportunity to distance myself from the data allowed me to develop depth and richness of perspective which may not have been otherwise afforded. The interpretation and analysis was facilitated by discussion with committee members. As interpretation proceeded, the work of coding and sorting data to represent the categories developed in writing.

As a researcher undertaking ethnographic qualitative research, I would recommend that others develop discourse with someone who successfully completed a similar study and used a similar method. Ethnographic research is work that is time intensive and iterative. I

was able to benefit from the gracious sharing of my committee members who were present to review thoughts, feelings and insights. As well, I had informal support from others not involved in the research, but I felt I intruded on their time and energy. The use of the "Ethnograph," as a computer managed data system, was helpful for data retrieval. However the bulk of time was spent in manual data analysis and reflexivity throughout the data collection process. As well, as the quantity of data collected was large it was, at times, difficult to manage. Learning to let go of it, and to do justice to privilege the voices of the caregivers was discovered.

Personal struggles with the meaning of data and situational crises extended the completion of the written analysis. Time efficacy is especially significant in studying the effects on AIDS caregivers because the disease is so unpredictable and changes may occur rapidly.

### Conclusion

An ethnographic study funded in part by the Health Science Research Foundation, was implemented to explore and describe the psychosocial experiences of AIDS family caregivers. The study was guided by an eclectic model of social support and stress theory. Recommendations for the reformulation of the model were made. The major findings of the study reveal the "work" of the AIDS family caregiver. The majority of the findings from this study validated the results of previously published empirical research, and extend nurses knowledge of AIDS family caregiving. Recommendations for nursing practice, education and research were provided. These recommendations were based upon the findings of the study.

The processes of reflection and reflexivity were discussed in relation to study methodology, personal self-growth and skills as a researcher.

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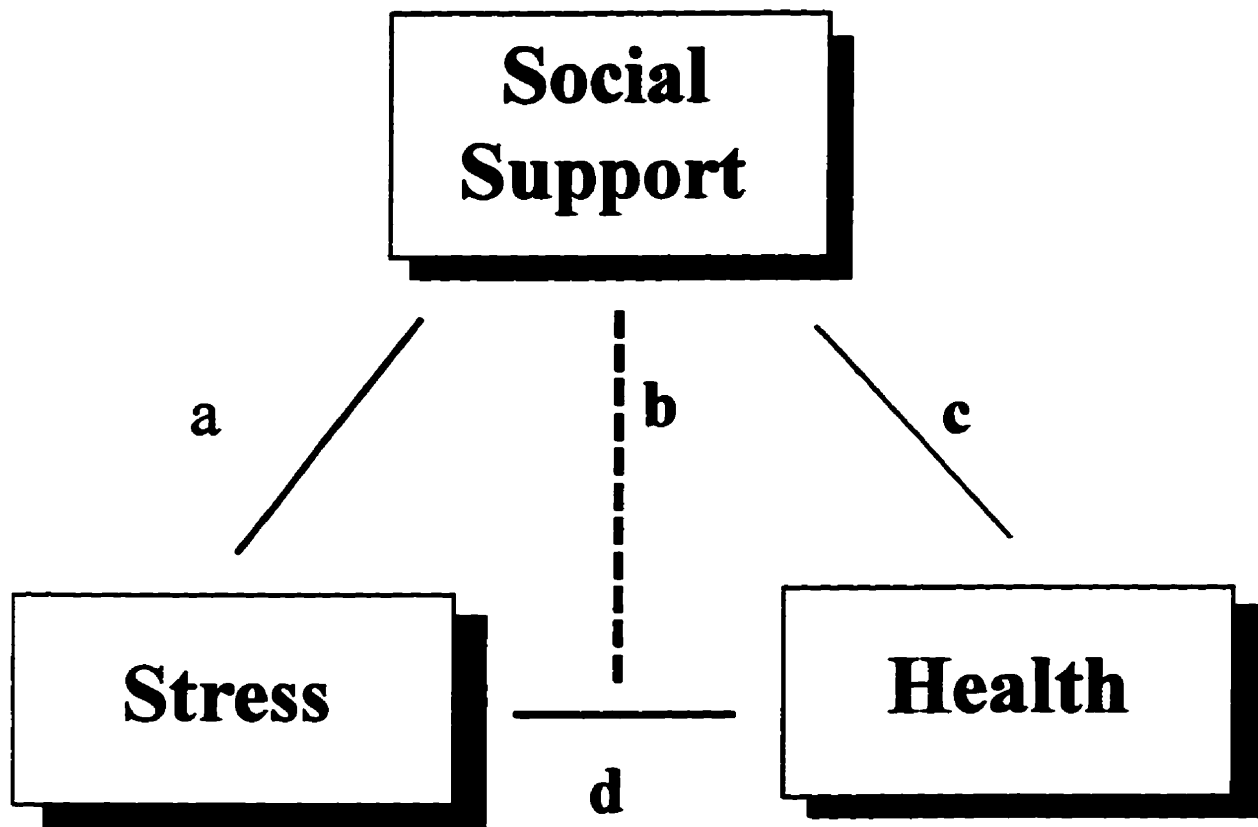
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**Appendix A: Model of Social Support**

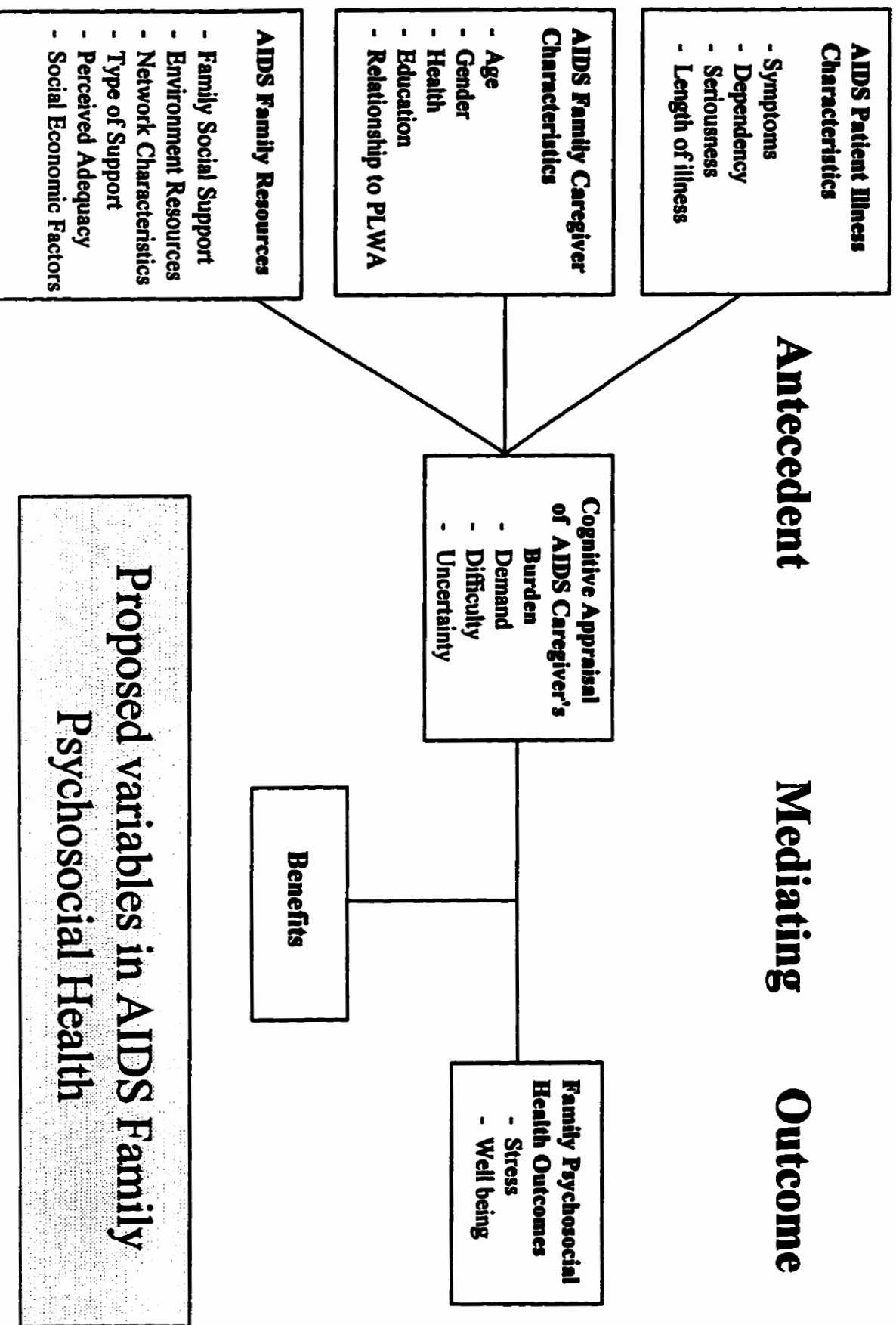
## Appendix A





**Appendix B: Model of Family Psychosocial Health**

# Appendix B



**Appendix C: Letter of Permission: Name Release**

## **Appendix C**

### **Letter Requesting Permission to Release Name**

Hi there, my name is Sonia Jablonski-Praznik and I am a master's nursing student at the University of Manitoba. XXXXX has approached you to ask your permission to allow me to discuss a study I am conducting. Would you be agreeable to allowing me to take a few minutes of your time to explain the study?

## **Appendix D: Invitation to Participate**

**Appendix D**  
**LETTER TO SUBJECTS REQUESTING PERMISSION TO RELEASE NAMES**  
**( XXXXXX Hospital )**

Dear \_\_\_\_\_:

I am sharing this letter with you on behalf of Sonia Jablonski-Praznik, RN, a master's nursing student at the University of Manitoba. She is studying the experiences of families caring for a person with AIDS and how they see their caregiving situation.

I am asking your permission to give Sonia Jablonski-Praznik your name as a possible participant in the study. If you do not wish your name released, please call me at xxx-xxxx. If I do not hear from you by \_\_\_\_\_ I shall assume it is acceptable to you to give Sonia your name. Sonia will be contacting those who give their permission by telephone to see if they are interested in participating in the study. She will arrange a suitable interview time and will also answer any other questions about the research then.

If you decide to participate, no information about you or your family will be shared with health professionals caring for your family member. The information will be strictly confidential. Whether or not you decide to participate will in no way influence the care received by your family member.

Thank you kindly for considering this request. Sonia has asked me to inform you that she understands that this may be a particularly stressful time for you and appreciates any time you might be able to offer.

If you have any questions about the research study Sonia can be reached at xxx-xxxx.

Sincerely,

**Appendix E: Telephone Explanation**

## **Appendix E**

### **Telephone Explanation of Study**

Hello, my name is Sonia Jablonski Praznik. Thank you for responding to my invitation. As the invitation outlined, I am a graduate student at the University of Manitoba. As a part of my Master's degree in Nursing, I will be conducting a study of the experiences of families who are caring for someone living with AIDS.

The general purpose of the study is to explore and describe your own thoughts and feelings about your family caregiving experiences. I am also interested in knowing what you think the effects of caregiving are on your health and what you perceive your health needs to be. I will ask you general questions about your caregiving situation, and more specific questions related to your personal experiences caring for a family member with AIDS. If you prefer not to answer certain questions, you do not have to.

If you agree to participate, I will interview you two to five times for approximately one hour each time. The interviews will take place at a time and place convenient to both of us. The interviews will be tape recorded and later transcribed onto paper to allow more accurate recording of your comments. There are no right or wrong answers to the questions I will be asking you. You are the expert because of your caregiving experiences. If you decide to participate, and later, for whatever reason, wish to withdraw from the study, you may do so.

This study has been approved by the Ethical Review Committee of the Faculty of Nursing at the University of Manitoba. All the information you provide me will be confidential. Your confidentiality and or the confidentiality of your family, will be maintained. A numbered code will be used to identify the information shared and your name will not appear on any written notes about the study. Any writing from this study that becomes published will be written in a manner such that individual statements could not be linked to you. The tapes and transcripts may be reviewed by my thesis chair, Dr. Linda Kristjanson and Professor David Gregory another member of my committee will review the transcripts, but again your confidentiality will be maintained.

Do you have any questions in regards to this study? I would be happy to answer them for you. Do you feel you may be interested in participating in the study? If you are agreeable to participating, may I review the requirements I listed in the invitation to participate? We can then arrange a time and place to meet and sign the consent form, and then the first interview will be begin.

Thank you for taking the time to respond to my invitation.



**Appendix F: Written Explanation**

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## **Appendix F**

### **Written Explanation of Study-All participants**

My name is Sonia Jablonski-Praznik, and I am a registered nurse with experience in family nursing within the community and hospital. I presently am a graduate student in the Master of Nursing Program at the University of Manitoba. I am interested in studying and describing the experiences of family members who are caregiving to a person living with AIDS (PLWA), as a part of my program of study.

To do this, I would like to interview family members who are/have taken care of a person living with AIDS. If you agree to participate, you will be interviewed two to five times, in your own home, or another convenient place, at a time convenient to you and me. Each interview will last approximately one hour, and will be tape recorded.

During the interviews, I will ask you some questions about your caregiving experience in general, and then focus in on your personal experiences of caring for the PLWA. If you would prefer not to answer any of the questions, you do not have to. If at any time you wish to discontinue the interview, you may do so. If you decide to participate, but later wish to withdraw from the study, you may do so.

All information revealed by you will be kept confidential, and your anonymity will be safeguarded. The audio tapes of your interview will bear a code number, as will the transcriptions of those tapes. Your name will not appear on these items. The only place your name will appear is on a master list matching names with code numbers, which will be seen only by me, and kept in a locked file. The master list and audio tapes will be retained for a period of seven years. Any presentations or publications that arise from this study will be written in a way that preserves all participants' anonymity. There will be no way that the information presented could be linked to you.

Your participation in this study may not benefit you directly. There may be some inconvenience to you associated with the time involved for the interviews. It is hoped, however, that information gained may help nurses and other health providers know how to provide better support to family caring for someone with AIDS. If at any time you have questions or concerns, do not hesitate to discuss them with me. I can be reached at XXX-XXXX. A copy of this explanation and of the consent form will be provided to you for your records.

Your participation in this study is welcome and appreciated.  
Thank You.

**Appendix G: Consent Form**

## Appendix G

### Consent Form

Title of the study:

A Descriptive Study of the Psychosocial Impact of AIDS on Family Caregiving.

Investigator

Sonia Jablonski-Praznik, graduate student in the Master on Nursing Program at the University of Manitoba.

If I choose to sign this form my signature below means that:

1. I have read and understand the explanations of the above mentioned study and have had all my questions and concerns about this study answered satisfactorily.
2. I have been offered a copy of this consent form and the explanation form to keep.
3. I am willing to participate as a subject of the study.
4. I agree to be interviewed two to five times, at a place and time convenient to me and the investigator.
5. I agree to be tape-recorded during these interviews.
6. I am under no obligation to answer any questions that I do not wish to answer.
7. It is clear to me that I may withdraw from this study at any time without any fear of reprisal.
8. That all the information I provide to the researcher will be kept confidential.
9. I understand that only the investigator and her thesis chair, Dr. L. Kristjanson will have access to these tapes, and only the investigator, her thesis chair and internal thesis member Professor David Gregory, will have access to the tape transcripts, and that my confidentiality will be maintained. Dr. J. Campbell will only have access to grouped summaries of the transcripts.
10. I understand that I may not attain any direct benefits from participating in this study.

If I have any questions at any time throughout this study, I may reach the investigator, Sonia Jablonski-Praznik, at XXX-XXXX, or may contact Sonia's thesis supervisor, Dr. Linda Kristjanson, at XXX-XXXX.

SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

WITNESS \_\_\_\_\_

I wish to receive a written summary of the results of this study.

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

\_\_\_\_\_

**Appendix H: Family Demographics**

## Appendix H

### Family Information Questionnaire

1. Marital status - Married \_\_\_\_\_ Divorced \_\_\_\_\_  
Never Married \_\_\_\_\_ Common Law \_\_\_\_\_
2. Gender Male \_\_\_\_\_ Female \_\_\_\_\_
3. How old are you? 18-30 \_\_\_\_\_  
31-40 \_\_\_\_\_  
41-50 \_\_\_\_\_  
51-60 \_\_\_\_\_  
60+ \_\_\_\_\_
4. Do you have any children? If so, what are their ages?
5. Could you tell me the highest education you have achieved?  
less than high school \_\_\_\_\_  
high school \_\_\_\_\_  
college / university \_\_\_\_\_  
other (please describe) \_\_\_\_\_
6. Do you work outside the home? Yes \_\_\_\_\_  
No \_\_\_\_\_  
  
full time \_\_\_\_\_  
part time \_\_\_\_\_
7. If you work outside the home, please describe the demands of your job.
8. What is your relationship to the person living with AIDS?

**Appendix I: Interview Guide**

## **Appendix I**

### **Interview Guide**

#### **Focused Questions**

- 1) What has your life been like since you became aware that your \_\_\_\_\_  
(son/daughter/lover/friend/spouse/mother/father) has been diagnosed with HIV/AIDS?
- 2) When did you begin caregiving? What has your life been like since you became a caregiver?
- 3) What was your life like before that time?
- 4) What has helped you the most in getting through this?
- 5) What are some of the obstacles, problems, concerns you have encountered as a caregiver?
- 6) What kind of help would you offer someone in a similar situation?
- 7) Has your relationship with \_\_\_\_\_ changed since you began caregiving?



### Focused Questions

- 8) What kind of things do you do for \_\_\_\_\_?
- 9) How much of your time do you think you spend in caring for \_\_\_\_\_ (PLWA)?
- 11) How long has it been since \_\_\_\_\_ was diagnosed with AIDS?
- 12) How would you describe \_\_\_\_\_ (PLWA's ) health?
- 13) How does \_\_\_\_\_ (PLWA's) T4 cell count seem to affect \_\_\_\_\_ his/her health and care needs?
- 14) What is the T4 count now?
- 15) Do you know how \_\_\_\_\_ acquired the AIDS infection?
- 16) How has the way \_\_\_\_\_ (PLWA) acquired the virus (if any) affected your relationship with him/her? Has this been something you have been able to discuss together?

**Appendix J: University of Manitoba Ethics Approval**

The University of Manitoba  
FACULTY OF NURSING  
ETHICAL REVIEW COMMITTEE

**APPROVAL FORM**

Proposal Number N#94/11

Proposal Title: "A DESCRIPTIVE STUDY OF THE PSYCHOSOCIAL IMPACT OF AIDS ON  
FAMILY CAREGIVING."

Name and Title of  
Researcher(s):

SONIA JABLONSKI-PRAZNIK  
MASTER OF NURSING GRADUATE STUDENT  
FACULTY OF NURSING  
UNIVERSITY OF MANITOBA

Date of Review: JUNE 06, 1994.


APPROVED BY THE COMMITTEE: JUNE 06, 1994.

Comments:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Date:

June 08/94

  
LORNA GUSE, PHD      ACTING Chairperson  
ASSOCIATE PROFESSOR  
UNIVERSITY OF MANITOBA FACULTY OF NURSING  
Position

**NOTE:**

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/04/22/se

**Appendix K: St. Boniface Hospital Approval**



October 12, 1994

Hôpital  
général

St-Boniface

General  
Hospital

Sonia Jablonski-Praznik  
2371 Burrows Avenue  
Winnipeg, Manitoba  
R2R 1S8

**Re: Access to SBGH for Study Entitled:  
A DESCRIPTIVE STUDY OF THE PSYCHOSOCIAL  
IMPACT OF AIDS ON FAMILY CAREGIVING**

Dear Sonia Jablonski-Praznik:

I am pleased to inform you that your research access request has been approved. You may proceed with your study on the understanding that:

- 1) any significant changes in your proposal will be submitted to my attention prior to implementation;
- 2) you review the enclosed policy on confidential information and then sign and return the enclosed Pledge of Confidentiality;
- 3) you inform us when your data collection is complete. This information helps us coordinate research access requests and minimize competing demands of research study protocols on patients and nursing staff time.

We encourage you to make presentations to hospital staff about your research. Also, please consider writing a short story about some aspect of your research project for our Nursing Division newsletter, Nursing Dialogue. Upon completion of your study, we request that you provide us with a brief summary of your final report.

Thank you for selecting St. Boniface as the site for recruiting participants for your study. Please feel free to contact me with your questions or concerns. Should you encounter any site-related difficulties during the course of your study, I would appreciate being notified of these.

All the best with the completion of your study.

Sincerely,

Kaaren Neufeld, R.N., M.N.  
Director of Nursing Education and Research  
Tel. (204)237-2736

KN/mj

7\Access\Letters\Jablonski.094