

THE CAREGIVERS OF PERSONS LIVING WITH HIV/AIDS:

**THE EXPERIENCE OF CARING FOR
A DYING FAMILY MEMBER AT HOME**

by

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Abstract

While some research has been conducted on HIV/AIDS family caregiving, it is limited in addressing the experience of family members who provide care to persons with HIV/AIDS (PWHIV/AIDS) who are dying at home and planning for a home death. Furthermore, much of the general family caregiving research focuses on caregiving tasks and related effects on the caregiver. The purpose of this study was to explore the day-to-day experiences of family members who care for their dying loved one at home with HIV/AIDS. Seven family members who were caring for or had cared for a PWHIV/AIDS at home in the last year were interviewed using an unstructured interview format. Verbatim transcripts of the interviews were analyzed using the constant-comparative method and the methodological guidance of grounded theory.

The data analysis contributed to the development of a substantive theory of HIV/AIDS family caregiving. The findings revealed that work characterized the experiences of family members while they lived in a world of uncertainty and stigma. Promising to fulfil the wishes of the loved one lead family members to engage in both personal and pragmatic work. In order to manage their work, caregivers developed various strategies such as seeking support and working as a team. Several conditions affected the caregivers'

strategies such as the accessibility of services and the nature of support. These conditions and strategies ultimately resulted in a variety of consequences that affected the caregivers' bereavement.

HIV/AIDS family caregiving was an intense, emotional, and powerful experience. It was an experience filled with pride and enrichment, or conversely, with anger and disillusionment. Coping with the extensive demands of HIV/AIDS family caregiving required considerable time, energy, and commitment that often went unrecognized and unsupported. Findings reflect a significant need for interventions designed to provide direct and effective support for HIV/AIDS family caregivers. Failure to address the needs of caregivers is not only morally and ethically unacceptable but also demonstrates a myopic view of the caregivers' experiences. The richness of the caregivers' stories and the impact on their lives cannot be denied and they demand creative, professional solutions.

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Finally, I thank my husband Doug. You have sacrificed so much without ever complaining. Your love, understanding, and support were of immeasurable sustenance to me. Thank you.

Dedication

This work is dedicated with a deep love and respect, to my mother, Mary, who taught me so much about caring, compassion, and understanding through her example. It is dedicated to my family who share, with me, her loss.

Chapter One

Background to the Problem

Death is a concept that instills fear and seriously impacts family members in a society where death is generally unaccepted and denied (Macklin, 1989). The physical and emotional devastation of the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) (HIV/AIDS) produces extraordinary challenges to the health care system and to family members who provide home palliative care to persons with HIV/AIDS (PWHIV/AIDS). For example, Raveis and Siegel (1990) found that family members provided approximately two-thirds of all care for PWHIV/AIDS. The provision of this care often leads to fatigue, emotional and physical exhaustion, and severe financial burden (Raveis & Siegel). At a national AIDS family caregiver conference (Health & Welfare Canada, 1990), family members identified several difficulties they faced when caring for PWHIV/AIDS:

- Withdrawal of friends and regular support systems.
- Discrimination from their communities.
- Anxiety, confusion, ignorance and misunderstanding from health professionals.
- Inadequate transportation, health resources, and financial support.

- Worry, shock, anger and depression around initial diagnosis.
- The experience of loss when the loved one dies, accompanied by the perception that death puts an end to suffering.

Thus, HIV/AIDS threatens family members by creating "catastrophic" changes in the overall functioning of family life (Dolan & Nokes, 1992; Tiblier, 1987). Anderson (1989) suggests that if a cure is not found soon, it will be a rare family that has not been personally affected by HIV/AIDS. While the HIV/AIDS epidemic is less prevalent in Canada than in the United States, Anderson's comments are nonetheless important in placing into context the critical nature and effect of HIV/AIDS on the family.

The challenge of HIV/AIDS

While research is available on the impact to families who provide care for persons with cancer (Brown, Davies, & Martens, 1990; Holing, 1986; Hull, 1989; Martens & Davies, 1990), it does not address the unique challenges faced by individuals who provide palliative care to PWHIV/AIDS. That is, the disease process initiated by HIV/AIDS is different. HIV/AIDS is generally considered to be fatal, has no cure, has few effective treatments, and has both acute, short-term and chronic long-term phases. In addition, many caregivers of PWHIV/AIDS are themselves infected with HIV. Caregivers

who are HIV positive witness deterioration and death that may forecast their own fate, thus increasing the already emotionally charged caregiving tasks (Dick, 1992; Shilts, 1987).

The multiplicity of societal taboos associated with HIV/AIDS and the fear of contagion pose a second challenge for family members. HIV/AIDS phobia, prostitution, homosexuality, bisexuality, and intravenous drug use (IVDU) are issues that are often overwhelming for caregivers (Macklin, 1989; Moffatt, 1986; Pearlin, Semple, & Turner, 1988; Takigiku, Brubaker, & Hennon, 1993). Moreover, the stigma associated with HIV/AIDS can lead family members into a conscious conspiracy of silence where a PWHIV/AIDS illness or death is attributed to other causes such as cancer (Barbo, 1987; Barouh, 1992; Worden, 1991). Toward this end, families often terminate usual support systems leading to a growing feeling of isolation and burden (Grief & Porembski, 1988; Tiblier, Walker, & Rolland, 1989).

A third challenge faced by HIV/AIDS caregivers is the definition of the "traditional family" (Matocha, 1989) that is generally accepted by North American society. Traditionally, the family is defined as including people, united by the ties of marriage, blood or adoption; constituting a single household; interacting and communicating with each other in their respective social roles of husband and wife, mother and

father, son and daughter, brother and sister; and creating and maintaining a common culture (Burgess & Locke, 1953, p. 7-8).

Contemporary definitions explain the family in legal terms as "either one or more persons related by blood, adoption, or marriage" (Liss, 1987, p. 771). Clearly these definitions eliminate any relationship which is not bound by blood, adoption or marriage. Consequently, many family members of PWHIV/AIDS are not accepted as part of the traditional family, are viewed as having a "stigmatized lifestyle" (Brown, 1992), and are isolated from the usual support systems shared by many traditional families (Matocha, 1989). Moreover, insurance, housing and survivor benefits are often withheld from those in nontraditional families, often leading to poverty and inadequate housing for the surviving caregiver (Gold, 1994; Sussman, 1989; Sweet, 1994). Hence, a broad definition of family is most useful when studying family members of PWHIV/AIDS. For example, a definition of family could include the family of origin, family of procreation, co-habiting couples, friendship networks, and the emergent family of caregivers which often evolves following an HIV/AIDS diagnosis (Tiblier, Walker, & Rolland, 1989).

A final challenge for family members who care for PWHIV/AIDS is highlighted by Schoen (1986). Schoen and others (Brown, 1992; Giacquinta, 1989) suggest that caregivers, particularly younger spouses and lovers,

experience a tremendous strain when dealing with a life-threatening illness and accompanying issues of death and loss at a time in life when they have not acquired the maturity and perspective that often accompany middle and older age. Added to this strain is the fact that many HIV/AIDS family caregivers are men, who in North American culture usually receive less preparation than women for nurturing roles (Brown & Powell-Cope, 1991).

The provincial scene

As of March 1995, a cumulative total of 1,969 cases of AIDS has been reported in British Columbia (BC Ministry of Health, 1995). While these cases account for approximately 20% of the AIDS epidemic in Canada (Health Canada, 1994), they do not include the number of persons testing HIV positive who will likely go on to develop AIDS. Additionally, the actual number of AIDS cases is probably about 20% more than surveillance shows because of underreporting (Calzavara, et al., 1990).

Goldstone (1993) posits that there will be incremental increases in the number of persons diagnosed with HIV/AIDS in British Columbia over the next two decades. In examining the utilization of HIV/AIDS care programs at St. Paul's hospital, Goldstone (1992) found that the number of PWHIV/AIDS who die at home had decreased substantially over a two year period. While an investigation of this shift is underway, Goldstone suggests that exhaustion

among caregivers contributes, among other things, to this increase in hospital bed utilization for palliative care.

In response to the increasing numbers of persons who are diagnosed with HIV/AIDS and the potential economic impact, the British Columbia Royal Commission on Health Care and Costs (1991) recommends that family members play a pivotal role in providing home-based palliative care to PWHIV/AIDS. However, Goldstone's (1992) study indicates that there may be human costs in providing such care. Nevertheless, family members will be faced with the many demands of caring for a loved one requiring palliative care at home.

Summary

Traditionally, within nursing, the patient has been viewed as the focus of concern. Efforts to help family members are justified in terms of the benefit to the patient. An alternate view is represented by family-focused care (Aranda-Naranjo, 1993; Atkins & Amenta, 1991; Davies, Reimer, & Martens, 1994) or the patient and family as the unit of care (Health & Welfare Canada, 1989a). Family-focused care is based on the belief that family members are legitimate targets for nursing interventions, regardless of their role in supporting the patient. Family members are viewed as individuals who are affected by the illness and who must cope with the demands that illness places

on them. Family members who care for PWHIV/AIDS are faced with many unique challenges. Additionally, the number of family members affected by HIV/AIDS will increase. As provincial (BC Royal Commission, 1991) and national governments (Health & Welfare Canada, 1989b) encourage home-based palliative care, family members of PWHIV/AIDS are faced with many demands in caring for a loved one requiring palliative care at home.

Statement of the Problem

While some research has been conducted on HIV/AIDS family caregiving (Brown & Powell-Cope, 1991; Dolan & Nokes, 1992; Greif & Porembski, 1988; Pearlin, Semple, & Turner, 1988) it is limited in addressing the experience of caregivers who provide care to PWHIV/AIDS who are dying at home and planning for a home death. Furthermore, much of the general family caregiving research focuses on caregiving tasks and related effects on the caregiver (Bowers, 1987; Lindgren, 1993; Marks, 1987). Therefore, in order to gain an understanding of what day-to-day life is like for family members, an exploration and description of the experiences of family members who provide home palliative care to PWHIV/AIDS is required.

Purpose of the Study

The purpose of this research was to explore the day-to-day life experiences of family members who care for PWHIV/AIDS who are dying at

home and planning for a home death. Interest in investigating the experience of family members stemmed from four observations that the researcher has made in clinical practice: (1) Family members often are the primary support system for PWHIV/AIDS; (2) Caring for a PWHIV/AIDS at home produces a significant source of stress for family members; (3) Family members may need preparation, support, education, and the skills to care for PWHIV/AIDS who are planning for a home death; and, (4) Family members who care for PWHIV/AIDS are a concern for nurses.

Conceptual Rationale

There were four main concepts that guided the area of investigation and literature review for this study (See Figure 1). The concepts of family caregiving, HIV/AIDS as an illness, and palliative care are combined to illustrate the relationship between these concepts and depict the central area of interest in this research. That is, the experience of family members (family caregiving) who provide care to PWHIV/AIDS (HIV/AIDS as an illness) who are planning for a home death (palliative care). The fourth concept, valuing, is portrayed as the overarching concept.

The relationship between family caregiving, HIV/AIDS as an illness, and palliative care is important when exploring the day-to-day experiences of family members caring for PWHIV/AIDS. That is, a review of these concepts

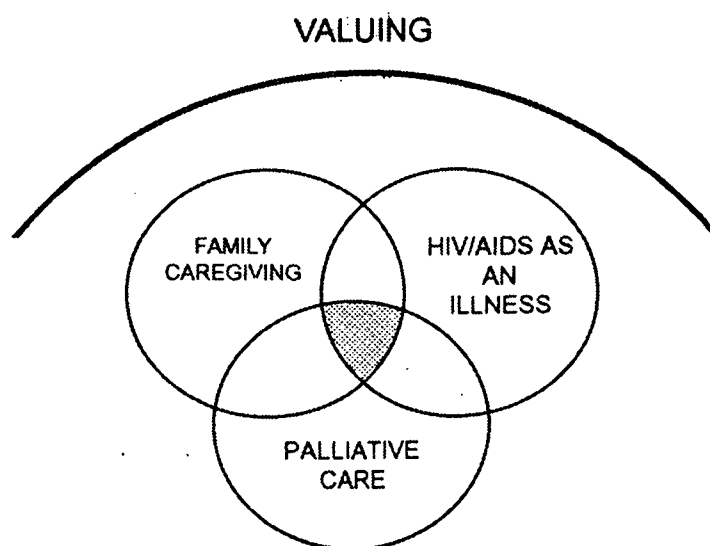


Figure 1. Conceptual Rationale

ultimately adds strength to this study by revealing themes that may provide the researcher with insight into the caregiving experiences of family members of PWHIV/AIDS, by identifying the unique challenges of HIV/AIDS as an illness and its affect on family members, and by differentiating palliative care service delivery for PWHIV/AIDS from the traditional model of palliative care.

Davies and Oberle (1990) also provided guidance for this study by articulating the supportive role of the nurse in palliative care. While this model was developed from research with cancer patients, and serves as a guide to the provision of nursing care, the overarching concept of *valuing* is applicable to this study. This concept implies an inherent respect and worth for people that includes comprehending the world from the view of the patient (or research participant). It is within the spirit of this concept that the researcher was interested in family members' caregiving experiences. That is, the concept lends support and direction to the overall attitude or mind-set of the researcher. Thus, the concept is depicted as overarching the concepts of family caregiving, HIV/AIDS as an illness, and palliative care.

Chapter Two

Review of the Literature

Persons with HIV/AIDS are frequently cared for by family members during the chronic and palliative phases of the illness (Hitchens, 1994; McShane, Bumbalo, & Patsdaughter, 1994; Raveis & Siegal, 1990). In order to gain a better understanding of the context of this situation, a review of the literature will focus on the following:

- Family caregiving in the context of chronic illness and cancer.
- Research and lay literature on HIV/AIDS as an illness as it relates to HIV/AIDS family caregiving.
- An examination of HIV/AIDS palliative care.

Chronic illness

The chronic illness trajectory framework, developed by Corbin and Strauss (1992), and applied by Nokes (1992) explains the changing and unpredictable nature of HIV/AIDS as a chronic illness. The dying phase generally takes into account the progressive and chronic nature of HIV/AIDS (Boland & Conviser, 1992; Goldstone, 1992; Nokes, 1992; Raveis & Siegel, 1990). Therefore, since this study explored HIV/AIDS family caregiving in the context of what Corbin and Strauss term the "unstable", "downward", and "dying" phases in the chronic illness trajectory, an examination of the

literature related to caregivers of the chronically ill and those with cancer is warranted.

Caregivers of the chronically ill and those with cancer

The literature suggests that there are risks to assuming the family caregiver role. A great deal of this research and lay literature on the impact of caring for the chronically ill has focused on caregivers of the demented elderly (Barnes, Raskind, Scott, & Murphy, 1981; Chenoweth & Spencer, 1986; Ekberg, Griffith, & Foxall, 1986; George, & Gwyther, 1986; Lindgren, 1993; Mace & Rabins, 1981; Marks, 1987; Rabins, Mace, & Lucus, 1982; Rabins, Fitting, Eastham, & Fetting, 1990; Zarit, Reever, & Bach-Peterson, 1980) and those with cancer (Addington-Hall, MacDonald, Anderson, & Freeling, 1991; Holing, 1986; Howell, 1986; Hull, 1989; Kristjanson, 1989; Kristjanson & Ashcroft, 1994; Lewis, 1986; Martens & Davies, 1990; Northouse, 1984; Smith, 1990; Stetz, 1987; Stetz & Hanson, 1992). A review of this literature reveals some common themes in the family caregiving experience that provides insight into the experience of family members who care for PWHIV/AIDS.

Studies have documented the physical, emotional, social, and financial burdens associated with providing support and assistance. Chronic fatigue, physical exhaustion, sleeplessness, burnout, and deterioration in their own

health are among the physical burdens commonly experienced by family caregivers (Chenoweth & Spencer, 1986; Ekberg, Griffith, & Foxall, 1986; Holing, 1986; Horowitz, 1985; Howell, 1986; Kim & Keshian, 1994; Stetz, 1987; Stetz & Hanson, 1992). For example, in a study of family caregivers of persons with Alzheimer's type dementia, Marks (1987) found that family members provided an average of 120 hours per week of extensive physical care: helping older family members with eating, walking, dressing, taking medications, and managing chronic health problems such as incontinence. Moreover, Mace, Rabins, and Lucas (1982) found that 87% of caregivers in a sample of 55 families reported chronic fatigue as a major physical burden to caregiving. These unending caregiving tasks can lead to significant changes in the overall health status of family members (Haley, Levine, Brown, Berry, & Hughes, 1987; Howell, 1986). Chenoweth and Spencer provide a well articulated description of one family members' experience:

By the time I placed him in a nursing home, I'd been about eighteen months without a full night's sleep. I used to sleep on the floor close to the doors and the lights would all be on - he'd have every light in the house on. And he would be wandering from room to room. And I would try to get snoozes [in order] to be able to watch him when he was more active ... So I was

running all over the house with my pillow and blanket, trying to capture a few hours of sleep. And that can get you to the point where you become very debilitated (p. 271).

Horowitz (1985) suggests that caregivers of the frail elderly experience emotional burden resulting from a constant concern for, (1) the ill person's safety and health, and (2) the need to come to terms with the changing nature of the relationship. In addition, some authors have found that emotional tensions and stress are high in family members who care for dying family members (Holing, 1986; Lewis, 1986). Northouse (1984) suggests that communications about death and feelings of separation and loss are central issues for family members during the cancer illness. Juxtaposed with these issues are feelings of depression and anxiety (Deimling & Bass, 1986), anger (Chenoweth & Spencer, 1986; Rando, 1988; Thobaben 1988), and guilt (Rando, 1988) that are common for family caregivers. These feelings may result from emotional exhaustion, stress from changes in roles within the family, or significant lifestyle changes (Smith, 1990). Thobaben (1988) articulated that caregivers often feel frustrated, guilty and bitter as the ill relative becomes increasingly dependent.

Family caregivers also experience social burdens including restrictions on time and freedom (Mace & Rabins, 1981; Stetz & Hanson, 1992),

disruption of personal routines and leisure activities (Chenoweth & Spencer, 1986; Deimling & Bass, 1986) and role conflicts associated with having to balance the needs of the sick with those of well network members (Chenoweth & Spencer; Rando, 1988). Miller (1983) cited that caring for a person with a chronic illness often prevents caregiver participation in leisure and social activities. In a study of caregivers of persons with senile dementia, Haley, Levine, Brown, Berry, and Hughes (1987) found that family members had significantly less contact with outside support systems and friends. Consequently, social isolation is common for caregivers (Fengler & Goodrick, 1979).

Economic burdens are also experienced by family caregivers, particularly when caregiving disrupts work performance resulting in missed time from work and unemployment (Horowitz, 1985). For example, Muurinen (1986) reported that 60% of caregivers of persons with cancer experienced income loss as a result of time lost from work to provide care for the ill family member. However, Stetz (1987) points out that these economic burdens, although considerable, are less stressful and more easily adapted to than physical, emotional, and social burdens.

Family members of PWHIV/AIDS experience many of the same burdens that challenge caregivers of other chronically ill people. The

caregiving responsibilities can require a restructuring of personal, professional, and social lives, leading to financial burden, social isolation, physical exhaustion, and extreme emotional stress. As such, an examination of the literature on caregivers of those with cancer and chronic illness is helpful in understanding general family caregiving issues. However, this literature is limited in providing an understanding of the unique aspects of HIV/AIDS family caregiving. While there may be challenges common for all caregivers, each subgroup of caregivers face unique stressors, often related to the characteristics of the care recipient. Issues of communicability, stigma, and multiple and premature losses are common in HIV/AIDS family caregiving (Moffatt, 1986; Ostrow & Gayle, 1986; Schoen, 1986; Shilts, 1987). Therefore, in order to identify the gap in nursing knowledge that this research seeks to address, current literature on HIV/AIDS family caregiving will be reviewed.

HIV/AIDS family caregiving

Several authors have indicated the need for systematic inquiry on HIV/AIDS family caregiving (Brown & Powell-Cope, 1991; Raveis & Siegel, 1990; Giacquinta, 1989). Unfortunately, family caregiving fails to be identified as a major priority for HIV/AIDS research (McCain & Zeller, 1994; Ragsdale, 1993), even though the HIV/AIDS epidemic alters and affects the

lives of many (Carter, 1989). Nonetheless, HIV/AIDS, as a syndrome, has been the focus of much research, and some studies are available on HIV/AIDS family caregiving. As well, HIV/AIDS has been predominantly featured in the news media, in theatre, in movies, and in various nonresearch publications. The fact that such lay sources exist adds strength to the argument that professionals need more insight into the experiences of HIV/AIDS family caregiving. Therefore, in order to gain a perspective about issues of HIV/AIDS family caregiving, both research literature and lay materials are reviewed.

In reviewing the HIV/AIDS family caregiving literature, it is important to acknowledge the context of the available literature. Much of the research and lay material is from the American experience with HIV/AIDS. The geographic and socioeconomic variables, homecare, hospital, and health service infrastructures differ greatly in their response to HIV/AIDS. These differences occur even within our own Canadian, provincial, and municipal systems. Furthermore, some of the research reviewed was conducted in the late 1980's, representing a different era in the HIV/AIDS epidemic. Although this literature is useful in providing insight into the HIV/AIDS family caregiving experience, it is recognized that this information must be viewed in the context of the factors identified (ie. location and time the information was

collected) and that there may be differences in family caregiving experiences as a result of these factors.

Lay literature

Danny and I were very, very close. It was hard; it's still hard. I got through it the best I could. I went to work every day. After work I took the bus down there, stayed four or five hours, made dinner, took the bus home, went to bed, and got up and did the same thing, seven days a week (Hitchens, 1992, p. 26).

Families of PWHIV/AIDS are confronted with a multitude of issues. Not only do family members face similar issues to those of caregivers of chronically ill people and persons with cancer, they face unique problems related to HIV/AIDS. A review of the lay and consumer oriented material reveals some common themes that are experienced by many family caregivers of PWHIV/AIDS. Specifically, issues of stigma, communicability, untimely death and multiple loss, are common in HIV/AIDS family caregiving and have been identified as having a significant impact on the caregiving experience. Thus, a brief review of these themes adds support for the need for scientific inquiry into the HIV/AIDS family caregiving experience.

Stigma

HIV/AIDS is a disease that, for many, results in a socially unspeakable loss (Worden, 1991). Tiblier (1987) suggests that family caregivers of PWHIV/AIDS are in danger of stigmatization because of the lifestyle behaviors associated with contracting HIV/AIDS. In their video, A death in the family, Wells and Wallace (1986) portray a mother's anguish at watching her son die, and the guilt associated with not being able to *do something* about her son's homosexuality. In a touching account, Barbo (1987) explains her ordeal of caring for a son with HIV/AIDS who was not accepted by a homophobic society. This experience is similar to partners who have provided day-to-day care for their loved one dying of HIV/AIDS (Moffatt, 1986; Monette, 1988).

Because of the stigma associated with HIV/AIDS and HIV/AIDS phobia, many family caregivers fear that they will be rejected, isolated, and judged harshly if the cause of death of their loved one becomes known. In a video on HIV/AIDS family caregiving, Dick (1992) illustrates this fear of disclosing the cause of a loved one's illness. This fear is justified given the intense discrimination and persecution that is often faced by HIV/AIDS family caregivers (Martelli, Peltz, Messina, & Petrow, 1993). For example, Martelli, Peltz, Messina, and Petrow (1993) cite the case of Ricky, Robert,

and Randy Ray, whose HIV positive status, as a result of hemophilia, led to the burning of their family home in Florida. Incidents such as these have led many family members to assume a conspiracy of silence (Kubler-Ross, 1987; Murphy & Perry, 1988; Vachon, 1990). Indeed, families will often lie and attribute death to cancer or some cause other than HIV/AIDS (Worden, 1991). However, Worden suggests that such deception ultimately takes its emotional toll in fear of discovery, anger that a cover-up is necessary, and possible guilt.

Communicability

Considerable information was found to support the notion that HIV/AIDS can stimulate fears of contagion and death (Craig, Rene, Wlodkowski, Roszak, & Schwarz, 1990; Dick, 1992; Gawthrop, 1994; Martelli, Peltz, Messina, & Petrow, 1993; Moffatt, 1986; Shilts, 1987; Vachon, 1990; Wells & Wallace, 1986; Worden, 1991). For example, in a keynote address to HIV/AIDS caregivers, Vachon (1990) disclosed the fear of contagion that her family experienced as a result of an association with a PWHIV/AIDS. This fear and discrimination frequently exists against and within families (Martelli, Peltz, Messina, & Petrow, 1993). Possibly the most revealing sense of fear of contamination is depicted in the movie Longtime Companion, where the director portrays the fear not only within the gay community early in the HIV/AIDS epidemic, but also amongst health care

providers. Wells and Wallace (1986) depict similar fears in their video A death in the family.

Untimely death and multiple loss

Hitchens' (1992) book of stories written for and by PWHIV/AIDS and their families, reflects the experiences and distress of caregivers and the emotional pain encountered when anticipating an untimely loss. This pain is best illustrated by Hitchen:

My life partner of seven years, Christopher Esposito, was rushed to the hospital in a coma. "AIDS," they said. "Six months," they said. I clasped my hands over my ears, but the message penetrated through. Death. Destruction. Gloom. Doom. I screamed the loudest scream I ever heard in my life. It emerged from my gut and built up momentum as it raced to my heart, to the lump in my throat, to my mouth. But no sound passed my lips as the scream echoed through my brain (p. 13).

Caregivers of PWHIV/AIDS express the unfairness and powerlessness felt at losing a loved one in the prime of life (Aranda-Naranjo, 1993; Barbo, 1987; Oerlemans-Bunn, 1988; Trussler & Marchand, 1993). Shilts (1987) explains how these untimely deaths often increase awareness of personal mortality when caring for a loved one with HIV/AIDS.

In a support group for HIV/AIDS family caregivers, Barouh (1992) explains that emotional pain caused by multiple loss of friends, family, and partners is common. In fact, it is not unusual for these caregivers to attend several funerals per month (Martelli, Peltz, Messina, Petrow, 1993; Monette, 1988). In a made-for-television movie, Craig, Rene, Wlodkowski, Roszak, and Schwarz (1990) depict the untimely and multiple losses experienced by a group of gay friends over an eight year time span. Ultimately, the movie shows the experience of losing a support network of friends and the emotions and fears of dealing with multiple loss.

Research literature

HIV/AIDS affects not only the person who contracts the disease but everyone who lives with and cares about that individual (Macklin, 1988). Using grounded theory methodology, Brown and Powell-Cope (1991) conducted extensive interviews with 53 family members who were taking care of people at home with symptomatic HIV infection or AIDS. A substantive theory of HIV/AIDS family caregiving resulted from this study and culminated in Brown and Powell-Cope's 1992 book on caring for a loved one with HIV/AIDS. The purpose of this study was to describe the experience of HIV/AIDS family caregiving and, though the intent was not to focus specifically on the experience of caring for dying persons at home, it

illustrated some interesting findings related to living with loss and dying. For example, living with loss and dying posed three sources of uncertainty for caregivers: whether to remain hopeful about the PWHIV/AIDS' survival, not knowing which illness or opportunistic infection would hasten death, and not knowing when death would occur. The authors identified facing loss, putting the future on hold, and maximizing the present as possible stages and strategies that caregivers experience.

Chekryn (1989) interviewed 10 Vancouver family members who were related to seven deceased PWHIV/AIDS who received home nursing services through a hospice home care program. The purpose of this exploratory study was to determine the experience of HIV/AIDS as a terminal illness from a family perspective. The interviews revealed that family members of PWHIV/AIDS faced many of the same stressors as any family coping with a dying relative. However, Chekryn points out that these family members face additional stressors related to the newness of the disease, the stigma attached to HIV/AIDS, and the complex management and caregiving issues. One of the caregiving issues of particular interest was the PWHIV/AIDS' resistance to involve health professionals in care. This resistance created an enormous burden on family members who were taxed with the major caregiving responsibilities.

This retrospective study provides some valuable insight into the experience of family members caring for a dying relative. Specifically, the study contributes to a beginning understanding of the complexity of HIV/AIDS family caregiving. The fact that this study was conducted in Vancouver makes the findings relevant to this proposed research.

Dolan and Nokes (1992) explored the experiences of New York Puerto Rican family members living with HIV/AIDS. This qualitative study, using a phenomenological approach, explored three families in which a member had become infected with HIV either directly through sharing needles with an infected person or through unprotected sex with a person who had a history of IVDU. This sample was chosen to determine if families differ in their reactions to HIV/AIDS depending on how their loved one was infected. The study found three themes as being common in all families: loss, reaching out, and hopes for children, though the theme of loss was experienced and expressed differently within each family. For example, some families were able to learn from their losses and enhance coping skills while others experienced extreme anger and bitterness. Giacquinta (1990) identified similar feelings in relation to loss in her description of a bisexual man who was dying from HIV/AIDS.

The findings of this study concentrate on the unique experiences of a

specific cultural group (Latino families) living in an economically disadvantaged section of New York city. While the experience of loss is explicated in the research, the PWHIV/AIDS were relatively healthy and, thus, the experience of caring for a loved one who is in the process of dying was not explored. In addition, this study aimed to explore families as a dyad or triad. As such, the perspectives of individual family members were not addressed. While the concept of loss is illuminated in this research, the focus is mainly on early anticipatory losses of family members.

Greif and Porembski (1988) explored what helped or hindered caregivers' abilities to cope with the death of a loved one with HIV/AIDS. The purpose of this study was to identify intervention strategies aimed at assisting a significant other to deal with death. The authors conducted 11 retrospective interviews with caregivers and found that bereavement support groups, support from friends, caring health care professionals, and a renewed faith in God were helpful in coping with the death of a loved one. Additionally, the study suggests that persons who had an optimistic attitude towards their illness positively impacted the coping abilities of caregivers. Concurrently, those persons with negative attitudes towards the illness represented a great challenge to family members. Further difficulties faced by caregivers hindered their ability to cope. For example, emotional tension

between lover and the parents of PWHIV/AIDS was common. Furthermore, some participants identified that doctors and nurses often treated PWHIV/AIDS like "guinea pigs" and expressed anger at the treatment they witnessed. Coupled with this treatment was the lack of information presented to caregivers regarding the overall health status of the PWHIV/AIDS.

The coping abilities and strategies delineated by Greif and Porembski (1988) provide some important information when planning interventions for caregivers of PWHIV/AIDS. However, the purpose of the study was not to address the experience of caring for a PWHIV/AIDS at home; therefore, it did not seek to understand the day-to-day living experiences of these family members. Additionally, most of the deaths in this study occurred in hospital and therefore findings cannot be generalized to the home situation.

In their study of the stress of HIV/AIDS caregiving, Pearlin, Semple, and Turner (1988) explored the experience of gay men in San Francisco who provided care to PWHIV/AIDS at home. In this study, three types of stressors were identified. First were stressors that were associated with the demands of housekeeping, caregiving tasks and the management of financial and legal affairs. The authors found that these caregivers were often responsible for taking on such roles as confidant, lover, housekeeper, nurse, and paramedic. Moreover, the caregiver was required to act as a liaison to

physicians, home health nurses, and compensatory systems (ie. social security).

A second stressor involved the uncertainties that arose from the reality that many homosexual caregivers are exposed to the same set of health risks as the patient. That is, the caregiver may have been a lover of the patient or may have followed a similar lifestyle and pattern of sexual practice. Towards this end, the authors maintain that it is understandable and common for these caregivers to face uncertainty about the future.

Stressors that created problems in the occupational, economic, and social lives of caregivers were a final stressor identified in this study. Pearlin, Semple, and Turner (1988) explain that one is usually not only a caregiver but a worker, breadwinner, and participant in a social network. As such, competing demands in all roles result in significant stress. The authors further acknowledge that this type of stressor is common to caregivers of others (ie. parent caregivers of chronically ill children), and suggest that the interrelated stressors of the caregiving role adversely affect the overall well-being of the caregiver.

Although this research was not aimed specifically at addressing the experience of caring for a dying family member at home, it does provide a rich description of the common stressors experienced in HIV/AIDS family

caregiving. However, because San Francisco hosts some of the best health care services for PWHIV/AIDS worldwide, it is difficult to generalize the findings of this study to populations living in other areas (Pearlin, Semple, & Turner, 1988). In addition, the decision trail of the authors is difficult to follow. That is, the authors indicate that the study was exploratory and involved intensive interviews yet fail to provide specifics about the methodology. Consequently, it is difficult to ascertain the transferability of the findings.

Ferrell and Boyle (1992) wanted to understand the experiences of surviving male partners who provided care to persons dying from HIV/AIDS. A convenience sample of five informants was obtained from the office of a home nursing care service. Face-to-face interviews and content analysis revealed two major conceptual categories: Strategies the survivors developed to care for their partners during terminal illness, and the bereavement experiences of the survivors. An examination of the concept of caregiving strategies illuminated findings that the authors suggest will help caregivers in developing skills to decrease the risk for complicated bereavement. Findings illustrated the positive aspects of the caregiving role (renewed commitment to caring for a loved one, an opportunity for personal growth, and the ability to be more productive in both the caregiving role and professional life) with the

exception of caregivers' negative experiences in dealing with the health care system. These negative experiences are similar to those enunciated in other research and consumer oriented literature (Brown & Powell-Cope, 1991; Gawthrop, 1994; Health & Welfare, 1990; Monette, 1988; Pearlin, Semple, & Turner, 1988).

The major intent of this retrospective study was to develop nursing interventions by exploring the caregiving strategies used by caregivers and, examining the surviving partners' experience with bereavement. The intent of the research was not to describe the day-to-day lives of caregivers.

Nonetheless, the research provides some useful perspectives about HIV/AIDS family caregiving that have not been found in other literature. One point in the report that is unclear is the setting in which care was provided. Although the authors intimate that care was being provided at home, the examples in the research report are mainly related to problems in dealing with the health care system and describe hospitalized incidents. However, because the study focuses on nursing interventions for community health nurses, it is assumed that the majority of care was provided in the home.

In a comparative study, Atkins and Amenta (1991) examined family adaptation to HIV/AIDS and other life-threatening illnesses. A nonprobability convenience sample of 26 clients and their families, from both groups, were

asked questions from two instruments that measured stress producing factors, negative emotions, illness anxiety, depression, trust, rules prohibiting emotional expression, and role flexibility. Findings from the study uncovered that families of PWHIV/AIDS experience significantly more stress, more rules prohibiting emotional expression, lower trust levels, and more illness anxiety than other families. The authors provide several explanations for this statistical difference including lack of financial resources to provide adequate health care services, the stigmatized nature of HIV/AIDS, accumulated and multiple losses, and lack of formal and informal support systems.

Although this study does not examine the unique experiences of providing care to PWHIV/AIDS who are dying at home, it does point out some important differences between families of PWHIV/AIDS and those with traditional hospice diagnoses. This difference is critical in the development of palliative care programs aimed at caring for PWHIV/AIDS and their families. Accordingly, a short review of the discourse on the debate surrounding HIV/AIDS palliative care is useful to add strength to proposed research.

Palliative care

A review of the discourse on HIV/AIDS palliative care reveals differing opinions on palliative care practice for PWHIV/AIDS. Most agree that palliative care for PWHIV/AIDS challenges current and traditional

palliative care practice (Downing, Braithwaite, & Wilde, 1993; Foley, Flannery, Graydon, Flintoft, & Cook, 1995; Goldstone, 1992; Higginson, 1993; Martin, 1988; Martin, 1991; Morissette, 1990; Von Gunten, Martinez, Neely, & Von Roenn, 1995). Morissette maintains that the palliative care philosophy is a universally applicable approach for all terminally ill people, but suggests that working with persons in the terminal phase of HIV/AIDS is equally or more demanding than that of cancer. The hospice philosophy of relieving pain and untoward symptoms rather than curing the underlying disease is appropriate for some PWHIV/AIDS and their families and in conflict with the goals of others. However, Martin (1991) believes that hospice care aptly applies to the care of PWHIV/AIDS when the goals of care are comfort rather than cure. Comfort, though, may mean aggressive treatment for symptom management that is common in PWHIV/AIDS but different from that of persons with cancer (Fraser, 1995; Martin, 1991; Stephany, 1992). For example, many believe that intravenous (IV) Gancyclovir is an aggressive, acute treatment for Cytomegalovirus (CMV) retinitis. Yet, for many, maintaining one's eyesight, up until the time of death, is a quality of life issue, and thus, palliative in intent. These contrasting views are an example of many issues that are at the heart of the intense debate surrounding HIV/AIDS palliative care. That is, which

treatments are curative and which are palliative?

The first papers (in 1986) that could be found on HIV/AIDS palliative care in Canada delineated the need for a model to meet the unique challenges brought on by the HIV/AIDS epidemic (Downing, 1986; McLeod, Smith, & Willoughby, 1986). As such, a model of integrated palliative care was developed (Health & Welfare Canada, 1989b) to address some of the unique concerns of the HIV/AIDS population (namely the desire for active, aggressive symptom-oriented treatment up until the time of death) and to differentiate traditional models of palliative care aimed at persons with cancer (See Figure 2) from HIV/AIDS palliative care (See Figure 3).

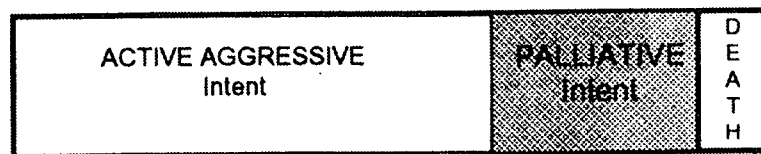


Figure 2. A model for cancer care



Figure 3. A model for AIDS palliative care

Figure 2 depicts the traditional model of cancer care. With cancer, palliative care clearly begins when cure is no longer possible, and the intent of care is to alleviate or palliate the disease through the control and relief of symptoms. Conversely, in HIV/AIDS care, there is not such a clear transition. Active, aggressive treatment is often continued close to death and components of palliative care begin both at the time of a diagnosis of HIV or AIDS. Therefore the division between aggressive and palliative care is blurred along the HIV/AIDS disease trajectory (Health & Welfare Canada, 1989b). This model of HIV/AIDS palliative care helps to place into context the period of palliation, that is, from the time of diagnosis until the time of death. While these models have served as a template for palliative care programs, questions remain about the appropriateness of some aggressive care for PWHIV/AIDS during the palliative phase (Cumming, 1993; Gunten, Martinez, Weitzman, & Von Roenn, 1991). Thus, the debate on palliative care models for PWHIV/AIDS continues to evolve. Acknowledgement of this debate and the differentiation in care models is important to understanding principles of palliative care for PWHIV/AIDS and their families.

Further model development has occurred since 1989 (Downing, Braithwaite, & Wilde, 1993) to address the more active/aggressive investigations and treatments by some Canadian palliative care programs and

to address recent questions about euthanasia (See Figure 4). Although the *Victoria Blue, Green, Yellow (BGY) Model* is not HIV/AIDS specific, it is






Treatment Approach Model					
Model Type	Acute Care Active	Palliative Active	Palliative Comfort	Palliative Urgent	Euthanasia or Suicide
Intent	Cure Modify Quantity Life Quality Life	Yes Yes Yes/No Yes	No No No Yes	No No No Yes	No No End Life Yes
Comfort By	Rx Disease	Modify	Meds	Meds	Avoid Dying
Comfort Within	1-6 Mos	1-6 Wks	1-2 Days	1-2 Hrs	1-2 Min.
Investigations	Yes	Yes	No	No	No
Rx Surgery	Yes	Yes	No	No	No
Rx Radiation	Yes	Yes	No	No	No
Rx Chemo/Horm.	Yes	Yes/No	No	No	No
Nerve Block	No/Yes	Yes	No/Yes	No	No
Rx Sympt. Only	No	No	Yes	Yes	No
Expect Change in Condition	Decline then Improve	Decline & Improve	Improve or Decline	Decline	Death
Side Effects	Expect	Expect	Yes/No	Yes	To Family
Treat Complic.	Yes	Yes/No	No	No	No
Death Expected as Outcome	No	No	No/Yes	Probable/Inevitable	Yes
Accelerate Death	No	No	No	No/Yes	Yes
Meds Titration	Increm.	Increm.	Increm.	Incr/Decr.	Lethal OD
Common Routes Used	PO PR SC IV	PO PR SC —	PO PR SC —	— — SC IV	Various Techniques

Figure 4. The Victoria BGY palliative care model

useful because it acknowledges the range of palliative care approaches (blue, green, yellow) required when caring for PWHIV/AIDS. The model is congruent with the integrated model for HIV/AIDS palliative care (Health & Welfare Canada, 1989b) in that it recognizes the need to begin palliative care at diagnosis while integrating aggressive aims to provide optimal palliative care to PWHIV/AIDS. Thus, this model, combined with the philosophical approach of the Health and Welfare model, provides guidance to this study by describing the PWHIV/AIDS who is dying at home and planning for a home death.

Summary of the literature review

The literature review reveals that present knowledge about the day-to-day life of family members who provide care to PWHIV/AIDS who are dying at home lacks depth and is incomplete. The lack of established concepts and theoretical frameworks to understand HIV/AIDS family caregiving creates a fragmented approach to research done in this area. Although an abundance of literature exists on caregivers of chronically ill people and those with cancer, it is not clear whether HIV/AIDS caregiving affects family members in the same way. Only a few qualitative studies have focused on the experiences of family members of PWHIV/AIDS. In addition, most of these studies need to be viewed in the context of the time and location that they occurred. Thus,

further research is required to build an understanding of the concepts that are relevant to family members caring for PWHIV/AIDS who are dying at home. In light of this review and subsequent knowledge gap, the research question is identified.

Research Question

The aim of this research was to gain a beginning understanding of what day-to-day life is like for family members who care for PWHIV/AIDS who are dying at home and planning for a home death. Therefore, the research question that guided this study was: What is day-to-day life like for family members who are providing care to PWHIV/AIDS who are dying at home?

Definition of Terms

For the purpose of this study, the following terms were defined:

Family member - refers to any individual that a PWHIV/AIDS identifies as being significant to him or her, regardless of kinship ties, common household, or marital status.

PWHIV/AIDS - Martin (1991) maintains that there are no absolute indicators for demarcating the end stages of HIV/AIDS and in fact, a definition is difficult given the unpredictable, changing nature of HIV/AIDS. However, Martin offers some clues that point to advanced disease. For example, the end stage of HIV/AIDS is generally considered when the PWHIV/AIDS has been

diagnosed for many months, physical status is deteriorating, and increasingly frequent opportunistic infections are present (ie. CMV Retinitis & Mycobacterium Avium Complex). Additional indicators may be extensive Kaposi's sarcoma (KS), severe wasting syndrome, and a progressive decline in mental status. The palliative performance scale (PPS) (Figure 5) (Victoria Hospice Society, 1993) offers further guidance in delineating this definition. The PPS takes into account ambulation, activity, self-care, and conscious level and provides a clear and measurable method to assess change in a person's condition as death approaches. As such, the PPS was used to help the researcher in determining the PWHIV/AIDS with advanced disease. Thus, for the purpose of this study a PWHIV/AIDS was defined as a person with advanced HIV/AIDS, with a PPS of 50% or less, who is dying at home, is planning for a home death, and is receiving palliative care in the blue, green or yellow mode (See Figure 4) as delineated by Downing, Braithwaite and Wilde (1993).

Home - any dwelling that the PWHIV/AIDS currently resides in that is separate from an institution that provides health care. This study does not require that the family member share the same household with the PWHIV/AIDS, but this family member must be making a significant contribution to the overall caregiving tasks.

<i>Palliative Performance Scale</i>					
%	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80	Full	Normal Activity <i>with Effort</i> Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Normal Job/Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby/House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Required	Normal or Reduced	Full +/- Confusion
40	Mainly in Bed	As Above	Mainly Assistance	Normal or Reduced	Full or Drowsy +/- Confusion
30	Total Bed Bound	As Above	Total Care	Reduced	Full or Drowsy +/- Confusion
20	Moribund	As Above	Total Care	Minimal Sips	Full or Drowsy +/- Confusion
10	Moribund	As Above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	---	---	---	---

Figure 5. Palliative Performance Scale

Assumptions

The following assumptions were inherent in this research study:

- An understanding of the day-to-day lives of family members can be attained through grounded theory research methods.
- Family members will be able to describe their experiences with caring for a loved one who is dying at home.
- The information shared by family members is based on their perceptions of their experience.
- The dying at home phase presents some unique challenges and experiences for family members.

Chapter Three

Research Method

Strauss and Corbin (1990) define grounded theory as a "qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon" (p. 24). The objective of this method is to develop theory that explains basic patterns common in social life (Chenitz & Swanson, 1986). Because this approach is derived from symbolic interactionism, the focus is on the social and psychological processes grounded in social interaction. In other words, family caregiving is viewed as a socially interactive process that supports the ill person, in this case, the ill PWHIV/AIDS.

Symbolic interactionism focuses on the "inner or experiential aspects of human behaviour, that is, how people define events or reality and how they act in relation to their beliefs" (Chenitz & Swanson, 1986, p.4). Herbert Blumer (1969) elaborated on Mead's (1956) theory of symbolic interactionism by adopting three assumptions that guide the research method. First, "human beings act toward things on the basis of the meanings that the things have for them" (p.2). Second, "meanings of such things are derived from, or arise out of the social interaction that one has with one's fellows" (p.2), and third, "these meanings are handled in, and modified through, an interpretive process

used by the person in dealing with the things he encounters" (p.2).

Direction for research activity

The symbolic interactionist perspective provided guidance for conducting research activities in three ways. First, symbolic interactionism suggests that human behaviour, to be understood, must be examined in interaction. As such, the setting and events that influence behaviour are analyzed (Blumer, 1969). Second, human behaviour is best understood by comprehending the world from the participant's perspective (Chenitz & Swanson, 1986). Therefore, the researcher was both a participant and observer in the world of those being studied. Last, Blumer suggests that in order for knowledge to be understood by peers, the researcher, as observer, must illuminate the meaning gained from the experience as a participant. Thus, symbolic interactionism supports that the researcher constructs meanings about phenomena based on the interpretations of interactions they have with themselves and the research participants.

Grounded theory

Grounded theory techniques are useful in contributing to a knowledge base that has not been subjected to much formal inquiry and about which little is known (Burns & Grove, 1987; Chenitz & Swanson, 1986; Sandelowski, Davis, & Harris, 1989). Additionally, this method allows for the flexibility

that was required for the exploratory nature of this study. As Glaser (1978) points out, it is a method that frees one to "discover what is going on, rather than assuming what should be going on" (p. 159). As such, the qualitative, holistic approach of grounded theory served as a valuable heuristic in understanding and explaining human experience. Therefore, grounded theory methods were used to address the research question and to direct the research process.

The grounded theory approach is reflected in the design features of this study. Participants were located through theoretical sampling (Strauss & Corbin, 1990) and analysis of data was by the constant-comparative method (Corbin, 1990; Stern, 1994; Strauss & Corbin, 1990). Assumptions about the situation being studied were not put aside but rather, were used in order to understand the processes being observed (Baker, Wuest, & Stern, 1992). Finally, the findings disseminated to colleagues will reflect a beginning synthesis of theory systematically generated to enhance understanding of family members' experiences in caring for a loved one with HIV/AIDS who is dying at home.

Selection of Participants

Sample Selection

In grounded theory, reliability is established by ensuring that one's

sample is appropriate (Morse, 1991). Theoretical sampling (Strauss & Corbin, 1990) was used to guide the selection of participants for this study.

Theoretical or purposive sampling is a form of non-probability sampling in which all participants are deliberately selected by the researcher according to the direction and theoretical needs of the study. Theoretical sampling is driven by the need to collect more data and to examine linkages or categories in the data. Thus, in theoretical sampling, participants are selected for a specific purpose (Morse, 1991; Woods & Catanzaro, 1988), that is, those participants who can articulate the experience of caring for a PWHIV/AIDS who is dying at home.

With theoretical sampling, the number of participants is based on the goal of achieving theoretical completeness (Sandelowski, Davis, & Harris, 1989). In this study the researcher was able to establish the core variable and associated themes throughout the data analysis. In other words, the researcher found no further data to develop the properties of a defined category (Glaser, 1978). Because qualitative methods support the inclusion of as much information as possible (Lincoln & Guba, 1985), the sample represented as many variations as possible with the following criteria:

- Participants were at least nineteen years of age,
- Participants were family members of PWHIV/AIDS with advanced disease who were either at home and planning for a home death, or had already lost a loved one to HIV/AIDS in the last year,

- Participants were able and willing to articulate from their perspective, the day-to-day experiences of caring for a PWHIV/AIDS who was dying at home or had planned for a home death,
- Participants were able to communicate in English,
- Participants were accessible to the researcher, that is, the participants resided in the Vancouver lower mainland or on Vancouver Island.

Selection Process

The participants for this study were recruited in a variety of ways. For example, a letter (Appendix A) was sent to AIDS Vancouver, the BC Persons with AIDS society, the nurse manager of the palliative care unit at St. Paul's hospital, and a home care coordinator at the Vancouver Health Department. The purpose of this letter was to share the nature of the intended research. Follow-up telephone calls were made to: (1) gain support for the research project; (2) identify further methods of participant recruitment; and (3) request participation in identifying potential participants. Additionally, conversations with colleagues involved in HIV/AIDS community care created an opportunity to gain one participant on Vancouver Island.

To ensure that there was awareness of the research project within the HIV/AIDS population, the researcher wrote and published a short advertisement in the BC Persons with AIDS society newsletter (Appendix B), requesting participation from family members. Concurrently, a brief overview

of the study was presented at a team meeting of home care nurses and long term care assessors at the Vancouver Health Department. Participant information sheets (Appendix C) were distributed at this meeting as well as to the nurse manager of the palliative care unit.

To summarize, participants for the study were accessed through community agencies and health care providers that identified family members who were willing to participate in the study and by individual responses from the community newsletter. All respondents received information about the study either from the participant information sheet or through the community newsletter. Respondents were asked to contact the researcher by telephone to discuss the study, provide an opportunity to ask questions, and to make arrangements for an interview. Written informed consent (Appendix D), demographic information (Appendix E), and permission to tape-record the interview were obtained at the time of the interview.

Description of the sample

The sample for this study consisted of seven family caregivers of persons with advanced HIV/AIDS ranging in age from 31 to 65 years of age. Four of the seven participants were partners or lovers in gay relationships, two were mothers caring for their dying sons, and one participant was a sister caring for her dying brother. All participants ($n=7$) shared the same

household with the PWHIV/AIDS throughout the caregiving experience. Two participants, one from another province and one from another city, relocated from their permanent place of residence to care for their dying loved one. More than half of the sample had post secondary education. At the time of the caregiving, two participants were employed full-time and one part-time outside the home. Two participants were unemployed and receiving income assistance, one was unemployed, and one was retired. All but one participant had lost their loved one to HIV/AIDS at the time of the interviews. All caregivers anticipated and desired that their loved one die at home. As well, all of the caregivers in this study commented that home was the preferred location of death articulated by their loved one. Four of the six deaths occurred in the home and two occurred after being admitted to the hospital for respite care.

Data Collection

May (1991a) suggests that one-time interviews are appropriate when, for a variety of reasons, informants are difficult to access. Data for this study were collected by one face-to-face, open-ended interview with individual family members. Interviews lasted between two and a half and four hours. Interview locations were selected by participants to ensure that the interview took place in a comfortable environment. All of the interviews were

conducted in the homes of the family member who was or had been involved in the caregiving experience. Mutually convenient interview times for the participant and the researcher were arranged. All interviews were tape-recorded and subsequently transcribed by the researcher. While repeated interviews would have been ideal, time and resources made it impossible to have a second interview with all but two participants. Thus, following the interviews and resulting data analysis, telephone interviews were conducted with two participants to allow for clarification on points that were unclear to the researcher, to encourage participants to expand on selected points, and to validate the results of the data analysis.

All of the interviews began with an open-ended prompt such as, "Tell me what an average day is/was like for you." The purpose of this approach was to elicit the participants' perspective with as few probes as possible. As the data analysis progressed, the nature of the interviews changed with the questions becoming more specific. This specificity assists in (1) gaining further information, (2) testing preliminary findings, and (3) looking for commonality and difference in the participants' stories (May, 1991a). An example of the sample prompts for the interview can be found in Appendix F. Observational field notes (Lincoln & Guba, 1985; Boyd, 1990) and theoretical memos and diagrams (Corbin & Strauss, 1990; Strauss & Corbin, 1990) were

also used during data collection. These ideas and observations were written immediately following all interviews in order to ensure more accurate and thorough recollection of the circumstances and to add richness to the data. Data were also obtained from the collection of newspaper clippings and a review of videos pertaining to HIV/AIDS family caregiving experiences. This collection and review served to "insure density and provide multiple perspectives for illuminating social phenomena" (Hutchinson, 1986, p. 115). Additionally, the researcher kept a journal to express personal feelings and reflections throughout the research process. Hutchinson points out that "only through self-awareness of mind-set can the researcher begin to search out and understand another's world" (p. 115). Toward this end, journal writing can assist in sustaining heightened levels of awareness during the study.

Data Analysis

As indicated, the researcher used grounded theory methods as described by Glaser (1978), Glaser and Strauss (1967), and Strauss and Corbin (1990) for the systematic analysis of interview transcripts. The constant-comparative method (Chenitz & Swanson, 1986; Glaser & Strauss, 1967; Strauss & Corbin, 1990) aims to search for a main theme or core variable that has three characteristics: "... it recurs frequently in the data, it links the various data together, and it explains much of the variation in the data" (Hutchinson,

1986, p. 118). Strauss and Corbin (1990) suggest that data collection and analysis are carried out concurrently to capture all potentially relevant aspects of the data as soon as they are perceived. As such, data from different interviews are compared for similarities and differences. This process is the main source of effectiveness in grounding theory in reality (Glaser & Strauss, 1967).

In grounded theory, the basic units of analysis are not the actual raw data, but the conceptualizations of the data (Strauss & Corbin, 1990). In other words, incidents or events that are recorded are analyzed and given a conceptual label. In turn, concepts that are related are then grouped to form categories. While these categories are also generated by making comparisons to highlight similarities and differences, they are "higher in level and more abstract than the concepts they represent" (Corbin & Strauss, 1990, p. 7). As such, categories are the "cornerstones" of developing theory (Corbin & Strauss). That is not to say, however, that simply grouping concepts is what makes a category. The development of a category includes generating a more abstract concept by identifying its properties and dimensions, the action by which it is expressed, and the consequences it produces (Corbin & Strauss). Corbin and Strauss indicate that the development of more abstract concepts

will lead to the definition of a well explained, powerful category and that, over time, categories can become related to one another to form a theory grounded in the participants' reality.

Coding

The Ethnograph computer program (Seidel, 1988) was used to code and re-code all interviews and memos and to sort and manage the code files. The process of open coding (Strauss & Corbin, 1990) allowed the researcher to generate questions to guide subsequent interviews with family members and ultimately safeguarded against subjectivity and bias (Strauss & Corbin). Open coding (the process of breaking down, examining, comparing, conceptualizing, and categorizing data) through line-by-line analysis, was done to generate findings and to compare events, actions, and interactions for similarities and differences. Conceptual labels (Strauss & Corbin) were developed by asking questions such as: What is this? What does it represent? The conceptual labels were grouped together to form categories which in turn, were defined according to their properties (characteristics of a category) and dimensions (location of property along a continuum) (Strauss & Corbin). "In vivo" information (Glaser, 1978, p. 70) provided an important source of codes. At the same time, memos and field notes assisted in formulating abstract ideas and creative thinking throughout the data collection and analysis.

While open coding allowed the researcher to determine categories and related properties and dimensions, axial coding (Strauss & Corbin, 1990) directed the researcher to generate a substantive theory of HIV/AIDS family caregiving. In axial coding the researcher follows a set of procedures to put data back together in new ways after open coding, by making connections between categories. Strauss and Corbin specify and affirm that this "paradigm model" (p. 99) leads to precise and solid theoretical construction. The paradigm model has six categories that link the subcategories to a core category in a set of relationships. The first category, **causal condition**, are the events, incidents, or happenings that lead to the occurrence of the phenomenon. This category explores the causes of the phenomenon, as well as its nature and dimensions. The core category or **phenomenon** is the second category which identifies the core variable that accounts for variations in the data and to which other categories relate directly. The phenomenon occurs within a set of conditions or the **context** which captures the social world of the individuals engaging in the phenomena. In other words, the phenomenon occurs within a certain context and brings about certain behavioral responses described as **action/interaction strategies**. This fourth category describes how HIV/AIDS family caregivers manage, handle, or cope with the phenomenon. **Intervening conditions** that facilitate or constrain the strategies taken represent

the fifth category. Finally, the **consequences** identify the outcomes or results of the strategies that HIV/AIDS family caregivers implemented.

Issues of Validity and Reliability

Research conducted using qualitative methods requires different criteria to assess validity and reliability than those applied to quantitative methods. Sandelowski (1986) recommends that the criteria of credibility and fittingness be used instead of internal and external validity. Likewise, auditability and confirmability replace the criterion of reliability. Efforts to ensure rigor during this research project included several strategies that are grouped under the headings credibility and fittingness, auditability, and confirmability.

Credibility and fittingness

Credibility is concerned with the lived experience as perceived by the participants and is achieved in two ways: When the participants are able to recognize themselves and their experiences in the descriptions and interpretations of findings, and when professionals and lay people also are able to recognize the experience from descriptions. Fittingness addresses the ability to fit the data into the findings from which they are derived. That is, findings must be well grounded in the life experiences of participants. Credibility and fittingness for this study were achieved in several ways. First, after the researcher identified the relationships among the categories, according to the

above paradigm, these relationships were verified against statements in the interview data. In other words, data sources (making comparisons of the interview data) and data collection procedures (interviews, personal journal, observational fieldnotes, newspaper clippings, theoretical memos and diagrams) were triangulated to determine congruence among them (Sandelowski, 1986). Second, the researcher shared her interpretations and descriptions of the interviews with two participants in a follow-up telephone interview. Participants were asked to comment on the truth of the descriptions and impressions derived from the interviews in order to verify the validity of the data analysis. Finally, the researcher presented preliminary findings from this study to two HIV/AIDS family caregivers in Victoria who were not part of the study and to nursing colleagues (some of whom were HIV/AIDS family caregivers) at a national HIV/AIDS conference. These steps were used to contribute to the "trustworthiness" of the research (Lincoln & Guba, 1985).

Auditability

Auditability refers to the "decision trail" (Sandelowski, 1986) used throughout the research process. As such, the researcher must present the situation and data in enough detail so that others are able to arrive at similar conclusions. Accordingly, the final research report describes: (1) How the researcher became interested in examining the experience of family members

who care for PWHIV/AIDS who are dying at home; (2) The purpose of the study; (3) How the sample was selected; (4) How the data were collected; (5) The length of time for data collection procedures; (6) The setting of the data collection; (7) The data analysis process; and includes (8) Excerpts of the data in the research report. Additionally, the researcher has made assumptions explicit about the subject matter in order to interpret her own behavior in relation to the participants. Furthermore, the researcher shared all steps of the decision trail with thesis committee members both verbally, and in the final written report, to ensure that the decisions can be followed.

Confirmability

Confirmability or freedom from bias was established when the criteria of credibility, fittingness, and auditability were met.

Ethical Considerations

This research was subject to ethical review according to the guidelines set forth by the University of British Columbia Behavioral Sciences Screening Committee. In addition, ethical review and approval was obtained from the Vancouver Health Department research committee, and St. Paul's hospital ethics committee.

Spradley (1979) stresses that the rights, interests and sensitivities of the participant must be safe guarded. To this end, each participant was informed

verbally and in writing of the purpose and nature of the study. The anonymity of each participant was assured and protected. All participants were apprised that their participation was voluntary and of their right to withdraw from the study at any time without penalty. Concurrently, participants were assured of their right to stop the tape recorder or to have any section of the tape erased at any time. Audiotapes were stored in a locked cupboard. Written, informed consent was obtained from each participant prior to his or her participation in the study.

All interviews were conducted with the intent of promoting a relaxed, sensitive, and informal manner. Though clinical experience with HIV/AIDS family caregivers supports the view that most individuals welcome an opportunity to discuss their experiences, provision was made for these family members to discontinue the interview if they wished to do so. None of the subjects requested that the interview be cut short. Furthermore, follow-up supportive counselling from a nurse or social worker was available for those participants who identified such a need. One participant expressed the desire for counselling and was referred to the Vancouver Health Department.

Support for the researcher

Although Quint (1967) identified difficulties nurses face in providing skilled and sensitive palliative care more than two decades ago, practising

nurses continue to rank death-related encounters as among the most problematic they face (Western Consortium for Cancer Nursing Research, 1987). These death-related encounters include relationships that nurses establish with family members (Brewington, 1994). It was expected the interviews for this research would be intense and emotional. Thus, support mechanisms for the researcher were built-in throughout this study to preserve the researcher's integrity (Davies & Oberle, 1990) or to handle the emotional reactions that resulted from the research process. Support mechanisms included debriefing, after any intense interview, with a member of the thesis committee, and summarizing personal reflections by journaling thoughts, feelings, and perspectives during the research process.

Chapter Four

Results

Using the procedures for axial coding as delineated by Strauss and Corbin (1990), a substantive theory of HIV/AIDS family caregiving was developed (Figure 6). The final paradigm illuminates the core category or **phenomenon**, as *work* in the **context** of *uncertainty and stigma*. *Promising to fulfil the wishes* of the loved one (**causal condition**) leads family members to engage in the *work* of HIV/AIDS family caregiving. In order to manage and cope with both personal and pragmatic *work*, family members develop various **strategies** such as maintaining balance, being with, taking charge, seeking support and so on. Several **intervening conditions** such as the nature of support and the accessibility of health and social services, affect the strategies that caregivers use to deal with the *work* associated with HIV/AIDS caregiving. These conditions and strategies ultimately result in either positive or negative **consequences** that affect the bereavement period following the loss of a loved one.

While the paradigm model (Figure 6) depicts somewhat of a linear process, in actuality it is meant to characterize the relationships between the categories. Since each category contains various subcategories, they will be presented separately but should be viewed in the context of the whole.

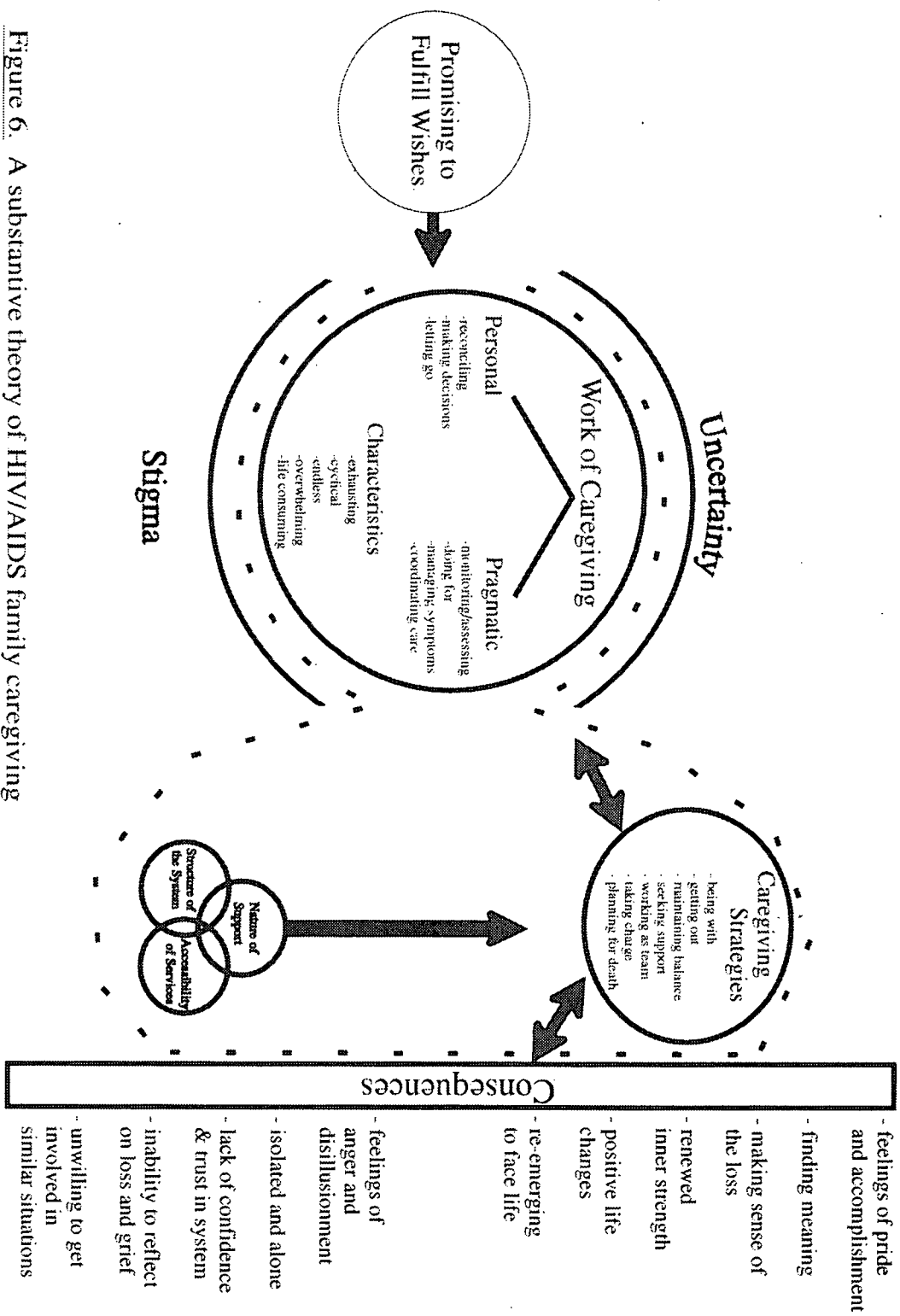


Figure 6. A substantive theory of HIV/AIDS family caregiving

Promising to fulfil wishes

The work involved in caring for a dying family member at home resulted from family members promising to fulfil the loved one's wish to die at home and to be cared for by "certain people." All family members stressed their desire to fulfil their loved one's wish to die at home because of the loved one's fear of or aversion to dying in hospital:

The only thing that G. was absolutely terrified about, and I mean absolutely terrified about, was that he did not want to die in the hospital. He wanted to die at home. And he was terrified that he was going to have to go to the hospital and I told him, if I have any say in the matter, you will not die in the hospital.

Another family member moved from her home town to care for her dying brother who wished to die at home:

It was the only way that J. would get his wish to die at home. He wanted to die in his own home and the only way that that could be done was if I was here ... J's greatest wish was not having to go to the hospital. He did not wish to go to the hospital and that's all there was to it. And I thought, why should he have to go? Why should he have to go and die in a hospital?

This sister commented on the gratification that she felt in being able to fulfil her brother's dying wishes:

There was a lot of fulfilment because I could do for him what he wanted. I could give him his last wishes so to speak ... the most important one though, was that he was not to end up in hospital or in hospice. That was the most important one.

Some family members felt unsupported by health care providers in their

decision to care for their loved one at home, but "threats" to withdraw services only strengthened their commitment:

I almost felt like I was being threatened - that they were going to pull all the help away, that the home support agency was going to pull all the help away because they were giving me more hours than what I was supposed to have I guess. And I said, that's fine, if you have to do that, if you feel that is what you have to do then that's fine. And they phoned me and they actually had a bed for him in hospice and I said, no, but if you have to pull out that's fine. But it's out of the question. He is not leaving this apartment until it is over. That was my promise.

Even though health care services were available to all caregivers, the extent to which they were utilized varied and were dependent on a number of different circumstances. Generally, those with HIV/AIDS and their family members were reluctant to allow "strangers" to provide any personal care:

I mean, we didn't want anybody coming over and wiping his butt. He didn't want that. He wanted me to do that because he trusted me. He didn't want a total stranger to come over and do that.

Those with HIV/AIDS did not want to die in hospital amongst "strangers". They preferred to be in their own home, to be cared for by "certain people", and to be surrounded by those who they knew and loved. Family members promised their loved one that they would be able to die at home, be cared for by them, and that they would also be present during the dying experience:

He wanted to be at home, he wanted certain people to care for him, and he wanted certain people with him. He wanted his mother there and he wanted me there. I had to be there with him to go through it and come hell or high water, I was going to be there and we were

going to do it at home. That's what he wanted. You can't argue with wishes like that - you just have to do it.

Frequently, family members and those with HIV/AIDS were faced with accepting home help that did not meet their needs or that only created more work for the caregiver. Health care providers were often unwilling or unable to contribute in a way that was helpful to the caregiver and loved one. These experiences lead family members to reaffirm their commitment to care for their loved one as they had originally promised:

The other thing that really, really annoyed me was when he was at home and home care was coming in and he had reached 30 days where his port had not been accessed. So they sent in a nurse to do that and it took her 45 minutes to do it. She didn't know how much heparin to use. I had to tell her. and J. was scared. I mean, we are talking about a direct line going into somebody's heart, and they are sending people out who don't know how to use it? When she left, the first thing that J. said to me was, "don't ever let her in this house again." And I said, "don't worry, I won't. I will take care of you." I will learn to do it because it was the only way that he was to stay at home. I would gladly have done anything myself to avoid going through that situation again.

A mother, caring for her dying son, commented on her experience with care providers who were unprepared to do HIV/AIDS work:

We had home support people who would not come into the home and home nurses who would not come into our home. The ones who did, they didn't want to be here, that was obvious. And it took hours to educate them. You would get them in the door and try to explain and they never did any personal care, I managed that. They were just so frightened. They would go to change his sheets, and god, they were just very, very frightened. It made it really hard. So I basically did it all and that's what he wanted anyway ... we were so tired but he didn't want to go into the hospital so we did the best we could.

Those with HIV/AIDS wanted very much for their partner or family member to provide care for them, be with them, and ensure that they were able to die at home if possible. In response, family members promised to fulfil their loved one's wishes. Fulfilling their promises resulted in the work of caregiving.

The work of HIV/AIDS family caregivers

Work was the central phenomenon that characterized the experiences of family members caring for their dying loved one at home. Work is conceptualized as the experiences, actions, and behaviours associated with caring for someone with HIV/AIDS at home. The work involved in HIV/AIDS caregiving exerted a profound influence on caregivers' lives and pervaded the entire caregiving experience; it never completely disappeared, but varied in intensity, timing, and content. HIV/AIDS family caregivers described the nature of their work as a "cycle", a "responsibility", and as "overwhelming", "ongoing", and "never ending". Family members identified two types of work: personal and pragmatic. Personal work involved reconciling that a loved one would eventually die, making life and death decisions, and letting go. Practical work included the more "hands-on" aspects such as doing for, monitoring and assessing, managing symptoms, and so on.

Characteristics of HIV/AIDS work

The work involved in HIV/AIDS family caregiving was exhausting and required considerable time, energy, and commitment. When prompted to explain their day-to-day lives, caregivers described the cyclical and endless nature of their work:

I was up at six o'clock in the morning. Get up, wake him up, give him some pills and then he'd go back to sleep. At seven or eight o'clock, wake him, give him another pill or two and then he'd go back to sleep again. Then at 10 or 11 he'd come out of the bedroom and it was like, okay, he needs IV gravol now if he hadn't already thrown up. I had buckets all over the apartment. I mean, it was the only way. So then I'd give him a bath and get him a bite to eat. After that he would then get a fair bulk of pills and then in the afternoon it was more pills and then all the running around that had to be done. To the pharmacy and arranging appointments. And the appointments were pretty outrageous. Some weeks there would be eight, nine, maybe 10 appointments, you know, constantly ... and I'd arrange for the appointments which means because he was on GAIN with social services, you'd have to book a taxi through them. And then get him dressed and bundled up and get organized and get his pills organized and we would run off and do what we could if he could tolerate it. You know, you're constantly arranging because nobody else will. There is never a let up you know ... And then he'd have cravings for certain things. It would be a two week run on Big Mac's or something. So, off I'd go to McDonald's. So this is how the days would go. And then it would be deciding what to have for dinner and making sure he brushed his teeth because he had dental problems. And he had a nasty herpes infection so we had those problems to deal with and the three or four different creams to apply ... And then it was checking to see if he had a bowel movement. And then he started complaining of stomach pain. Well you have to decide, is it because he's plugged up or is it because he needs an adjustment on his MOS? You know, you just never get a chance to just sit back and say, uh. You're constantly thinking and constantly working. And this would go on from six o'clock in the morning until 10 or 11 at night

and then he'd wander off to bed and then I'd sit up and have a drink or two to unwind and climb into bed at one or two in the morning. It was a cycle. The same cycle would repeat itself six o'clock the next day. You're just going with no time to stop.

For another family member, caring for her dying brother was worse than caring for a baby:

It starts to overwhelm you. It becomes your whole life and it's worse than caring for a baby because you can bundle a baby up and go but you can't take this person out of that bed. They're bedridden and you can't do anything about it. So it's almost worse than having a baby in the house. It's 24 hours a day.

Family caregivers often wanted and needed to be involved extensively in their loved one's care, even though it meant relinquishing their own independence for a length of time. One partner considered the work as a willing sacrifice for someone he cared for deeply:

I didn't do anything else except care for him. Dinners with friends or going out, forget it. I just told everyone to leave me alone, that I don't have time for them now because I'm devoted to this. I wouldn't have had it any other way.

Other caregivers felt they were the best people to take primary responsibility for the care of their loved one:

It's not the same if I can't look after him myself. If he goes there (to the hospital), there will be somebody else looking after him and it's not the same.

Caregivers were willing to take on the responsibility for caregiving and forego many of their own needs, but it was not without costs:

I didn't realize just how much wear and tear it was on me because when you're in it, all of the sudden you just get this adrenalin. I mean, it flows and it just keeps going. You don't realize just how much of yourself you are giving but you have to give alot. You give your entire life so that you can care for this person.

Family members were offered help from a number of different sources but as many caregivers explained, this "help" did little to allow them to withdraw from the sole responsibility of caregiving. Even though caregivers were able to divide some of their jobs among other family members, friends, volunteers, or health care workers, the primary responsibility remained their own. Family members differentiated between help and responsibility:

One of the problems that I ran into with my son was that people were willing to help but they weren't willing to take responsibility. They were willing to do running around and that kind of stuff but nobody wanted to change diapers, nobody wanted to do that kind of stuff and nobody wanted to be left on their own with him ... so that was one of the main problems. People would help but they wouldn't take full responsibility. I couldn't just leave. One of us, my husband or I always had to be here.

To regain strength and energy to continue caregiving at home, many caregivers used hospital respite care services. They hoped that this service would lessen their responsibility and offer a much needed break from day-to-day caregiving. However, having the loved one in hospital only contributed to their work:

D: He was hospitalized three times in the last year, and for me as a caregiver, hospitalization was more work than having someone at home.

R: In what way?

D: I found I had to be more alert about his condition. I had to be conscious about what everybody else was doing for him as well as what he was or wasn't doing. I caught all kinds of mistakes such as missed medications. His last hospitalization I cleaned his room. You know, I took care of changing his bed, his clothes, bathing, all those kinds of things. And it's really exhausting when you're trying to get a break. But, you're whipping up there at lunch time, spending a couple of hours there, going back to work, going back to the hospital at night, walking the dog, and then going back to the hospital again. You are on this huge roller coaster that never seems to end.

Personal work

Caregivers of PWHIV/AIDS engaged in personal work while caring for their dying loved one at home. Three activities comprised personal work:

- *Reconciling* that a loved one will eventually die;
- *Making decisions* related to cessation of treatment;
- *Letting go* which is characterized by the struggle of wanting the loved one to live while realizing that they will die.

Reconciling that a loved one will die was a major component of the personal work involved in HIV/AIDS caregiving. Reconciling began when family members noticed a decline in the loved one's physical condition and the resultant perception that their loved one was dying rather than getting better. Often caregivers characterized reconciling as a series of stages or transitions. One mother compared reconciling to a similar process she weathered in finding out that her son was gay:

I think you go through stages. It's the same when you find out your child is gay. You can't believe it. Go, go get checked out and make sure you know what you're talking about is the first thing. Then you get over it. And then after a while you accept it. And I think it's the same thing with this ... knowing that he's dying.

All family members were able to resolve and accept the impending death of their loved one. However, getting through this stage was "hard":

You know, it's okay for somebody else to get sick and die but when this person is part of your life it's different ... so I didn't go into denial, but I certainly did not want to accept that he was going to die. I mean, nobody does. So I started this countdown. I was expecting him to die, but that was hard to face. Really hard.

It was very hard to watch that. Very hard. But at the same time I was prepared. I knew that J. was dying. I had accepted that and that made it alot easier to deal with. But as much as you prepare yourself and as much as you know it's happening, it's still very difficult to watch that.

Reconciling was also difficult when family members had little control over the situation, resulting in feelings of helplessness:

You are going through hell. I mean, you're standing everyday at the side of the bed of someone you love who is dying and you can't change it. There is nothing you can do. You can't sell your soul. They are dying, that's it. And you have to watch that and accept it.

Reconciling was made more difficult when their own beliefs about the death differed from that of others:

My husband did not believe that C. was going to die until six months before he did. He always used to watch the news and he'd hear about a miracle cure somewhere and he'd get so excited. He thought this cure was going to be it - it was going to save C ... finally he realized that C.'s body was too badly damaged. Even if they found a cure for

AIDS at that moment, it wasn't going to do any good. So it was difficult living with that. With one parent who is trying to go for every miracle cure and I had already accepted that he was going to die.

Another dimension of reconciling involved discussions between caregivers and their loved one about their past and present life together.

Discussions often focused on the "good times" that they shared:

We talked about all of the good times that we shared. Even when he was sick, there were reasonably short periods where he would go into a remission and we talked about how much good quality time we had together.

These discussions were possible because of the relationship shared between the PWHIV/AIDS and the caregiver. All shared close bonds with their loved one and cherished the time they spent together:

... it was really weird because here we were talking about this profound love that we had for one another and the commitment that we shared and we had never had those discussions before. I thought, wow, wouldn't it have been great if we could have done this all along. But we were having this conversation now and that's all that mattered.

Making decisions related to the cessation of treatment and **letting go** of their loved one were also components of personal work. For example, in many cases, family members struggled with wanting their loved one to live and at the same time, knowing that they were dying. Repeatedly, caregivers expressed their conflicting feelings about life and death:

I mean, I knew that he was terminal but the thing is that even if he was, if he just stayed sick, that was okay. Just don't die on me ... that

was what I was hoping for. Stay sick. I'll take care of you. We can bandage this and bandage that but just stay sick. Don't die on me.

Part of you wants him to go because then he won't suffer anymore and then part of you thinks that that is being selfish. So you try not to feel guilty because you want to see him go more quickly and then you can't sell your soul to make him better. There is no cure. There is nothing that can be done. He is going to die. So you have to accept it even if you don't want to. You can't have any pretence about it. It isn't fair. It robs you. It robs you and it robs them.

Making decisions, particularly related to the cessation of treatment for opportunistic infections, complicated caregivers' personal work. Being placed in the position of a proxy decision maker for their loved one contributed to the intensity of their work:

He had peritonitis and we talked about it and he said (the doctor), you've got to make a decision. It's up to you. Of course I didn't want to know about it. I didn't want to make that decision. I didn't want to know about it, didn't want to hear about it ... you know, the legal implications alone are phenomenal ... it's 100% responsibility ... I literally had control of his life ... I said, I think we should let nature take its course and stop the medications. That was the most difficult decision that I have ever had to make in my life. Very, very difficult.

Reconciling that a loved one would die and letting go of the loved one was a profound and difficult experience for family members. This experience was less complicated when family members were able to reflect on and discuss their life with the loved one, when they were aware of the wishes of their loved one, and when the loved one could participate in decision-making as one family member pointed out:

I knew what he wanted. We had talked about it long before he got sick. So, when the time came, there wasn't any problem really. We were very open and honest with each other. I held his hand and ran my fingers through his hair and I'd tell him, it's okay, you don't have to fight this. It's acceptable for you to let go. So it was easier because I knew what he wanted.

Pragmatic work

Caregivers of PWHIV/AIDS assumed the major responsibility for caregiving in end stage illness when loved ones were unable to do for themselves. Four activities comprised pragmatic work:

- *Monitoring and assessing* for change's in the loved one's health status;
- *Doing for*, including concrete tasks such as assisting with bathing, toileting, turning, medications, and various therapies including home intravenous (IV) therapy and skin and wound care;
- *Managing symptoms* associated with advanced HIV disease including pain, nausea and vomiting, diarrhea, dyspnea, and so on;
- *Coordinating care* which included interacting with the health care system, participating in decision making and advocacy, and organizing the PWHIV/AIDS health care.

Monitoring and assessing

Family caregivers vigilantly monitored and assessed the PWHIV/AIDS in an attempt to respond to the relentless changes in their loved one's health status. As caregivers noted changes, they decided on a course of action such

as calling the doctor, changing medications, or rushing the sick person to the hospital:

I noticed that everything was swelling out. His feet were swollen, his arms were swollen, his stomach was swollen and he was losing weight. And I watched him like a hawk and finally I called the doctor because I was sure he had peritonitis and sure enough I was right.

Sometimes, caregivers were able to predict imminent death after noticing changes in their loved one:

When he was first bedridden I knew that it was not going to be that long. Everyone said that he would bounce back and I said, no, he's not. And everybody thought he was going to get better so they actually pulled some of the help out ... but you see a pattern there and you know that it's just not going to last.

Caregivers often became "advisors" to others in similar situations because of the knowledge they had gained through their experience. While some caregivers did not feel confident or comfortable in this role, others viewed it as an opportunity to help:

... I said, J. is more ill than meets the eye. And sure enough, his partner started calling me almost daily because we had given him my history and he would call and say, "what do you think that I should do about this?" He's got a fever and it's really bad. Before I knew it, I was an advisor. And finally he called me and said this and that and I said, take him to emergency. I said, they may not admit him but take him anyway ... and sure enough he did and they admitted him and he never came out. But it was getting too much for him and I could see it.

The constant monitoring and assessing involved in HIV/AIDS family

caregiving took a physical toll on family members which contributed to their exhaustion:

It's just so hard. I can't sleep at night. It's like I've got a built in alarm clock. I have the monitor that I keep out here and if he turns over or anything, I can hear him. But yet, I'm so tired by the time nine o'clock comes around that I usually go to bed. And I wake up at 12, and I wake up at three, and I wake up at six. It's just like a built in alarm clock, to go in and check on him.

Doing for

Doing for encompassed the physical, concrete, pragmatic work of HIV/AIDS family caregiving. Caregiving tasks included acts such as preparing meals, house keeping, bathing, toileting, positioning in bed, giving medications, and more complex measures such as IV therapy and skin and wound care. Caregivers went to great lengths to accommodate and meet their loved one's needs. For example, family members took great measures to ensure that their loved one ate. Making "special foods" was perceived as a sign of love and concern for their ill family member:

I make him special puddings and things like that. Now he's cut down to soups. He used to like baked chicken but he can't eat that anymore so I just give him what he wants. I mean, I want to make sure that he eats something because it's important you know ... when I get the groceries I write down everything that C. really likes. Specifically put down what I want for him.

Another example of accommodating to the needs of a loved one was described by this family member:

He was in alot of pain. Very bad KS in his groin and edema in his legs so it was really difficult to get him around. But I accommodated him as best as I could. I can sew a little bit so I made these great big balloon pants with an elastic waist. He was just the envy of the cancer clinic.

Male caregivers were more prone to promoting independence than females who were involved in caregiving:

It's really a situation of trying to run the house and take care of him and trying to give him some feeling of independence at the same time. Like you know, I didn't want him to feel like I was taking care of him all the time.

Conversely, female caregivers were more likely to "do everything" possible for their loved one when faced with the realization that their loved one would eventually die:

I can accept that he is dying but it's just that I want to make him as comfortable as I can and I want to do everything for him. If I can get anything he wants I'll get it. Anything I can do I'll do because I know I'm not gonna have him that long.

Doing for also encompassed tasks such as continence care, giving treatments such as IV therapy, and managing medications. None of the caregivers in this study had previous experience in caring for a dying individual and many "flew by the seat of their pants." One mother described how she managed to get the "knack of things" in providing continence care to her dying son:

He couldn't get up to go to the bathroom so I put attends on him. At first I put them on at night but now I put them on day and night. At first when I put them on him he'd pull them down. What a mess his bed used to be in. And sometimes he'd dirty his bed. So now I've got the knack of putting them on so that the legs are pretty tight ... I got a shower curtain and cut it in half and pulled it the long way over his bed so now I can just change the underneath sheet. So it's just things like that that I had to figure out.

Even when faced with complex care issues such as IV therapy, caregivers were prepared to learn in order to fulfil the promise of caring for their loved one at home:

We had problems with his IV. It was constantly stopping or plugging up. And I used to get W. on the speaker phone and I'd be across the room all hooked up and say, how hard can I push on this thing? And one time I pushed and blood came out the other side of the catheter and oh great, you know. So it's a real learning process.

Providing home IV therapy posed particular challenges in communities where home care nurses were not certified in this skill. Nonetheless, one mother persevered in order to keep her dying son at home:

I learned how to do IV's at home cause the public health nurses couldn't do them and he did not like staying in hospital ... and it was really, really difficult but it was easier for me to learn how to do IV's than have him in hospital.

Managing and giving medications was another component of doing for. Family members feared that they would be unable to manage medications and were concerned that they would harm their loved one. However, as family members became more familiar and comfortable with medication management,

their level of confidence increased:

You have to really learn alot but it's not that difficult because you just sit down and learn it. Like he had bottles and bottles of medications when I first came. And it scared me because I thought, oh god, I'm never going to be able to remember all of this. There are a million different kinds ... so I had to figure out the difference. But when I first came, I thought I'll never. I'll probably kill him by giving him something I'm not supposed to for god's sake and he'll be gone. I had visions. I did. I was really scared for awhile but then you become quite good at it so I knew if he needed pain medication increased and when he needed breakthrough and so on.

Managing symptoms

Managing the symptoms associated with HIV/AIDS was another component of pragmatic work. Family members managed a variety of symptoms including nausea and vomiting, diarrhea, constipation, and behavior associated with HIV/AIDS dementia complex. However, family members repeatedly discussed their experience in managing their loved one's pain.

Family members often associated symptoms such as pain with suffering:

He was having an incredible amount of pain. He could not get comfortable, he just couldn't get comfortable. His stomach was so distended from whatever, in his joints and everywhere because his liver had failed and he was just bleeding and his joints were just swollen and inflamed and he was in an incredible amount of pain. Do you know what it's like for a mother to watch that? We just kept putting the Morphine to him until he went to sleep so that's probably what he died of.

Family members were greatly relieved when symptoms were controlled. The absence of pain and suffering helped one mother accept the imminent death of

her son:

He wasn't suffering near as much (as others) and so I sort of came to terms with it. As long as he wasn't suffering I was happy about it ... I just thank God that he is not suffering ... he's just so comfortable and I'm so pleased ... he's so relaxed. He's just waiting to go, just peacefully waiting to go. And I don't know, I'll be sad when he's gone, but I can be thankful that he didn't suffer the pain ... I know that it will help alot. You know, that he didn't go through that.

Ensuring that symptoms were managed was critical for family members in fulfilling their promise of keeping their dying loved one at home. Caregivers went to great lengths to manage the patient's symptoms in effort to prevent admission to hospital:

He was not in any pain but the itching drove him nuts, just nuts. It was so bad and of course the more he scratched, the worse it got. And then he got a secondary infection. I mean, I did everything, We had his head wrapped and everything. I said to G., I'll handcuff you (laughing) if you don't stop scratching. I mean we used everything. I had a pharmaceutical supply here ... it was so bad that they wanted to put him in the hospital but he did not want to go back to the hospital and I could do better. So, I learned how to give medications IV so that he didn't have to go back (to the hospital).

Even with adept symptom management skills, family members sometimes had difficulties, for example, with "catching up" to the pain:

I only lost control of it once ... all of the sudden it just took off the scale. I don't know what happened and I couldn't catch up to it fast enough using the formula. So I got him to the hospital and I said, his pain is out of control right now ... they brought it under control within 24 hours but they ended up giving him pretty wicked doses to get it in control. But, all of the sudden, the formula didn't work.

Coordinating care

Caregivers wanted some relief from their caregiving activities to avoid reaching the point of overload when they could not "go it alone."

Coordinating care was a less visible aspect of pragmatic work but required considerable time and energy:

I started to put these (services) together. I could get somebody to come in a couple of hours here and a couple of hours there so that I could go do the running around. It was a lot of work talking with all those people and arranging it all but eventually it worked out.

Caregivers often arranged help from either health care professionals, volunteers, friends, or other family members. Family members felt responsible for ensuring that helpers had straightforward, concrete information to enable them to partake in the caregiving tasks. Preparing this information was time consuming but necessary, and added to the work:

D: ... everything was laid out. I had one of those big dosette things with the lid on it.

R: You were well organized.

D: Well, I felt I really had to be in fairness to the people coming in because they are here for four hours a week. I had a different person on each day of the week in the day and it was me on the weekend. So I felt in fairness to them, everything had to be really laid out because people don't really know what the situation is. They don't live with it so it has to be really straight. So I had a big chart of all his medications, what they were and what the regular dose was and if it could be given extra and how much to give and this kind of stuff. And it really paid off to be organized. It made the arranging a lot easier if I had everything ready.

Family members were usually placed in the role of communicating to others about the PWHIV/AIDS condition, particularly as the loved one became more ill or less able to interact. A sister, caring for her dying brother, told how her role as a care coordinator included being a spokesperson:

Well he was having alot of pain and he didn't want to say anything but he was and I knew that because you do. It comes from being there with him all the time. And the nurse, she was great because she would sit down and say, "okay C., what are we going to do?" And I'd say this is what I think should be done and we'd toss it back and forth and she'd say, "yep, sounds like you know what you are doing." She realized that I knew what I was talking about. She saw that I was doing everything - managing the place, managing him, getting things all set up. I was her contact to find out what was going on.

Caregivers' knowledge reinforced their roles as spokespersons. They were constantly explaining and updating health care professionals, family, friends, and others on the condition of their loved one. Caregivers were sometimes worn out by the stress of explaining again and again their loved one's health status. Other times, caregivers found relief in talking with others about their situation. One mother, who had travelled from the east coast of Canada to care for her son, appreciated the contacts she had with health care providers, even though it meant telling her story repeatedly:

At first there were so many. The homemaker, the home care nurse, the physiotherapist. They all seemed to want to know the same thing. But it was okay because it sort of breaks up the day and gives me somebody to talk to about this whole thing.

In conclusion, work was identified as the central phenomenon in the experience of family members. To explain this work more explicitly, an analysis of the context in which this work occurs is provided.

Context

The work of caring for a PWHIV/AIDS dying at home occurred most often in the context of uncertainty and stigma. Feelings of *uncertainty* for family members arose from the perpetual and unpredictable changes accompanying HIV/AIDS. Uncertainty meant caregivers had little control over day-to-day events. Family members spoke about the rapid transformation in their loved one's health status and how difficult it was to predict what would happen next. Family members began to understand the unpredictable and uncertain nature of HIV/AIDS most often when faced with a situation in which their loved one was placed at risk. For example, one man described how leaving his loved one at home unattended resulted in some frightening implications:

... we were going for lunch and he didn't feel quite up to it. So he said, "you go, you'll only be gone for an hour and it's just down the street so go." So I went and when we got home he could barely breathe. We had to call an ambulance to take him to the hospital. So you know, I got a bit frightened by that and didn't want him left alone because that pneumonia just came on. He was just feeling a little bit queasy and an hour later he could barely breathe so it's pretty scary stuff.

Family members spontaneously characterized the constant changes inherent in HIV/AIDS caregiving as a roller-coaster. A roller-coaster, with its many ups and downs, reflected the lack of control caregivers experienced:

You know, it's one day at a time and be prepared for anything and then some. You don't make plans ... if we planned to get away for the weekend, no, there was a curve. It's just this huge roller coaster ride, it's a definite roller coaster. Up and down and up and down, and up and down. And you just, you're never stable. You never know what's going to come next.

The uncertainty of all of this has been the most difficult thing to deal with. Both of us were very much organized. Very type A - everything has to fit in this little box and be able to be put away ... and you just can't do that when you're dealing with this kind of illness. A number of business trips that I had planned had to be cancelled at the very last minute. Social things that we were committed to we had to call off or leave early ... so the unpredictability of it all was really difficult ... it was like this huge roller coaster that never seemed to end.

As mentioned earlier, some family members "knew" that the death of their loved one was near. This certainty allowed these family members to prepare and make plans for the impending death. However, uncertainty characterized even these situations:

The doctor put a big sign to not resuscitate on the fridge because he said, "I think he's going to die in the next couple of hours so I think I'll just wait here with you people." He waited and waited and he waited ... well C. didn't die that day. The next day he was feeling a little bit better and the next day even stronger. And we had called the funeral home and talked to the funeral director and said, "I think this is the day that he is going to die." A few days later, the doctor came to see how it was going and C. was sitting up in bed reading the sports page. And he remained very alert all week and then on Saturday he

died. But on Friday he watched the whole hockey game on TV. So you never know. I mean, we thought it would happen but you're just never sure.

Dealing with *stigma* was a major factor affecting the work of HIV/AIDS family caregivers. All participants experienced stigmatization in one form or the other either from relatives, health care providers, friends, or society in general. They had to deal with prejudice, loss of friendships and relationships, and living with secrecy. A mother talked at length about the stigmatization that her family experienced as a result of caring for her dying son in a small rural town on Vancouver Island:

A health care worker did not keep confidentiality and told her daughter about C. who was in my daughter's class at school. And for a year and a half, she blackmailed J. (daughter) saying, "if you don't give me this or that, I'm going to tell everybody." Eventually J. told us because it was a real strain on her. It was a real strain because there was all kinds of AIDS jokes going around.

We were told that the only way the boys could return to school was if they always carried a bottle of bleach and a green plastic garbage bag with them.

... and she had to be taken out of school ... she was physically and mentally harassed something awful and the school was not able to guarantee her safety. They did try but it was very, very difficult ... they escorted her from class to class and they escorted her to and from school. She hated it. She ended up being on medication because she was so terrified ... and she saved her money to buy a car and several times her windshield was smashed at school. There were things scrawled on the car. She was spat upon, and she was called faggot lover constantly, just constantly.

The incredible anguish felt by this family lead the mother to consider drastic action, something she had not disclosed before:

D: Actually I'll tell you something I haven't told many people. I know this is on the tape ...

R: I can shut the tape off.

D: No, it's okay. It's okay because I imagine other people go through it. At one point, this is going to make me cry, I had considered killing myself and my family. Isn't that a terrible thing to say? It just seemed that we were being inundated from everywhere.

Experiences of stigmatization were not isolated to caregivers who lived in rural areas; family members in large urban centres also endured the prejudice associated with caring for someone with HIV/AIDS. Even health care providers, due to a lack of knowledge about HIV/AIDS and the methods of transmission, contributed to experiences of stigmatization. Time and time again, participants told stories of home health care workers coming "dressed to the nines" to do tasks such as cleaning, cooking, and laundry. For example, one man described his experience with home help:

... I kid you not, the woman dressed completely in plastic. She had a plastic overcoat, she put plastic boots on, a plastic cap. I was waiting for a face mask but that never appeared ... she was folding clothes but with surgical gloves. I said, why are you wearing surgical gloves? She said, well, you know, it's an infectious disease.

Another family member described an experience where hospital workers' avoidance of the PWHIV/AIDS contributed to the pain of family members:

They always put him in isolation no matter what ... they didn't want to care for him. They were afraid. We always had to be there (at the hospital). One time we left and we came back and what a disaster. Soon after we had left he had woken up and had to urinate and he was hooked up to IV's and the sides were up on his bed so he buzzed the buzzer. And nobody answered and nobody answered and nobody answered. So he tried to climb out of bed and he fell ... By the time we got back, we were gone for an hour and a half, he had hypothermia. When we arrived, he was still on the floor and the buzzer was still on. The care is just horrendous up there ... so someone had to always be there.

Caregivers also experienced difficulties when other family members and friends found it hard to accept that their loved one was dying of HIV/AIDS.

Family members described devastating experiences when support was lacking:

We had some very close friends and they were very religious people and they said it was God's will and that we were being punished. So we didn't really realize how they felt until our family had been invited to a barbecue at their place just about the time they had found out about C. When we arrived we were presented with paper plates and plastic utensils ... Each time it happened we were devastated. We assumed wrongly that people - our friends - would accept this.

Caregivers suggested this lack of support accompanied the disclosure of either homosexuality or a diagnosis of HIV/AIDS. One caregiver talked about her families' reaction to her brother's sexuality and diagnosis of HIV/AIDS:

I think they had real trouble dealing with the fact that my brother was gay. He wasn't going to carry on the family name, he was gay, my god, what a terrible thing to do, and now he's going to die of AIDS. How dare you. It was, we don't want any part of it. So they weren't there for either of us. Didn't even call to see how he was doing.

The stigmatization experienced by this sister resulted in the loss of a relationship she shared with a man:

... he just had a fit. He said, you mean you touch him? You touch him without gloves? Well then he got really into a state of panic ... it scared him. It really scared him ... it caused alot of tension and it ended the relationship ... he was really afraid. I think the biggest fear was somehow that I was going to end up with it.

Stigmatization often lead family members to hide or keep "secret" the HIV/AIDS diagnosis. Fear of being shunned or pitied by others, of losing employment, or of protecting other family members resulted in caregivers being placed in the uncomfortable position of masking what was going on in their lives. A gay man, caring for his dying partner explained his feelings about hiding the cause of his loved one's illness:

I lied about the relationship. I just said it was my son. I said, my son is terminally ill and he's going to die ... I felt really shitty. I felt really shitty about that. But I knew I couldn't say anything about that so I felt really lousy.

Even when caregivers wanted to disclose the reason for their loved one's illness, they were often encouraged to "keep the secret" in an effort to protect others. Two mothers described their dilemma when others attempted to persuade them to keep the secret:

My own kids, some of them are hiding it ... they say it's cancer ... but I would (after he dies) want people to give to the AIDS society but how can you do that when your kids don't accept this? And I've talked to them and said you're just making a fool of yourself trying to cover it up ... I don't want to hide it. I'm not ashamed of him.

I remember when he was first diagnosed with full blown AIDS and we were very upset and we had asked the people at the hemophilia clinic

about telling the other two kids and they were really into secrecy at that point ... you try to keep it a secret as long as possible. God, that's hard, is that ever a hard thing ... we were told not to tell the kids. Secrecy is the hardest thing.

The personal and pragmatic work required by family caregivers, in combination with realizing their loved one was going to die, dealing with uncertainty, and facing the effects of stigmatization, was often overwhelming and exhausting for family caregivers. In response, family members utilized a variety of strategies to manage.

Caregiving strategies

Family members developed and utilized various strategies to assist in dealing with, managing, expressing or responding to the work of caring for PWHIV/AIDS. Strategies included *being with*, *getting out*, *maintaining balance*, *seeking support*, *working as a team*, *taking charge*, and *planning for death*.

Being with was a strategy used to express family member's commitment to care for their dying loved one at home. Statements such as, "I don't know what I'd do if I couldn't be with him", "It's just something I have to do", and "This is the place I had to be", all signify the importance that caregivers placed on *being with* their loved one. *Being with* made the work easier in three ways. First, the ability to *be with* and care for their loved one

helped family members to respond to the needs of the PWHIV/AIDS. Second, *being with* ensured that those with HIV/AIDS were well cared for, giving caregivers a sense of comfort. Often caregivers felt uneasy in allowing others to help with the work. For example, when family members sought support from health care providers, they felt compelled to "get right back":

... even when they are here I wouldn't be out all the time. I'd still be here ... I'd take the dog out for a walk maybe but I would want to get right back. You know, I don't want to stay out too long.

Finally, family members acknowledged that *being with* their loved one helped significantly in accepting that their loved one would die. Family members described the importance of spending time with the dying loved one because little time was left. Therefore, the strategy of *being with* was also used as an opportunity to spend time together to reconcile that a loved one would die. One caregiver pointed out the importance of spending time with his dying partner:

Every minute is important because you know what the end result is so that time is important to spend together ... it helps in the long run because imagine how you'd feel if you didn't spend that time. I would've been feeling really bad right now. But I spent the time with him. I was with him and that made it okay.

Getting out was a second strategy - it enabled family members to get a break from the constant and relentless demands of HIV/AIDS caregiving.

Getting out was comprised of activities such as going for a walk or going for

coffee or dinner with friends. *Getting out* allowed family members to continue their work:

... you know, I'd get out for dinner once in a while, just to get away from it. You know, to get a way from it for awhile. You just had to. How can you be here day in and day out and not have a break?

Getting out helped caregivers to cope with and express feelings associated with the caregiving situation. Caregivers often felt frustrated, sad, overwhelmed, helpless, and angry about their circumstances. Yet, they felt they should be upbeat and positive. Caregivers did not want to share their negative feelings with the PWHIV/AIDS:

Sometimes I just had to get out. I mean, things would well up inside me and I had to let it out but I couldn't do it in front of him. So sometimes I would get upset when he was down and I'd go walking, sometimes for miles and miles and I would bawl the whole way.

Some nights if his mom was here and the homemakers were here, just to get rid of frustration, I'd go to the Second Narrows Bridge and walk across it a couple of times ... just to get out, just to scream, to yell, to blow off steam.

Getting out was not always easy for family members. In some instances, those with HIV/AIDS did not want their loved one to leave them alone:

On one hand he would say, you need to get out. Go to the gym, go for a walk or go out for lunch with a friend. But if I did, he would say, what took you so long? So it was like that double edged sword. So the drift was, I don't want you to go any place. I want you here. That became very clear.

In such situations, getting out conflicted with the caregivers' work, so they would find ways to legitimize their *getting out*:

I stayed on with it (the support group) because it was my only connection. It gave me a reason to get out of the house. A legitimate reason.

Getting out was sometimes hindered by the family members' discomfort in leaving their loved one with someone else, especially when the family member lacked confidence in the skill of the relief person:

The service that we got was two days a week for two hours so I thought great, I can get out and do a few things because the whole idea was for me to be able to go out when they were here so I could get out for a break. Well, this guy just ignored everything I said and I came back later and said, look, this is not going to work. I mean, if he can't do what I need him to do then how can I leave?

When trusting relationships were formed with even one care provider, *getting out* was possible:

It's so important to have that person that you can trust. I mean, I didn't want to leave him with just anybody so I wouldn't. To trust them so that I could actually go out for a walk and say, I'm going out for a couple of hours and I wouldn't have to worry.

Maintaining balance was another strategy used by family members to deal with the work associated with HIV/AIDS caregiving. Family members tried to *maintain balance* between caring for themselves and caring for their loved one. Some family members were better at *maintaining balance* than others. Some were selfless at their own expense:

I was sick, and I'd broken my wrist. I was supposed to be getting physiotherapy but I didn't even have time to think about physiotherapy. I didn't even have time to think about me.

Family members worried about the consequences if they themselves became ill as a result of neglecting their own needs:

At that point I decided that I want whatever (support) I can get. I was running on nothing but adrenalin. I wasn't sleeping properly. I wasn't eating properly ... I was trying to get my energy up because I knew that if I went down, we were going to be in big trouble.

For this reason, caregivers sought to maintain balance. As much as some caregivers wished to be selfless, it was very difficult to suspend completely their own physical and emotional needs. A contradiction between altruistic intentions and the human needs of caregivers surfaced:

... you put your stuff on the back burner. You don't pay much attention to what you think or what you feel. Your whole focus just becomes making R. happy or doing whatever you can do make him comfortable, to make him happy. So, that's all you do. At that point, that's all I was doing. That's my entire focus. Everything else is secondary.

Maintaining balance was sometimes made difficult by the PWHIV/AIDS. One mother described her son's response when she told him she was going out of town:

... he was very, very upset with me. He had little shit fits about the whole thing. I felt guilty about it for a little while but I knew I had to go. He didn't want me to and that was hard. That was really difficult.

Family members learned to defend their own needs:

G. was very adamant. He didn't want anybody doing anything for him. He didn't want anybody in the house, you know, a stranger. He wanted me. He wanted me to do everything ... caregiving, being there 24 hours a day, just everything. And I was working and that made it worse and I wasn't sleeping and I thought, what about me? Well finally I told him, I just can't do this anymore. It's just too much. I can't do this all by myself. I need some help. So finally he gave in.

Seeking support was another strategy used by family members.

Seeking support assisted with personal work when caregivers were able to express the emotions and feelings related to their caregiving situation, and with pragmatic work when concrete support was found. Family members utilized both formal and informal support systems. Formal support systems included agencies such as home support and home nursing care. Help with laundry and house cleaning greatly alleviated the amount of work for caregivers, as did practical caregiving "tips." Family members appreciated the help they obtained from these agencies, especially when they developed a relationship with a consistent care provider they trusted:

I can talk to her about anything and she shows me different and easier ways to do things instead of me finding out for myself. Like turning him and that. And she'll explain to me about keeping him from getting sore. Anything I want to know. She says, just call if there's anything.

Formal support services also included support groups to deal with issues related to loss and grief and volunteers from HIV/AIDS service

organizations who would often stay with the PWHIV/AIDS while the family member tended to grocery shopping or other day-to-day activities required for caregiving:

I really think it's great (the support group) because they set a box of kleenex in the middle of the table and we can all tell our stories and it's just good to have other people.

... but they'll come in. One of them will come in and sit with him if I want so I can get out to do the shopping or go to the drug store or whatever.

Informal support systems included other family members and friends who were, to some extent, involved with and understood the caregivers' experience. Informal supports also included employers or acquaintances who had a "listening ear" and were understanding of the caregivers' situation. One man caring for his dying partner explained how his employer helped him to cope with his work:

I'm really fortunate in that my employer was incredibly understanding. There was never any question of me being able to take time off to facilitate his appointments ... I was incredibly well supported. I don't know how anyone could do it. I mean I would have had to quit or go on stress leave or something.

Another man talked about the support that he received from friends who were part of a care team that he had organized to care for his loved one:

The friends that were on the care team are still my friends and will remain my good friends for a long time. And I think they automatically supported me because they would stay with me for an hour after I got home (from work) you know, just stay and talk and see how I was doing.

There were times when caregivers failed to *seek support*. Failing to seek support stemmed from the caregivers' belief that they were placing a burden on others by asking for help:

... I haven't called on them because I know that they have their work.

You know, what I'm probably more concerned about is being a hell of a burden on somebody else more than anything.

Some family members managed their work by **working as a team**. By *working as a team* with physicians, nurses, social workers, home support workers, and other family members and friends, caregivers were able to feel more confident, useful, and supported in their work. *Working as a team* was a useful strategy for caregivers in two ways. First, as one family member simply explained, "two heads are better than one." That is, when caregivers and others worked together, they were better able to accomplish goals for the benefit of the PWHIV/AIDS. For example, the management and control of pain was an area where family members worked with others to accomplish the goal of comfort for the PWHIV/AIDS:

... you know, I could have a conversation with the nurse and say, well, he seems to be having a little more pain today and he's not too groggy. So then she'd say, "well we can do this and we can do that and what about this and what do you think?" You know, really working together. And then we'd talk about it and then I'd ask the doctor and well we would discuss it and he would say, well, Dilaudid as needed ... so that kind of participatory care is, I think really essential in a situation where someone is terminal and potentially in alot of pain.

A mother, caring for her young bedridden son shared with the researcher how *working as a team* enabled her son's last dream to come true:

... he said, "I want to see a Canucks game." And we thought, how are we going to do this? This kid is bedridden and we don't have any money anyhow ... and the home care nurse arranged it. She contacted the Canucks and got tickets for him and then she contacted his father's work and they arranged for a helicopter to pick them up and take them to the stadium.

Providing caregivers with an opportunity to gain acknowledgment and encouragement for their work was a second benefit to *working as a team*.

Often caregivers asserted that their work was not appreciated by others.

However, when caregivers used *working as a team* as a strategy to deal with their work, they often found themselves supported and valued:

His doctor at the cancer clinic was very much someone who believed in participating in care. This was a team effort ... it was the three of us sitting down in a room, her doing an examination and saying, these are the options. What do you think? And actually listening to me as if I was a reasonably intelligent being with an IQ higher than a salad fork. You know, that my opinion mattered ... so I think that's really, really important ... it makes the caregiver feel like they're not just changing the bed and getting someone to the bathroom. There is real value in your opinion.

A critical element of *working as a team* was the building of a consistent relationship based on reciprocal trust and respect. This trust and respect was particularly important when family members used this strategy with professional health care providers, some of whom were not used to the notion

of team work.

Not all family members used *working as a team* as a way to handle the day-to-day care for their loved one at home. Some family members were raised in a generation where "doctor knows best" and these family members preferred to be told by others what should be done. In other instances, caregivers were unable to relinquish and share control over their caregiving situation. However, the single, most often expressed reason for not *working as a team* was that others, specifically health care providers, were uninterested or impassive to engaging in any kind of participatory care. In these situations, family members employed the strategy of **taking charge**.

Taking charge was a strategy utilized by family members to initiate action or advocate on behalf of the loved one with HIV/AIDS. Caregivers found themselves having to *take charge* in situations where *working as a team* had failed, particularly in situations involving the health care and the social service systems. *Taking charge* was necessary when the caregivers' knowledge of the loved one's condition was disregarded or ignored:

I find it really frustrating that the people who were caring for him would quite often discount my opinion. And I had to really be firm and say, this is what I want to happen and this is what is going to happen before I would get a response.

Taking charge was also used when family members and professional

care providers disagreed. For example, when there were debates about treatment regimes and pain management, family members *took charge* in an attempt to ensure that their loved one received proper care. Because of their constant monitoring and assessing, family members usually noticed, more quickly than others, when treatment regimes and therapies required re-assessment or were not working. However, caregivers were not heard and they had to work even harder to obtain comfort for their loved one. One man described his difficulties in giving oral medications to his partner with severe dysphagia and how he had to *take charge* of the situation in order to facilitate a change:

He could barely swallow ... like why are you giving him oral medications? Why? It takes hours to get these pills down. Well, we are going to switch to IV now aren't we, so let's get moving. I mean, I'm telling him (the doctor) what to do. I had to otherwise nothing would have happened.

Taking charge was also used when caregivers witnessed inappropriate or potentially dangerous care situations:

I knew that she (the nurse) was doing it wrong and I said to her, you are doing that wrong and you are going to end up with air in his lung so don't do that ... I said, look, I want you to call and have somebody else to come and have a look at this because I know it's wrong ... now if I hadn't been there, he would have had a port full of air.

Taking charge was necessary when support services were causing more work:

I phoned up the agency and I said the two (home support workers) that

you sent down are not adequate and I explained why. I said, one is a social worker wanna be and the guy just wants to be a cook. I don't need a cook and I don't need a social worker wanna be. So can you send me somebody who is capable of cleaning without me having to be here because I find I have to be here. I'm not going away. I'm here. I'm watching them because they don't know what to do.

Another family member talked about the interference from a home support supervisor that necessitated him to *take charge*:

She kept wanting to come over here and supervise them. She didn't need to be here interfering with what was going on ... I kicked her out a couple of times ... there were control and power struggles. She wanted things done one way and I wanted them another. All that nonsense. And I ended up telling her to f-off and ended up getting another homecare agency. We fired that one.

Sometimes, staying in hospital created more work than having the PWHIV/AIDS at home even though the loved one was hospitalized for the sole purpose of giving the caregiver a break. In these instances where caregivers perceived hospital care as "intolerable" or "too much work", *taking charge* was a useful strategy:

The room was dirty, no one ever looked in on him, I had to bath him and change his bed, medications were missed ... it was an intolerable situation. So I said, I'm taking him home and she (the nurse) said, "you can't do that." No? Watch me.

Planning for death was a final strategy used by family members.

Planning for death included caregivers' actions to identify the wishes of their loved one in relation to death such as discussing advanced directives, living

wills, power of attorney, and planning for the funeral or memorial service.

Knowing their loved one's wishes gave family members confidence in their work:

It was easier because we talked about it right at the very beginning. He was quite adamant that there would be no heroic measures or anything like that so I knew what he wanted and I could carry that out.

Planning for death also helped to circumvent potential problems with other family members. More than half of the participants in this study were not related, by blood, to their loved one. As such, caregivers believed there was a possibility for interference and disagreement from the family of origin, even when the caregiver and loved one had shared a long-standing commitment with each other. One partner, caring for his lover, discussed how *planning for death* helped him avoid a potentially difficult situation:

... the only thing I asked him to do was, I said, you've told me but I want you G., to tell your mother. I said, I want that to come out of your mouth. I said, I don't want her to think that I concocted this. She's got to know what you want ... because we had had problems you know. So I didn't want to have to deal with more ... I had enough to deal with already without her down my back.

Some family members did not implement this strategy until days before the death of their loved one. Failing to *plan for death* in advance occurred mostly when family members had difficulty accepting that death was inevitable. However, once family members realized that death was near, this

strategy was employed:

... the doctor told me he only had a few days to live so I had to get my ass in gear. I had to get power of attorney. I had to get a will made up. I had to get all of that done because none of it had been done. Because I myself did not want to have to come to terms with it. I didn't want to have to come to grips with that.

Conditions influencing the caregivers' work

Strauss and Corbin (1990) define intervening conditions as the "broad and general conditions bearing upon action/interactional strategies" (p. 103). These conditions can be thought of as a broader structural context pertaining to the phenomenon (Strauss & Corbin). Three conditions had a direct affect on the work of HIV/AIDS family caregivers, and in turn, served to facilitate or constrain their strategies. They are, the structure of the health care and social service systems, the accessibility of services, and the nature of support. The interrelationship of these concepts are illustrated with a brief exemplar:

D. is working part-time while caring for his partner (J.) with HIV/AIDS. For the last month, D. has been receiving two hours of home support twice a week which he augmented with the help of friends and family members. J. is becoming more ill, requiring constant care. Additionally, J. has HIV/AIDS dementia which has severely altered his sleep patterns. D. stays awake all night to care for J., cares for J. throughout the day, and in the evening, goes to work at his part-time job. D. is at the point of exhaustion and is becoming ill himself. Therefore, he calls the home support agency and asserts that he needs help "now." The agency manager informs D. that he is not eligible for further home support hours. Because the system is not set up to deal with these situations (structure of the system), D. is unable to access further support (accessibility of services). Thus, D. takes J.

to the hospital emergency department where he is greeted by staff who ignore his opinions (nature of support) and inform D. that he will have to take his partner home because there are no beds available in the system (structure of the system, accessibility of services).

While it is acknowledged that the structure of the system, the accessibility of services, and the nature of support are closely interconnected, they are described separately for the purpose of this discussion.

The structure of the health care and social service systems

The structure of the health care and social service systems greatly interfered with the strategies used to manage the work of caring for PWHIV/AIDS. Caregivers repeatedly talked about rigid, impersonal, and demeaning systems that disregarded and diminished their experience and left little room for individualized, consistent, and compassionate care. Family members identified five issues that interfered with their strategies:

- A physician-dominated system;
- Multiple care providers;
- The rules and regulations governing home support;
- Limitations of respite care;
- Limitations of the social services system.

Family members had difficulties in dealing with a physician-dominated system. Waiting for doctor's orders (for such things as bowel care) and

witnessing hierarchy and power struggles between physicians and nurses, left caregivers frustrated and angry:

... you have to march to their drummer to have tests done or whatever else. You have to march to their drummer. And like, yeah, I've got all the time in the world to go home and come back at 3 o'clock. No I don't you know. It's a major effort to get him into the car and get him down here. For both of us. He was exhausted after a trip anywhere. But there's no flexibility. Everything has to run by their clock. Illness doesn't do that. It's terribly frustrating ... it's not a system that is built for this kind of care.

I have a lot of anger about the medical system and the social service system ... the medical system because of their real detachment from the patient as a human being and from the patient's caregiver as well ... just the impersonal nature ... the other side of it is the social services system that is so incredibly demeaning to people.

Caregivers described the need for a "new medicine" that actualized the interdisciplinary concept:

I think the system says that the doctor is god and the nurse is the, you know, TLC, I'll give you a back rub and this and that. I think some things have changed but there are still many people entrenched in the old beliefs ... so the new medicine has to involve everyone, not just the doctor. And it has to say, we have to listen to the patient and caregiver.

Caregivers also described problems with the numbers of different people they had to deal with. When care providers continually changed, coordinating care became a "nightmare" and contributed to the caregivers work. Each time that a new health care worker came into the home, family members had to teach, coordinate, and supervise them. One family member

aptly described this situation as the "revolving door":

For about two months we had a revolving door downstairs. We had public health nurses, we had some homemaker services coming in. It was just, everybody ... and they were all different. Never the same person ... just coming and going and coming and going ... it just, he felt really invaded. I felt really invaded. And let me tell you, how could I ever get a break when all these different people kept coming.

Situations of inconsistency were not isolated to the home situation:

... the (hospital) clinical teaching units, it's a joke. It's constant rotation. There is no consistency whatsoever and in most cases, no compassion because some of these people are just here to do their rotation in that section. Well, you're going to spend a month doing AIDS stuff, okay fine. And you know, it's renal the next month or whatever so there is no follow through. No consistency.

When the system was organized to provide consistent help, family members were able to develop trusting relationships with care providers. It was only when these relationships were built, that caregivers could truly get a break:

R: So you had the same person.

C: Yeah, which was really nice because he was so comfortable with her that it made me more comfortable ... I felt extremely comfortable. She was great ... she was very sincere and genuine. It wasn't an act you know ... almost like he was someone really special to her so it really helped me to get out and go for a walk or when I would lay down for a couple of hours I could actually sleep ... I don't have to feel worried that he's not going to get what he wants.

The way in which home support services were organized was also an issue. Generally, family members were appreciative of the help they received from these agencies. However, the rules and regulations governing home

support workers limited their ability to "take over" thus, posing barriers for family members who were trying to seek respite from their situations:

... no matter how much home care you get, I mean, the home support worker was really wonderful but he couldn't legally touch R.'s medications. If I went out the door, I had to leave all the pills in little cups with the times and I would have to leave syringes drawn off with MOS for breakthroughs and I'd say, if he needs a breakthrough, he can have that one at about that time ... so you don't have somebody who is going to come in and just do it. You have to leave all the instructions and all the rules. I had to lay all the stuff out ... it takes alot of time to organize, just to go out for a short time. It's hardly worth it so many times I didn't go.

Hospital-based respite care services also posed challenges for family members. More than half of the caregivers utilized respite care and revealed that it did little to relieve them of their work and often hindered the strategies they used to cope with their day-to-day life as an HIV/AIDS family caregiver. The inability to get a break was described as a major limitation of respite care by family members:

It was despicable. A horrible experience ... I spent an hour and a half with the nurse who interviewed me about all the things that needed to be tended to. Everything was written down ... so I left and went back at dinner time and I went into his room which was right across from the nurses station and he's sitting up in bed and he's bleeding. Like blood is trickling down into his food. And they didn't even know. They had no idea he was bleeding into his dinner ... nobody had checked on him since I left.

... when I came back the next day, he was in bed and I sort of looked at his face and his entire forehead was burnt. Burnt ... it was black. It was not just red, it was black and it was burnt. Burnt, singed. I

mean, it was a mess ... he's got dementia and they knew that but obviously somebody handed him some silver nitrate sticks to stop the bleeding. He doesn't know a silver nitrate stick from a toothpick. He wouldn't know what to do. He's never used it. He had no idea.

One caregiver explained her experience with respite care in a small rural hospital:

... I got a phone call from him about 3:30 in the morning ... he had thrown up in the middle of the night all over his bedding ... he buzzed the nurse and the nurse stood by the door and said, "what do you want?" And he said, "I've thrown up here and I need clean pyjamas and clean sheets." And she said, "I'm not doing that, you can wait until housekeeping comes in the morning" and she threw him a towel. She wouldn't enter the room. So I had to go up. We always had to change his bedding and we always bathed him when he was in hospital ... the hospital here is quite dreadful.

When asked if able to get a break while using respite care services, one family member replied accordingly:

... I didn't (get a break) because I always had to be there to supervise because if I wasn't, he wouldn't get the care.

The social services system also interfered with the caregivers' strategies. Caregivers had problems obtaining financial assistance to pay for their loved one's medications, transportation, dental work, and basic living expenses. Advocating and lobbying the social services system proved time consuming and energy draining:

We had to go through this whole big rigamarole to get him on general assistance first, and then apply for handicap status ... they can't take handicap status away once it's granted according to the law so it's

impossible to get. You've got to be fighting this and fighting them. Fortunately we were pretty political and got things pushed through but it's just a lot of extra energy.

Caregivers and those with HIV/AIDS felt humiliated at having to constantly ask for money:

... but there was always this sense, no matter what he needed, he had to go to a social worker and ask. Like if he had dental problems - at one point he had to have a crown done and it was an argument to get the crown down ... to get that money. To have to ask for it continually or apply to a social worker who just couldn't care less or just doesn't know what's going on. It's just so humiliating.

However, caregivers appreciated when social service providers were prepared to "break the rules":

I had a good rapport with his financial worker. A heck of a nice guy. And one of their financial workers had died of AIDS so they were really clued into the whole aspect of it you know. They had seen it and worked with it. So they had a lot of compassion where a lot of other offices wouldn't ... but he knew how to bend the rules to cover the costs ... he knew how to bend the system to cover the costs.

When sympathetic social services workers could not be found, family members learned to "cheat" and "fight" the system:

You have to be careful. To them, I was his landlord and he was living here as a roommate and I had to give him rent receipts to take in. If they had done that (withdrawn financial assistance), we would have been screwed. His medication bills were over one thousand dollars a month. There is no way we would have made it. So the insensitivity of the system, the sensitivity is just not there.

... I'm advocating constantly for things. Sometimes you just feel like you're banging your head up against a wall. It's just a constant battle.

And that shouldn't be because you're dealing with enough issues and you're dealing with stress and all the other things without having to constantly fight, constantly fight the system.

One caregiver summarized his optimistic attitude for the future with a few words of advice:

I think I'm seeing some changes ... I know that there are some improvements being made ... but if you want people in the community rather than in the hospitals, and most people would rather be at home, then make sure the services are there ... people who can do things. People who can make decisions. People who can let the caregiver have a break ... the system has to realize that the caregiver can't go on at that level, at that pace for that length of time. It's just too much of a stress on an individual.

Accessibility of services

HIV/AIDS family caregivers live in a world of uncertainty in dealing with the unpredictable nature of HIV/AIDS. At times, when the ill person's condition deteriorated quickly, family members required prompt intervention and support from health care providers. In situations where the caregiver also became ill or exhausted, prompt access to health care services was critical in allowing family members to fulfil their promise to keep their loved one at home. If home services were easily accessible, this prevented the PWHIV/AIDS from being hospitalized. The presence of a palliative crisis response team provided prompt access:

... the palliative care nurse had been in, filled the syringes, checked on J. and an hour later I listened to his breathing and I went, "oh, oh." I

gave her a call and she was back here in 20 minutes to give me the Atropine I needed. Because I phoned her and I said, "T., I need it, his breathing has started." And she said, "I'm on my way." And it was just, you know, that quick.

Prompt service, from a concerned home care nurse who was off duty, enabled this family member to be with his partner at the time of death:

... the doctor was getting panicky because we couldn't get a nurse. Finally A. (the nurse) phones up and said, "I've been thinking about you guys all day and just wanted to know how you were doing." I said, "we're desperate for a nurse. We can't get a nurse. There is nobody." He said, "I'll be over in 5 minutes." And he was there in like 3 minutes. I don't know what we would have done otherwise because I couldn't handle it myself.

Prompt access to health care services was only achieved when the system was set up to facilitate this or in cases where health care providers were willing, able, and flexible enough to give of their time and support. In most instances, caregivers experienced problems accessing services when most needed:

... the people that you really needed were the ones who were sort of doling it out bit by bit but it was like, I need help and I need help now. Not next week. He may not even be here next week. I mean, it was this kind of situation.

The rules and regulations governing the health care system posed barriers to prompt access. For example, one family member whose partner was near death, was advised by a home care nurse to call long term care to arrange for 24 hour nursing care. The response from long term care did little to ease the caregivers' need for immediate assistance:

I spoke to this woman and she said, "well you know, we don't usually have 24 nursing care until the last 72 hours." And I said, "who the hell needs somebody in the last 72 hours. I need somebody now. And besides, who the hell knows when the last 72 hours begins ... I said, I need help now ... he's got dementia, he needs personal care, he's bedridden, and he's probably dying.

The nature of support

Family caregivers of PWHIV/AIDS sought assistance from a variety of sources including health care and social service providers, volunteers, organized support groups, and other family members and friends. The most frequently mentioned characteristic of the support received was in terms of the personal nature of the individuals contacted. Caregivers defined support as "good" in relation to individual people that they came in contact with. Caregivers used many words to describe the qualities of those who offered supportive help such as nurturing, caring, sensitive, flexible, available, committed, capable, compassionate, and knowledgeable. Several caregivers explained the importance of these qualities in assisting them to manage their work:

I want somebody who is compassionate and understanding and knows what this is all about ... it helps me you know, to know that they are caring about him.

... he was wonderful. He was really good you know, very reassuring. Like, I'll take care of everything, don't you worry.

They finally sent me this woman F. and she was perfect. She came in and said, "you must be D." She looked in (the bedroom) and G. was sleeping and she said, "that's G." And she said, "you can go now - Just show me your cleaning stuff." And I left and when I came back 4 hours later, the place was, I couldn't believe it. It was like dynamite. It was amazing, just amazing ... she was a real sweetheart and she wasn't worried about, you know, catching it (HIV/AIDS) or anything.

Caregivers appreciated when their hard work was recognized and acknowledged. Caregivers often felt that they were not recognized for their contribution to the loved one's care. The feeling that "nobody understands" permeated the life of many caregivers. One caregiver articulated his need to be acknowledged:

I need to be nurtured and I need to be patted on the back and told, you're doing a good job.

When acknowledged, family members felt a sense of personal worth in knowing that their work was not in vain:

She (the nurse) told me I was doing a good job - that I was taking good care of him. I really appreciated that. I appreciated that someone noticed what I was doing - that somehow it was important.

Another caregiver talked about the reinforcement that he received when he took his partner to the hospital emergency room:

I was in with the nurse and she agreed with everything I said ... she told me I had kept a good history of everything. And then the doctor stuck his head around the corner and said, "can I talk to you?" So he took me back into their room and he said, "this is amazing." ... he really reinforced what I was doing. That I was taking good care of him.

Caregivers also required support in facing the impending death of their loved one. One family member asserted that without good counselling support, his work would have been unmanageable:

... I don't know how we would have done it without them (the social workers). They were our backbones ... but they were so flexible ... that support was probably the most primary. That was the best support we got. It kept us upright ... I don't know what we would have done without it.

When asked to explain how this support was helpful, this caregiver elaborated:

She (the social worker) told me the lovers tend to be forgotten. And her focus was, if you fall apart, what the hell's going to happen ... she saw an integral part of her job is to keep the partners reasonably healthy. We get supported so that we can continue to look after our lovers at home. So they were fabulous.

Support from the family of origin was also important to caregivers.

Some participants had estranged relationships with both their own and their loved one's families, mainly due to homophobic attitudes. There were cases where caregivers received no support from the family of origin. Some families were able to get past their feelings to support the caregiver, often after recognizing the level of commitment that the caregiver and partner shared. Sometimes this support was not forthcoming until after death. Nevertheless, caregivers appreciated and were often surprised when they received this unexpected support:

I think one of the biggest recognitions I got from my parents, particularly my mother. She said, "you've gone through something I hope I never have to." ... She said, "I don't want to have to go through what you have gone through - you are remarkable." Coming from my mother, whoa ... That was real good ... it's the acknowledgment you know. The full acknowledgment of what I did and of our relationship. That our relationship was as significant as any straight couple's relationship.

At times, caregivers experienced emotional pain and felt rejected and isolated when those they believed would offer support did not. Caregivers were saddened and disappointed, especially when the loved one's family was unsupportive. One man, caring for his dying partner, explained an experience that left him feeling alone and unsupported:

Probably for the last year and a half his family was not there. It was really disappointing. Really disappointing ... I kept phoning his mother and saying, "you know, he's not doing well, he's sick, he sleeps alot, he's losing weight, so you should come and see him." So she said she would come ... but she never did come down. So I phoned her again and she had some excuse but she finally did come down. But, afterwards, she never phoned ... she was really removed. That hurt alot. How could a mother not come and see her own son? That really hurt me.

Another caregiver talked about the little support that he received from his parents after the death of his loved one:

We had very little contact really. In fact, there were no flowers or no card or anything specifically about, we're sorry for your loss. I got a thinking of you card a couple of weeks after he died but certainly not what I saw from them when my sister's husband died ... you know there are phone lines between the provinces and there are also airplanes but you know, there was never any offer of coming out so I was disappointed by that.

Finally, one caregiver talked about the anger she felt when a long-time family friend did little to acknowledge that her son had died:

What we were very disappointed in and we have never recovered from it is what we consider to be our best friends, and J. had worked with him for 20 years and we all spent alot of time together over the years but they never called the whole time C. was sick and we would call them and they would not return the phone calls and they did not attend the funeral. And they never ever mentioned C.'s death. And J. is really, really angry about that and so am I. This is not how your friends are supposed to act.

Interactions with unsupportive individuals occurred most often with those with whom the caregivers came in frequent contact - physicians, nurses, social workers, and in some cases, volunteers. Caregivers repeatedly reported devastating experiences with health care providers that left them feeling angry, bitter, isolated, and disillusioned. For example, one caregiver described a shocking incident where his partner was sexually abused by a physician. This experience created immense difficulties for the caregiver in seeking support from other sources because the level of trust in health care providers was destroyed. In other cases, caregivers sought support from health care providers who were unwilling to respond, often in crisis situations. To illustrate, one mother recalled a horrifying experience that she had in dealing with an emergency response team when her son attempted suicide:

... about 4 months before he died, he tried to kill himself with an overdose of Morphine and sleeping pills ... within an hour he started to

throw up ... that was one of the hardest things because when he took all those pills my husband was actually at work and I didn't know what the hell to do ... so I phoned the emergency response team because I didn't know what to do and the emergency response team said they couldn't help ... what I needed was somebody to talk to. Somebody to sit with me while this was happening. Here my son was trying to kill himself after reading that damn book (Final Exit) and all the emergency response team could say was they couldn't help?

Caregivers of PWHIV/AIDS made assumptions that health care providers would be supportive, but the nature of support provided to family members often did not meet their expectations:

We went to see a social worker and I felt really good about this because I knew we needed this and it would help, but the woman was hopeless. She does not belong working as a social worker with AIDS patients at all. She has no understanding. She's very good at shuffling papers but as far as dealing with people on an emotional level and a supportive and psychological level, she is pathetic ... we were looking for a little bit more nurturing and that was never, never forthcoming. It never came ... I mean, I had no one. I was at my wits end.

I was profoundly disappointed in the level of care at what is supposed to be the primary AIDS facility in this province. I heard the nurses say things like, "oh, his partner is here and he's taking care of everything so you can ignore that one." No you can't. I'm not paid to be here doing this job ... I appreciate that there is some level of comfort and respect there, but at the same time, you need to be in here checking on him too and making sure that we are both okay.

Two different family members explained how their hopes for support were dashed when seeking support from community health services:

When C. was first diagnosed our family fell to pieces and I knew we needed help. I didn't know where to get the help so I phoned mental health and got an appointment. We went up to see them and they said,

"no, we are not equipped to deal with AIDS." That was it - they couldn't help us.

This woman (volunteer) called me from hospice and she wanted to know how I was doing. Well, I said, "I'm not doing that well today. Today is my birthday and birthdays were really big for G. and I." She said something that sort of triggered something inside me and I started crying. As soon as she heard me crying she said, "well, I'll let you go now, you take care of yourself," and then she hung up. Take care of myself? Why did you call? What did she expect? I mean, I told her that I was profoundly lonely and I started crying and she hung up on me ... so I was sort of left wondering, is this what they do? I didn't even get a chance to say goodbye. She said, "you take care of yourself and have a nice day," and then click, she hung up. She hung up, she literally hung up on me.

Another family member talked about receiving a sympathy card from the palliative care unit where his partner had been admitted for respite care:

They sent me this card that was like a going away card or a bon voyage card. All these first names of people that I didn't know who the hell they were. There was nothing personal. And the real kicker that added the most insult to injury was that there was a post-it note that was stuck inside the card that had not been removed. It said, G.C., died at home, D.M. partner. It should have been taken out. It was like, here, take the card and pass it along.

Finally, one caregiver, who was a nurse, talked about the difficulties he experienced when seeking support from other nurses on a palliative care unit:

I think health care professionals providing support to health care professionals forget that they are family - that they are there just to be there. I think there is an assumption that those of us who are health care professionals can bear the weight a bit more ... so they tended not to do alot ... I think they need to be more sensitive with health care professionals.

Family members attempted to make sense of why health care providers were unsupportive. Some family members suggested that care providers did not want to work with HIV/AIDS patients while other hypothesized that they felt uncomfortable in dealing with issues related to homosexuality:

You could just tell they just didn't want to be there ... their heart wasn't in it, you know, in this kind of care.

She seemed really afraid of us, like somehow we were totally different. In addition, family members mentioned things such as reduced staffing levels, heavy workload, disciplinary power struggles, and few opportunities for debriefing after stressful work incidents, as possible reasons for unsupportive behaviours. Family members often noticed that care providers were under extreme pressure and stress in their work environments. Family members stressed and acknowledged that professional care providers were unable to be supportive because they were not supported themselves:

Unfortunately, the majority of the nurses in the hospital are terribly overworked and they don't have time to spend with patients because the staffing is horrendous. Most people are aware that the staff isn't there like it used to be and there is a lot of reliance now on family and friends to do things.

Sadly, family members spoke about the level of burnout they witnessed and about the need for hospitals to be more responsive and sensitive to their staff:

I feel really sad about watching the level of burnout because there are not enough of them (nurses). They are exhausted. None of them are

debriefed after somebody dies. That process isn't there. They are burnt. The level of burnout I saw was incredible ... you know they have to take care of themselves and the employers need to make sure you do that which they don't. It's like production line mentality. No good.

Consequences

The strategies used by family caregivers to cope with their work resulted in several consequences that affected them personally and affected their bereavement. The consequences of caregivers' experiences were most clearly related to the strategies pertaining to support although all of the strategies were closely intertwined. For example, when caregivers were able to seek support, they were also better able to use the strategies of being with, getting out, taking charge, maintaining balance, working as a team, and planning for death. When they used these strategies, caregivers felt a sense of pride in what they had accomplished:

Nobody can take away from me the pride that I feel in having cared for him. And I know for a fact that there are a lot of families that turn their backs and you know, I just have a lot of feelings of pride that I didn't do that. That the one time that my brother most needed me, I didn't panic and run and that's a good feeling, a really, really good feeling.

When caregivers were able to build supportive networks with care providers and others, they were better able to find meaning, and make sense of their loss and the experience that they endured. Often caregivers expressed

how the experience helped them to learn new things about themselves:

It was a learning experience. It was a spiritual growth experience and you realize that you have a lot of inner fortitude. I mean, I always had a lot of patience but I didn't realize just how much patience I had. You develop and hone so many skills and you learn so much about yourself and what you are really capable of withstanding.

Additionally, family members talked about how the caregiving experience changed and made a difference in their lives and how they viewed the world:

I suppose that when you come through that whole experience and the whole experience leading up to that final experience, you develop a certain profound sense of something. I know that I definitely came out of it a different person. I came out of it with a different sense of life.

This world view often included a renewed sense of inner strength, spirituality, and a strong belief in life after death:

I developed a tremendous amount of spirituality that I never had before and as I said, an inner fortitude and strength that just wasn't there before.

Our spiritual paths will cross again, you know, at some point, on some other plane and on another level. I never used to think that but now I'm convinced. I'm convinced that our paths have crossed before. I'm convinced that things just don't happen, they happen for a reason. There is always a reason why things happen.

Their strength led these family members to assimilate their experiences and make constructive changes in other aspects of their lives:

I'm more accepting in some cases. But, in other cases, I am willing to make changes you know, outside myself. If I don't like the way things are happening, I'm willing to be a shit disturber to make changes whereas before I would have just complained and done nothing.

I've become less of a person to put up with bullshit. I will not tolerate a lot of what I used to. I get to the centre of it - I get to the core of it.

Positive consequences also occurred when family members were able to be with their loved one at the time of death and acknowledge the love and commitment they shared:

I consider myself really fortunate. I'm fortunate in the sense that I was loved and I was able to love someone so profoundly. I'm fortunate that I was there to say goodbye to him and hold him when he died. Not too many people have that opportunity. I mean, I was blessed and I was very fortunate and I'm thankful and I'm grateful for that.

... it was one of the most loving things that we could have ever done for a child - was to look after him until he died. We were able to be with him and say everything that we had to say to him. That's the best possible thing.

Those who were able to seek support that was meaningful were also able to re-emerge to face life without their loved one:

I'm not going to lay around and mourn. I have a lot of good memories. I had a lot of people to help me to see those good things, you know, they were part of the death experience if you will.

Conversely, when family members were unable to obtain supportive networks, they often felt angry, isolated and alone, disillusioned, mistrusting, and expressed that they would never again place themselves in the position of being a primary caregiver to a PWHIV/AIDS. These family members experienced more difficulties with their bereavement period and thus, were more challenged to find any kind of meaning in their situations. Caregivers described how the lack of support left them feeling cynical and skeptical about

a system that is supposed to be designed to support the caregiver:

I think I'm a lot more skeptical, a lot more jaded perhaps. I certainly don't have the respect for the medical community that most people do. My confidence level in the whole system is really, really poor. I just don't trust anyone.

... rose coloured glasses no longer exist. When you look at the world, you look at the world in general. You know, you try to smell the roses and all those kinds of things but you realize after this that the shit that goes on is really evident. The people that you have to deal with, it's just such a problem so I don't expect that that support will be there anymore.

Others felt disillusioned when they realized that the system was not as

supportive as they originally believed:

You develop this real sense of disillusionment because you are brought up to revere the system and have this blind faith in them but it doesn't work out and then you're left feeling really let down and disillusioned about it all.

We've always been brought up to believe that the medical establishment would do the best and that was what we were raised believing in. Like the government and others wouldn't screw us around and the medical establishment.

When useful support could not be obtained, caregivers felt isolated and alone

in their caregiving experience:

I don't know how the hell I went through that. It was just a fucking nightmare. Just a nightmare ... and I had no one, I mean, no one to talk to that could understand.

They seemed stuck in their grief and resentments:

What I find right now is I just get these overwhelmed periods of, it just sort of comes rushing back. Like I find myself going over conversations that I've had with doctors and how I should have insisted on this and how angry I was with them ... and I can't think about anything else at this point except that.

It just kind of replays in my mind ... it's all those things that happened with those people (health care professionals). It's all those things and all those conversations that keep replaying in my mind. You know, that emergency room guy that I'd like to run over with my truck a few times. And that's going to be a long time until I deal with that anger never mind my own stuff about his death.

These negative memories of the experience often lead family members to resolve to avoid similar situations in the future. Some partners of PWHIV/AIDS vowed that they would never enter a relationship with an HIV positive man. One partner, for example, now asks for evidence of HIV status before engaging in any kind of relationship.

Summary

Caring for a dying loved one at home with HIV/AIDS produced extraordinary challenges for family members. Work (personal and pragmatic) was the core phenomenon identified by family members who were caring for those with HIV/AIDS. This work was caused by the caregivers' promise to fulfil the wishes of their loved one. Caregivers lived in a world of uncertainty and stigma and developed various strategies to cope within this context.

Strategies were affected by conditions such as the structure of the health care and social service systems, the accessibility of services, and the nature of support. Conditions and strategies resulted in several consequences that either helped or hindered the caregivers' bereavement. Because of their experience, some caregivers felt relief when it was all over:

There's a real sense of relief when it is all over. There's really a sense of relief because it's so stressful. It just, it becomes your entire life. And it's work. It's work from every point of view. No matter how you look at it or how much you love the person. When you stand back and look at it objectively, it's just so much work.

Chapter 5

Discussion

The purpose of this study was to explore the day-to-day lives of family members providing care to persons with advanced HIV/AIDS who were dying at home. The data analysis revealed a number of salient findings that are summarized as follows:

- Work (personal and pragmatic) forms a major component of caregivers' experiences when caring for a loved one who is dying at home with HIV/AIDS.
- Throughout their caregiving experiences, family members live in a world of uncertainty and stigma.
- Caregivers utilize a variety of means (strategies) to cope with their workload, but the central one relates to the nature of support that caregivers of PWHIV/AIDS receive.
- Family members require individualized support from consistent and compassionate care providers with whom they have developed a trusting relationship.
- The structure of the health care and social services systems and their accessibility, affect the caregivers' ability to care for their dying loved one at home.
- Caregivers who were supported in their work were better able to cope with their bereavement; those who had little support, experienced difficulties.

These findings will be discussed under four headings. They are: (1) The importance of the work involved in informal caregiving; (2) The context of HIV/AIDS work; (3) Social support; and, (4) Outcomes.

The importance of the work involved in informal caregiving

The findings of this study identified that work (personal and pragmatic) characterized caregivers' experiences. Work is conceptualized in this study as the experiences, actions, and behaviours that are associated with caring for someone with HIV/AIDS at home. As early as 1944, Lindemann used the concept of work to describe the adjustment of family members following the death of a loved one. His term "grief work" delineated the behaviours that family members used to detach from the deceased and re-adjust to life following the loss of a loved one. As individuals engage in work following the death of a loved one, it is appropriate to suggest that family members engage in work prior to the loss as well (Martens & Davies, 1990).

Several papers in the literature also describe the concept of work as an accurate portrayal of the experience of caregiving. The concept of work as applicable to illness management is supported by literature, mainly related to caregivers of persons with advanced cancer, chronic illness, and the elderly. Fewer studies could be found that relate specifically to HIV/AIDS caregiving. Many of the studies refer specifically to pragmatic work while fewer refer to personal work.

Pragmatic work

Ward and Brown (1994) speculate that care at home for PWHIV/AIDS

involves substantial amounts of work. These authors identified housework and personal care tasks as two major categories of work. Similarly, Turner, Catania, and Gagnon (1994) found that informal caregivers to PWHIV/AIDS engaged in both domestic and personal care tasks. These findings are similar to a British study that examined the role of informal carers in supporting gay men who have HIV-related illness (McCann & Wadsworth, 1994) and to a U.S. study which describes the task difficulty and time demands of HIV/AIDS caregivers (Clipp, Adinolfi, Forrest, & Bennett, 1995). The conclusions found in these papers support findings from the current examination with the exception of household work which was not identified since several caregivers accessed home support services that provided house cleaning services.

Studies of caregivers of the elderly suggest that family members engage in providing 24 hour care to meet the extensive physical and mental needs of their loved ones (Lindgren, 1993). Bowers' (1987) paper on intergenerational caregiving refers to preventive and instrumental caregiving which further supports the concept of pragmatic work identified in the current study. Studies on caregivers of persons with advanced cancer and chronic illness also delineate and refer to pragmatic work. Martens and Davies (1990) studied the work of spouses in managing advanced cancer at home and suggest that family members engage in surviving and helping work which are similar

to pragmatic work. Furthermore, Corbin and Strauss (1988), in their detailed description of the concept of work within the context of chronic illness management, defined illness work as the actions that address the loved one's physical and emotional comfort. Parallels between illness work and the work of caregivers in the current study can also be drawn in relation to pragmatic work.

Personal work

Only one HIV/AIDS family caregiving study described the personal nature of the caregivers' work. Brown and Powell-Cope (1993) described "facing loss" as the caregivers' ability to confront the reality of eventual death of the PWHIV/AIDS and to begin to accept the impending loss. These results are similar to the subcategory of reconciling in the current study and also concur with anecdotal information on the experience of HIV/AIDS caregivers (Martelli, Peltz, Messina, & Petrow, 1993; Pohl, Kay, and Toft, 1990).

Studies on caregivers of those with advanced cancer and chronic illness also refer to personal work. "Taking stock" was identified by Martens and Davies (1990) as a term referring to the sharing and discussions between family members and their loved one about their past life together. Similarly, research on caregivers of persons with a chronic illness (Corbin & Strauss, 1988) suggest that caregivers engage in biographical work which corresponds

to the personal work that caregivers in this study engaged in to face and come to terms with their loved one's illness.

The context of HIV/AIDS work

Both uncertainty and stigma were factors that affected and invaded the lives of caregivers of PWHIV/AIDS.

Uncertainty

Feelings of uncertainty in HIV/AIDS caregiving had a profound affect on the day-to-day lives of caregivers. The unpredictable disease trajectory of HIV/AIDS coupled with the uncertain future related to loss and death characterized the uncertainty that caregivers felt. Uncertainty has been studied primarily in relation to experiences with chronic or life-threatening illnesses (Mishel, 1988; Mishel & Braden, 1987; Mishel and Braden, 1988), breast cancer (Hilton, 1988), and HIV/AIDS (Brown & Powell-Cope, 1991; Gordon & Shontz, 1990; Weitz, 1989). Gordon and Shontz identified uncertainty as a major theme in their hermeneutical inquiry that examined living with the HIV virus. Weitz found that uncertainty in the lives of those with HIV/AIDS focused on living with dignity, short-term functioning, and the prognosis of HIV/AIDS. Given the uncertainty experienced by PWHIV/AIDS, it is not surprising to discover that similar concerns about uncertainty were prevalent among family members in this

study. In fact, in a grounded theory study, Brown and Powell-Cope (1991) reported uncertainty as the major phenomenon that influenced and invaded the lives of HIV/AIDS family caregivers.

While uncertainty has been noted in other caregiving situations, such as cancer, it is a relatively unexplored concept in the family caregiving literature. Research about caregiver uncertainty suggests a relationship between uncertainty and the health of caregivers (Stetz, 1989), uncertainty associated with the outcomes of therapies (Blank, Clark, Longman, & Atwood, 1989), and the uncertainty and unpredictability associated with caring for the cognitively impaired elderly (Wilson, 1989). Much of this research is focused on the uncertainty of the illness itself which is similar to findings in this study in that caregivers often were unable to predict outcomes due to the unpredictable illness trajectory associated with HIV/AIDS. In this study, uncertainty in HIV/AIDS caregiving also pertained to the dying process. Even though some caregivers thought they sensed that death was near, this prediction was unfounded when the PWHIV/AIDS' condition suddenly changed for the better. This change often left family members more uncertain about when death was coming. Brown and Powell-Cope (1991) also emphasized that caregivers of PWHIV/AIDS experience an element of uncertainty related to loss and dying.

Stigma

HIV/AIDS family caregivers had to deal with social stigma related to the disease. A plethora of literature exists that reports on the discrimination and negative societal reactions against people with an HIV diagnosis (Herek & Glunt, 1988; King, 1989; Longo, Spross, & Locke, 1990; Tiblier, 1987; Worden, 1991). It is no wonder then to find that caregivers of PWHIV/AIDS also live with the stigma associated with HIV/AIDS.

Caregivers were often judged harshly and were targets for prejudice and harassment. Furthermore, the loss of close friendships, relationships, and conflicts within the family of origin were reported. The extension of stigma to significant others has been described in HIV/AIDS family caregiving literature (Geis, Fuller, & Rush, 1986; Giacquinta, 1989; Siminoff, Erien, & Lidz, 1991). Powell-Cope and Brown (1992) termed "guilt by association" as the stigma and discredit that significant others are obliged to share because of their close relationship to the stigmatized person. In their study on "going public" as an HIV/AIDS family caregiver, these authors described how family members let others know they were caring for a PWHIV/AIDS. Specifically, going public included a description of the tremendous personal suffering experienced by caregivers which was associated to HIV/AIDS stigma in the form of rejection, loss of friends, and harassment. In addition, studies of the

mentally ill (Wahl & Harman, 1989) suggest that stigmatization can have considerable negative consequences for family members. For example, Wahl and Harman noted that family members of the mentally ill experienced difficulties from stigma, including disrupted relationships with other family members and friends, and an unwillingness to disclose the loved one's diagnosis. The consequences of stigma identified in these two publications are also apparent in the current study. Findings from this study revealed that caregivers of PWHIV/AIDS suffer tremendously with issues of stigma that involve harassment, rejection, and the loss of relationships with friends, the family of origin, and significant others.

Walker (1991) implies that the secrecy that is attached to HIV/AIDS in families is a direct reflection of societal views that stigmatize the PWHIV/AIDS. For many caregivers, losing someone to HIV/AIDS is a socially unspeakable loss. The stigmatization that family members experience often influences whether the caregiver will tell or keep secret their loved one's health status. Family caregivers in this study talked about "keeping the secret" as a way to manage the stigmatization associated with being an HIV/AIDS family caregiver. Fears of being shunned or pitied, of losing employment, or of violating other family members, pervade the lives of family members in this study. Attempts to hide a loved one's diagnosis are well supported in

discussions about HIV/AIDS caregiving (Dick, 1992; Kubler-Ross, 1987; Martelli, Peltz, Messina, & Petrow, 1993; Murphy & Perry, 1988). For instance, according to Walker, family caregivers often refrain from disclosing their loved one's health status for fear of being rejected and to protect others in the family. Similarly, Geis, Fuller, and Rush (1986) found that lovers of those with HIV/AIDS often kept secret the diagnosis of HIV/AIDS for fear of being stigmatized by others.

It was discouraging to hear how stigmatization lead to substandard care for caregivers and their loved one. Although none of the studies on HIV/AIDS family caregiving identified this particular component of stigma, considerable attention has focused on health care provider's reluctance to provide care to those with HIV/AIDS due to negative perceptions of gay men and PWHIV/AIDS (Kelly, Lawrence, Smith, Hood, & Cook, 1987), fear of contagion (Dworkin, Albrecht, & Cooksey, 1991) and discomfort in working with the terminally ill and gay population (Sherer, Haughey, & Wu, 1989). In addition, studies of nurses' experiences in caring for PWHIV/AIDS suggest that those with HIV/AIDS and their family members may receive less care than others who are diagnosed with a chronic or life-threatening illness (Feinblum, 1986; Plant & Foster, 1993).

Social support

Caregivers in this study frequently described encounters with the health care and social service systems where their needs were unmet. The complex interplay between the structure of the system (how it is organized), the accessibility of services (the ease at which caregivers can obtain meaningful support), and the nature of support (the people), all were identified as conditions that greatly affected the support that caregivers received. A fundamental principle of palliative care is that the patient and the family together comprise the unit of care (Health & Welfare Canada 1989a). Yet, in this study, caregivers repeatedly recalled experiences that left them feeling unsupported. Support is a concept that has been used loosely in health care literature to denote the existence, quantity, and type of interpersonal relationships (Norbeck, Lindsey, & Carrieri, 1981), the functional context of these relationships (Kahn, 1979), and the perceived quality of this support (Weiss, cited in Dimond & Jones, 1983). Definitions of support are numerous. Thus, for the purpose of this study, *social support* is used in its broadest sense.

Family members in this study generally obtained support from the health care and social service systems and from other family members and friends. The nature of support from the health care system was a major issue

for family members. It was important for family members to develop positive and trusting relationships with health care providers in order to successfully cope with their work and face the impending death of their loved one.

Without this, caregivers experienced difficulties throughout their bereavement period. Research conducted on individuals with chronic illnesses supports that "reciprocal trust" is a necessary component of satisfying effective health care relationships (Robinson & Thorne, 1988; Thorne, 1993). Furthermore, research on palliative care patients with HIV/AIDS (Health & Welfare Canada, 1989b) argues that psychological support and interpersonal relations are paramount in meeting their needs. If these kind of relationships are necessary for those with a chronic illness, it would seem logical to suggest that the same is true for family members who care for those with chronic conditions.

The relationship among HIV/AIDS family caregivers and health care providers remains relatively unexplored. However, a few studies confirm the difficulties that family members face in their interactions with the health care system. Geis, Fuller, and Rush (1986) documented that lovers of PWHIV/AIDS who interact with providers in the health care system have encounters that generate "passionate disrespect" for the medical community and widespread anger over a wide range of issues. Greif and Porembski (1988) found that impressions of health care professionals by the significant others of

PWHIV/AIDS varied greatly from gratitude for their helpfulness to anger because of the way that they were treated. Furthermore, in a study of bereaved partners of PWHIV/AIDS, caregivers had to develop specific strategies to learn to deal with those in the health care system (Ferrell, 1992).

While a paucity of research exists to address the needs of family members who provide care to PWHIV/AIDS, considerable attention has been given to family caregivers of persons with cancer, Alzheimer's disease, and chronic illness. Hasselkus (1988), Hinds (1985), Hull (1991), and Morgan and Zhao (1993) all suggest that caregivers desire positive, open, and sensitive communication with their family members' health care providers. Findings from these studies lend support to this research in that participants frequently described supportive health care providers as sensitive, caring, available, and flexible. Additionally, caregivers who were able to work as a team with health care providers were more empowered and confident in caring for their loved one. This finding is supported by research on both caregivers of persons with cancer and those with Alzheimer's disease that suggest that caregivers tend to feel more empowered to care for family members when they are viewed as important members of the health care team (Hasselkus, 1988; Lovejoy, 1986). Lovejoy (1986) supports another salient finding in the current study: the need for family members to be acknowledged by health care

providers for the work that they do. When acknowledged and recognized for their work, family members felt a sense of personal worth and were empowered to continue in their caregiving situation.

Caregivers of PWHIV/AIDS used in-home supports and respite care as a method to gain support and get a break from the relentless demands of HIV/AIDS caregiving. While these supports are designed to promote the well-being of the caregiver, these supports did little to alleviate the work of family members. In-home support, provided by home support workers, only helped when the caregiver and worker could develop a trusting relationship. However, this was difficult given the large numbers of different workers with whom the family member came in contact. Moreover, the rules and regulations governing home support worker tasks (ie. medication management) interfered with the caregivers' ability to get relief. The literature suggests that care at home is the most desirable option for those with HIV/AIDS and their caregivers (AIDS Shelter Committee, 1990; Carney, 1990; Johnson, 1995; Ungvarski, 1989) and while the researcher believes this to be true, no empirical data could be found to support this belief. What is evident from this study however, is that further investigation is required to determine if and how these services are meeting the needs of both those with HIV/AIDS and their caregivers.

During the past decade, there has been considerable research on the impact of respite care programs on caregivers of the frail elderly (Burdz, Eaton, & Bond, 1988; Gilleard, 1985; Lawton, Brody, & Saperstein, 1989; Wan, Weissert, & Livieratos, 1980). Scharlach and Frenzel (1986) reported that respite care contributed to improved physical and mental health of the caregiver, better relationships between the caregiver and loved one, and increased confidence in the caregivers' ability to continue in the caregiving role. Additionally, this evaluation suggests that caregivers are immensely satisfied with the concept of respite care and its effects on their well-being. Anecdotal reports also suggest benefits to respite care (Cumming, 1993). In the current study there were drawbacks to receiving institutional-based respite care. Caregivers who used these services found that they were often unable to get a break, particularly after experiencing unsupportive incidents with health care providers and when their expectations for care differed from what the institution was able to provide. Although no studies could be found that explicitly support this phenomenon, Allen (1983) found that staff caring for more permanently institutionalized elderly, have limited time for, and give low priority to respite clients. Furthermore, Callahan (1989) argued that respite care has no impact on caregiver distress and that these services do little to support family members.

Another reason caregivers experienced problems with respite care is that they often found it difficult to stay away from their loved one. Caregivers of the frail elderly also spend inordinate amounts of time with their loved one, even though the purpose of respite care is to provide caregiver relief (Deimling, 1992; Knight, Lutzky, Macofsky-Urban, 1993; Petchers, Biegel, & Snyder, 1991). Toward this end, Beresford (1989) and Cumming (1993) assert that staff must be fully supportive and committed to the principles of respite care.

In this study, it became evident that positive support from the health care system was paramount for family members in dealing with and managing the work involved in HIV/AIDS family caregiving. When support was lacking, caregivers hypothesized about the reasons. Family members suggested that some care providers may not want to or feel uncomfortable with caring for those with HIV/AIDS. Their conclusions are supported in studies of health care providers' willingness to care for and attitudes about caring for those with HIV/AIDS. Nurses who were most experienced in HIV/AIDS patient care, employed in high-prevalence hospitals, and who considered themselves most knowledgeable about infectious diseases, consistently were less willing to provide nursing care for those with HIV/AIDS (Kemppainen, St. Lawrence, Irizarry, Weidema, Benne, Fredericks, & Wilson, 1992). In

addition, surveys have shown that students in the health professions and practicing nurses and other health care providers hold negative attitudes about individuals diagnosed with HIV/AIDS (Dworkin, Albrecht, & Cooksey, 1991; Bliwise, 1991). These authors posit that an unrealistic fear of contagion and a resistance to working with those who are infected are possible reasons for these negative attitudes. Others have found that negative attitudes toward homosexual men contribute significantly to attitudes about HIV/AIDS patient care (Bennet, DeMayo, & Saint Germain, 1993; Kelly, 1988).

In the current study, family members also suggested reduced staffing levels, heavy workload, and a stressful work environment as possible reasons why health care providers were unsupportive. Again, these conclusions are supported by the literature. HIV/AIDS hospice workers experience various types of work-related stress (Slone & Stephany, 1995; Strathdee, Flannery, & Graydon, 1994; Van Servellen & Leake, 1994) coupled with demanding ethical issues such as treatment issues, confidentiality, and suicide and euthanasia (Gold, Jablonski, Christensen, Shapiro, & Schiedermayer, 1990; Kuhl, 1994; Morissette, 1990; Ogden, 1994). Family members in the current study submitted that support for care providers, working with caregivers and those with HIV/AIDS, is critical. Although social support is not a panacea for work-related stress, evidence suggests that social support can ameliorate the

effects of stress in nursing (Mohl, Denny, Mote, & Coldwater, 1982).

Moreover, research on the quality of worklife of nurses found the highest ranking item identified by nurses as a supportive work environment (Attridge & Callahan, 1987). Finally, caregivers also suggested that those who do HIV/AIDS work may not be supported by the organizational structure within which they work. Several nurse administrators, academics, and others have emphasized the need for supportive work environments to assist staff to deal with the stressors associated with HIV/AIDS patient care (Brewington, 1994; Rose & Catanzaro, 1989; Perreault, 1995; Sowell & Lowenstein, 1988; Valdiserri, 1988). One author poignantly summarized the need for this caring environment by stating:

The caring environment that nurse administrators develop must be a reservoir of concern, compassion, and openness. It should be an environment where nurses can feel protected. This caring environment can become a source of support - a safe place where the AIDS epidemic cannot chisel away the core of the caring ethic (Brewington, 1994, p.28).

Outcomes

Findings suggest a critical relationship between the support that family members receive and their ability to successfully manage their work. Some

family members decided they would "never do this again." These family members lost confidence and trust in a system that they blindly assumed would care for their needs. These people vowed to never again engage in a close relationship with somebody dying from HIV/AIDS. They were those who were unable to seek appropriate support and felt isolated, angry, disillusioned, and alone. As a result, these caregivers experienced difficulties in making sense of their experience and of the loss that they had incurred.

Social support appears to be a necessary component for bereavement resolution (Broadhead, et al., 1983; Vachon, Sheldon, Lancee, Lyall, Rogers, & Freeman, 1982). Rolland (1990) noted that in HIV/AIDS family caregiving, the process of family coping with bereavement is severely compromised by societal stigma, and a lack of support that fosters isolation. Those who serve as primary caregivers may experience the actual loss of their loved ones invisibly, without the traditional acknowledgement that can be helpful in bereavement (Geis, Fuller, & Rush, 1986; Raveis & Siegel, 1990; Tiblier, 1987). Findings from the current study suggest that appropriate support from health care providers and others was paramount in aiding caregivers to reconcile their losses and find meaning in their situations. Murphy and Perry (1988) found that bereavement for caregivers of PWHIV/AIDS can be complicated by the lack of usual support and sympathy

received from others. Further evidence notes that appropriate support from health care providers may positively influence the bereavement outcome in those who have lost a loved one to HIV/AIDS (Ferrell & Boyle, 1992; Lennon, Martin, & Dean, 1990).

An understanding of the importance of social support provides an explanation for the differences in outcomes related to how HIV/AIDS family caregivers managed their work. This study, and others, demonstrate that supportive networks are essential and contribute to the caregivers' ability to effectively manage their work, find meaning in their situations, and make sense of their loss. Caregivers who were able to find meaning and make sense of their loss felt a sense of pride in their accomplishments, experienced a renewed sense of inner strength, and were able to make positive life changes based on their experience. They felt they had learned from their experience.

Limitations

The results of this study add to knowledge about the experiences of HIV/AIDS family caregivers. There are, however, some limitations that must be acknowledged. The quality and depth of the data may be limited by the researchers' novice experience with the research process and specifically with data collection and analysis techniques. However, the process provided the researcher with valuable learning to incorporate into further research

endeavors. Limited time and financial resources also precluded conducting a second interview with each of the family members who participated in the study. However, the analysis was validated with two participants, with two family caregivers who were not part of the study, and with nurses (some of whom were HIV/AIDS caregivers themselves) at a national HIV/AIDS conference. These individuals provided valuable direction for the further development of the concepts that were identified from the data.

Family members who agreed to participate in the study may represent a select sub-group of the population of family members who are affected by caring for those with HIV/AIDS who were or had died at home. Consequently, the findings of this study are limited to describing these participants' perspectives. It would be inappropriate to attempt to generalize the findings of this study to a larger population of HIV/AIDS family caregivers and to do so is not the intent of the researcher.

Finally, family members reported much anger and disillusionment in their experiences with health care providers. These family members may have been experiencing acute grief reactions to their loss. Hence, the findings must be viewed with this consideration in mind. However, it is equally important to acknowledge that this does, in no way, diminish or make the experiences of caregivers any less relevant or important.

The limitations described above must be taken into consideration when evaluating the results of this study. Nonetheless, the findings and conclusions drawn from this work have resulted in the identification of issues for nurses to consider when providing support and care to family members of PWHIV/AIDS.

Chapter Six

Implications for Nursing

The intent of this grounded theory study was to examine the experiences of family members caring for their dying loved one at home with HIV/AIDS. The findings of this study revealed that HIV/AIDS family caregiving was an intense, emotional, and powerful experience. It was an experience filled with pride and enrichment, or, conversely, with anger and disillusionment. Coping with the extensive demands of HIV/AIDS family caregiving required considerable time, energy, and commitment that often went unrecognized and unsupported. This was disheartening given that the researchers' clinical experience has shown that nurses working in HIV/AIDS and palliative care have the ability to provide skilled and sensitive care to their patients and families. However, the stories told by caregivers illuminate a critical need to look beyond preconceived notions of the "gold standard" of care that we think we are providing. Findings reflect a significant need for interventions designed to, (1) provide direct and effective support for HIV/AIDS family caregivers, enabling them to better cope with the stresses of their role; (2) continue providing urgently needed home care for persons with HIV/AIDS; and, (3) face death and find meaning in the loss they have experienced. Failure to address the needs of caregivers is not only morally

and ethically unacceptable but also demonstrates a myopic view of the caregivers' experiences. The richness of the caregivers' stories and the impact on their lives cannot be denied and their situations demand creative, professional solutions.

Placing the implications into context

Throughout the study, it was challenging for the researcher to bracket her personal views and feelings. An analysis of what is reported elsewhere in the literature, combined with the researcher's clinical experience and with findings from this study lead the researcher to a strongly held perspective of what might be required in health care to ease the work of HIV/AIDS family caregivers. Therefore, the implications that derive directly from the findings of this study are differentiated from the opinions of the researcher that are gained through other knowledge sources (ie. existing literature, clinical experience).

Care delivery systems

Implications from the study

Caregivers of PWHIV/AIDS utilized a number of programs and support services, particularly when they became ill themselves or when the caregiving responsibilities became unmanageable. Findings from this study suggest that caregivers experience difficulties in accessing consistent and prompt service

from the health care system. Family members indicated that prompt response in crisis situations was an important feature in the delivery of health care. In this study, prompt service was possible only in communities where services were specifically designed for these purposes. Otherwise, caregivers were able to promptly access services only when health care providers were flexible enough to respond. The inclusion of a community crisis response team in the continuum of care to PWHIV/AIDS would be a way of supporting caregivers through difficult times and in enabling the caregiver to continue to care for their loved one's at home as they promised. This type of community-based program, one that responds to the urgent needs of caregivers, has a great potential to alleviate the work of HIV/AIDS caregiving, prevent hospital admission, and reduce overall health care costs.

Family caregivers also articulated their frustrations when health care was delivered by various providers both in the home and in the hospital. As well, findings suggest that resources were often inconsistently matched with what the family member required. These findings suggest a need to evaluate the current staffing systems to allow family members to be matched with a consistent care provider. In addition, health care providers must also make the extra effort to ensure the best possible fit between the resources and the patient and family member. A family that receives unsuitable or unsupportive

services might reject the entire concept of care and support and perceive the experience as yet another example of failure of the health care system to meet their needs. It is imperative that health care providers explore families' expectations for care as well as assess their specific needs. In this way, health care providers can ensure that services are closely matched with what the family expects and needs.

Findings show that when caregivers are considered part of the health care team, and are supported by team members, they are more likely to be empowered and successfully utilize their strategies to cope with the work involved in HIV/AIDS caregiving. By building collaborative partnerships with their patients and families, health care providers are better able to identify the individual needs of caregivers and recognize and acknowledge the hard work that caregivers do. Thus, a multidisciplinary team approach would be useful for all aspects of HIV/AIDS care, and must incorporate a philosophy where the patient and family are the unit of care.

Finally, several family members described dreadful experiences in receiving palliative respite care. Respite care was only helpful in situations where caregivers were truly able to get relief from the constant demands of HIV/AIDS caregiving. Those who manage respite care services must ensure that the staff have a good understanding of the philosophy and principles of

respite care. A strong philosophical statement with clear program goals and objectives would help staff to understand the purpose of respite care. Similarly, if staff are involved in the development of the respite care program, they may be more likely to embrace this concept and fully actualize it.

Personal perspectives

Currently, this province promotes an integrated model of care for those with HIV/AIDS. While there are some advantages to this approach (Morrison, 1993), more than a decade has passed and it appears that the current model does little to relieve the relentless demands of caregiving and often contributes to a fragmented approach to care. A re-structuring of the current model is urgently required to ensure that caregivers and those with HIV/AIDS are well supported throughout their experience. It is likely that a centralized model, composed of two interlinked programs, would be helpful in supporting those infected and affected by HIV/AIDS throughout the illness trajectory, particularly (and realistically) in large urban centres where the HIV/AIDS epidemic is prevalent. Two components of this centralized model include an HIV/AIDS acute inpatient unit, and a dedicated HIV/AIDS community-based facility that incorporates palliative and long-term care, respite care, day programs, home support and home nursing care, and a community crisis response team. This centralized model would allow a more consistent

approach to care and would ensure that the unique challenges facing those with HIV/AIDS and their caregivers were met and supported by a team of individuals committed to excellence in HIV/AIDS care.

There are a number of salient features that must be considered in delivering health care to those with HIV/AIDS and their caregivers, regardless if the system is centralized or not. First, program planning must involve all stakeholders including representation from the HIV/AIDS community. Formal links must be established among hospital programs, community-based programs, and home. The provision of comprehensive care will be attained only if the relationship among these services are fluid, dynamic, and free of territorial issues.

A second aspect to consider in providing comprehensive and consistent care to those with HIV/AIDS and their caregivers is the development of a case management system. Given that family members reported difficulties in accessing consistent and prompt service from the health care system, it behooves us to implement programs that will provide care regardless of where the patient and family are in the health care system. A case management approach (Littman & Siemsen, 1989; Wright, Henry, Holzemer, & Falknor, 1993) that breaks down the walls between hospital and home is necessary. Without such a system in place, care will continue to be inconsistent,

fragmented, and unsuitable to meet the needs of those with HIV/AIDS and their caregivers.

The operationalization of a primary nursing model for both home-based and institutional care would also be helpful in alleviating the frustrations that family members reported in receiving inconsistent care. A primary nursing model, and possibly permanent shift assignments, would ensure that PWHIV/AIDS and their caregivers received consistent and comprehensive care. This model also allows nurses time to develop therapeutic relationships with their patients and families, ultimately creating a partnership built on reciprocal trust and respect.

Standards for the delivery of care to PWHIV/AIDS as well as a clear mission statement and program goals are another essential component in developing HIV/AIDS programs (Sullivan & Mills, 1990). A clear, consistent, and explicitly stated agreement among all staff on the goals of treatment for HIV/AIDS will ensure a common approach and feelings of support from one another (Flaskerud, 1987a).

Finally, the concept of respite care and how well it works with the HIV/AIDS population needs to be explored. If the family is unable to get a break, what is the purpose of having respite care? Evaluation of respite care and other HIV/AIDS related programs is imperative to ensure that the

programs are truly meeting the needs of the population. Thompson (1992) suggests that those involved in the delivery of health care programs must consider program evaluation as a critical element in the program planning and development process. Recent emphasis on health care reform coupled with increasingly vocal consumer groups has resulted in a strong emphasis on the importance of program evaluation (Johnson & Olesinski, 1995). Program evaluation therefore, is pivotal to understanding program effectiveness and/or efficiency, for improving program and service delivery, and for guiding resource allocation and policy development. As such, a comprehensive evaluation of programs geared toward those with HIV/AIDS and their caregivers is key to improving, changing, and expanding the services provided.

Educational preparation

Implications from the study

We are well into the second decade of the HIV/AIDS epidemic and it is clear that there continue to be significant knowledge gaps with respect to various aspects of HIV/AIDS care. The results of this study revealed that there are fundamental gaps in both technical and interpersonal skills that affect symptom relief and therapeutic relationships between nurses and those they care for. Nursing education (both undergraduate and continuing) must address

these issues to ensure that nurses are well prepared to face the challenges of providing skilled and sensitive care to those with HIV/AIDS and their caregivers. What is evident from this study is that a combination of technical and interpersonal skills, as well as acceptance of the PWHIV/AIDS and family members, are critical elements in preparing nurses who are competent to face the challenges of HIV/AIDS care. Such competency is essential if nurses are to develop relationships built on reciprocal trust.

Findings suggest that reciprocity and reciprocal trust are essential in developing effective relationships between health care providers and family members. The development of reciprocal trust was essential for family members in seeking support and respite from their daily caregiving demands; the development of reciprocal trust was dependent on the nurses' technical and interpersonal skills. That is, when nurses could competently provide skilled and sensitive care to PWHIV/AIDS and their caregivers, a relationship built on reciprocal trust was established. Thus, it is critical that nurses are taught to understand the relationship between technical and interpersonal competency and reciprocal trust.

Findings also revealed a critical need for nurses to not only have the technical skill and interpersonal knowledge, but also the ability to reflect on their practice. Alexander (1994) suggests that nurses play a crucial role in

supporting family caregivers and those with HIV/AIDS. However, for nurses to be supportive, they must be able to recognize their own ability or inability to interact in a meaningful way with family caregivers. Self-reflective practitioner's are able to realize the implications of their actions and the effect that they have on others. One way to develop nurses' self-reflection skills is to provide them with opportunities to discuss their actions in a non-threatening environment. Nurse educators can facilitate the development of self-reflection skills by using real-life case examples and debriefing sessions to help nurses think about the way in which they practice. Students can also be encouraged to develop self-reflection skills. The use of learning journals that encourage students to reflect on personal values, beliefs, and experiences while caring for PWHIV/AIDS and their caregivers would be a useful inclusion into HIV/AIDS curricula. In addition, nursing education, both for student and practising nurses, must provide nurses with the opportunity to explore and reflect on their personal feelings regarding HIV/AIDS contagion, sexuality, and death and dying.

Education for nurses working in the community or in hospitals must also address HIV/AIDS and the unique experiences that family members face in their caregiving role. It was apparent from this study that nurses require a better understanding of the role of respite care in helping to alleviate the

demands of HIV/AIDS caregiving. Ongoing, continuing education through seminars, workshops, and inservices must address the concept of respite care and its importance to the caregiver. Staff education and development must also be geared toward gaining a broader understanding and perspective of HIV/AIDS and its consequences on the PWHIV/AIDS and the caregiver. Given nurses extensive workload and time demands, creative methods for delivering this information must be developed.

Personal perspectives

HIV/AIDS presents challenges to nursing education. These challenges arise from our lack of clarity about what should be taught at the undergraduate level and in continuing education programs. The question is, how do we develop nurses to effectively care for those infected and affected by HIV/AIDS, and what needs to be included in this education? Formulating a community think tank that includes PWHIV/AIDS and their caregivers, nursing educators, clinicians, administrators, researchers, community-based organizations, and others is essential to answer these questions. However, there are some key elements that are critical to consider in developing both undergraduate and continuing education programs for nurses.

Undergraduate education

Knowledge of the medical, psychological, and social consequences and

ethical dilemmas of HIV/AIDS must be integrated in its entirety into the curriculum of beginning students (Flaskerud, 1987b). In other words, HIV/AIDS education cannot be combined throughout other course work, but rather, must be taught in its entirety. The development of a nursing curriculum which provides a solid theoretical foundation for understanding the multiplicity of issues facing those with HIV/AIDS and HIV/AIDS family caregivers is imperative. Basic knowledge of virology, epidemiology, universal precautions, and disease transmission must be combined with relevant learning experiences that illuminate the psychosocial and ethical consequences resulting from HIV/AIDS. Additionally, opportunities, such as meeting a PWHIV/AIDS would help to promote an acceptance of those with HIV/AIDS and their caregivers. What is critical throughout these learning experiences is the emphasis on interpersonal skills and the ability to develop therapeutic relationships with patients and families.

Death education and palliative care are also essential elements to incorporate into undergraduate HIV/AIDS education. Degner and Gow (1988) argue that the inclusion of death education in nursing curricula is integral to helping students conceptualize the complexity of issues facing those with a life-threatening illness and their family members. Nurse educators must seek out and maximize clinical learning opportunities to enable nurses to develop the

clinical and interpersonal skills to care for individuals facing loss and death. These learning opportunities are best suited to students who are in the final year of their program and are able to incorporate and assimilate their knowledge of helping relationships, concepts of death, loss, and grief, and the physiologic, psychologic, and emotional processes involved in caring for those with HIV/AIDS and their caregivers.

Continuing education

Some American authors have suggested mandating HIV/AIDS education (Brewington, 1994). While essential baseline knowledge and skills (ie. universal precautions) are necessary, it has been the researcher's experience that unless health care providers are motivated toward caring for those with HIV/AIDS and their caregivers, mandated education is often worthless. Staff members must want, desire, and choose to work in HIV/AIDS care. However, the researcher has also observed that staff who do not desire to care for PWHIV/AIDS often hold negative attitudes and unjustified fears about homosexuality and disease transmission. Studies on the knowledge, attitudes, and practices of nurses in HIV/AIDS care suggest that knowledge has increased but has not changed attitudes and practice (D'Augelli, 1989; Damrosch, Abbey, Warner, & Guy, 1990; Scherer, Haughey, & Wu, 1989). Continuing education programs therefore, must be developed, must address

negative attitudes and fears as well as baseline knowledge, and must be supported by the institution, both philosophically and financially. Flaskerud (1991) proposes a three-tiered psychoeducational model that is devised to address nurses' knowledge, clinical skills, and attitudes. The addition of interpersonal skill development would strengthen this model and could prove to be useful in helping nurses gain comfort in caring for those with HIV/AIDS.

One-to-one mentoring, although more time consuming for the educator, has great potential to enhance nurses' skills, increase confidence in dealing with complex situations, and change attitudes related to HIV/AIDS.

Incorporating Benner's work (1984) is essential in that more expert HIV/AIDS nurses could mentor those who are novice to HIV/AIDS work. A clinical nurse specialist in HIV/AIDS is a necessary addition to the team and must be shared between hospital and community to facilitate the development of nurses currently caring for those with HIV/AIDS and their caregivers and to ensure consistent approaches to HIV/AIDS care throughout the health care system.

The concept of reciprocal trust is also crucial to include in the education of beginning and practicing nurses. Reciprocity has received attention in the nursing literature, particularly with respect to the nurse-patient relationship (Kahn & Steeves, 1988; Marck, 1990; May, 1991b; Morse, 1991; Reutter & Northcott, 1993). Morse (1991) argues that reciprocity is a

necessary part of the therapeutic nurse-patient relationship. Thorne and Robinson (1988) contend that there are significant advantages to both patients and professionals when reciprocity, and in particular, reciprocal trust, is incorporated in health care relationships. The assimilation of reciprocal trust into nursing education and practice requires a shift in traditional health care philosophy. Nurses and other health care providers must broaden their focus towards encompassing the illness experience rather than simply attending to diseases and disease process (Thorne & Robinson, 1988). The development of acute listening skills, to curb preconceived notions about relationships between the health care professional and patient/family, and to solicit and respect the opinions and beliefs of family members, is imperative. Finally, building partnerships with our patients and families must be whole-heartedly embraced so that we can work towards providing family-focused care.

Support for the professional care provider

Implications from the study

The somewhat discouraging findings of this study related to caregivers' experiences with the health care system illustrate a need for health care organizations to become more actively involved with issues related to the care of those with HIV/AIDS and their caregivers. Caregivers pointed to a critical need for health care organizations to be more responsive and supportive to

staff. Health care administrators have a moral and ethical responsibility to create supportive work environments that enable staff to provide compassionate, sensitive, and skilled care to those with whom they come in contact. Therefore, mechanisms to support professional care providers would be useful in assisting nurses and others in dealing with the stress related to HIV/AIDS caregiving. For example, paid time off from work to attend support groups and debriefing sessions would be one way that administrators could support staff working in HIV/AIDS care.

Family caregivers witnessed burnout in nurses working in HIV/AIDS care and suggested that reduced staffing levels contributed to nurses' inability to provide skilled and sensitive care. Health care organizations can play a role in recognizing and advocating for staffing levels that are conducive to meeting the complex challenges that nurses and others face in caring for PWHIV/AIDS and their caregivers.

Personal perspectives

Supportive work environments are essential if nurses are to provide compassionate and skilled care to their patients and families. Without this environment, a domino effect occurs: nurses who are unsupported by their organization will ultimately be unsupportive to patients and family members. For support and genuine caring to be shared among family members, patients,

and nurses, there must be opportunity for nurses to feel accepted, respected, and honoured as unique individuals in the same manner that they profess to feel about patients and families (Neil, 1994). Open discussion and commitment to promoting such an environment is essential in contributing to the promotion of authentic self-knowledge and growth. Without this environment and opportunity for growth, caregivers will continue to witness burnout among nurses and others, and will experience detrimental effects as a result of the organization's inability to support nurses working in HIV/AIDS care.

Another essential element in supporting professional care providers is to ensure that staffing levels match the acuity of the patient population. Health care administrators must be aware of the unique demands placed on staff while caring for those with HIV/AIDS and their caregivers. They must also recognize the time and skill required to care for this population and advocate for further funding to increase nursing hours and support continuing education endeavors. Some HIV/AIDS care programs in the United States suggest that the time and skill required to care for PWHIV/AIDS and their caregivers is greater because of the multiple, complex problems associated with HIV/AIDS (Clark, Curley, Hughes, & James, 1988). Staffing levels must be conducive to meeting the complex challenges that health care providers face in caring for

this population. Determining adequate staffing levels is a complicated issue since current workload measurement tools do little to reflect the complexity of the patient care situation. Methods must be developed to accurately analyze and determine appropriate staffing levels for the care of those with HIV/AIDS. In the meantime, it is obvious that current staffing levels are inadequate, and health care administrators must attend to this immediate issue in order to prevent staff from becoming overwhelmed, fatigued, and overtaxed in caring for those with HIV/AIDS and their caregivers.

Nursing practice

Two issues specific to nursing practice emerged from this study. First, caregivers of PWHIV/AIDS need to find meaning and make sense of the loss that they have experienced. Creating and sharing supportive networks with health care providers and others helps family members reach some resolution and continue their life with a renewed sense of self and strength. Ferrell and Boyle (1992) assert that nurses are in a primary position to influence the bereavement outcomes of high-risk grievers. As such, nurses must be aware of the potential relationship between social support and caregivers' ability to find meaning in their loss and re-emerge to face life without their loved one. Therefore, nurses need to be aware that family members' who have little support during their caregiving experiences, are at risk for a difficult

bereavement period.

The findings also have implications for nurses in educating other health care providers and society in general. Often caregivers are the targets of HIV/AIDS related stigma. This stigma invades the work of HIV/AIDS family caregivers and has a profound and lasting effect on them. Frequently, caregivers experience prejudice from nurses, other members of the health care team, friends, other family members, and society at large. Unfortunately, the social stigma attached to HIV/AIDS continues to influence access and quality of care. Nurses who provide the majority of care to those with HIV/AIDS and their significant others may be in the best position to help their colleagues increase understanding and sensitivity when working with this population. Nurses can be powerful role models in facilitating the change of attitudes in others. Additionally, nurses can advocate to ensure that those who work with PWHIV/AIDS and their caregivers are properly educated in infection control techniques, universal precautions, caring for those with a terminal illness, and in helping others to understanding the unique aspects of caring for those with HIV/AIDS and their caregivers (Zelewsky & Birchfield, 1993). Similarly, nurses have the potential to help the community understand and accept those with HIV/AIDS and their family members by taking an active role in public education and policy development.

Nursing research

Findings reveal a number of areas to be considered for future nursing research. Work was identified as an important concept by which to understand the experiences of family caregivers of PWHIV/AIDS. Further investigation with larger numbers of individuals in differing circumstances is required to validate and further develop the concept of work as it relates to the management of end stage disease at home. For example, questions which remain to be answered include: (a) Are there differences between the work of partners in a gay relationship and those who are parents or siblings? (b) Are there differences in the work dependent on how HIV was contracted (ie. blood transfusion, IVDU, sexual encounter)? (c) Do men and women caregivers have different experiences with the work involved in HIV/AIDS family caregiving? (d) How does work differ for family members when the patient is hospitalized for palliative care? and, (e) How does the work of professional health care workers differ from that of family members?

The importance of providing and creating supportive networks for family members was also a significant finding in this study. Support appeared to be critical in allowing caregivers to manage and handle their work and to find meaning and make sense of their loss. Studies addressing the needs of HIV/AIDS family caregivers and their perceptions of helpful and unhelpful

behaviours from health care providers would add to the knowledge base and clarify how to design and implement effective supportive programs for family members who care for PWHIV/AIDS who are dying at home. The following research questions must be explored: (a) What are the needs of family members who provide care to those with HIV/AIDS at home? (b) What are family members' perceptions of helpful and unhelpful behaviours from health care providers? and (c) What effect does social support have on the caregivers' ability to manage and handle the work involved in HIV/AIDS family caregiving?

Findings suggest that caregivers experience several difficulties in dealing with the health care system. These difficulties and the lack of support from the system often lead family members to feel isolated and alone, angry and disillusioned. It is unclear whether these feelings relate more to an acute grief reaction following the loss of a loved one, or to the negative experiences that family members had with the system. Additionally, it is unknown how these feelings, particularly anger, affect the caregivers' bereavement.

Therefore, further research is required to answer the following questions:

(a) What is the source of anger? (b) Does the source of anger make a difference in how caregivers deal with their bereavement? (c) What are the effects of anger and support on the caregivers' bereavement course? (d) Does

anger become a vehicle for dealing with grief? (e) Does anger with the system decrease over time? and, (f) What is the fit between various types of support and various types of anger?

Finally, caregivers emphasized their difficulties with the services provided by the health care system. Research to determine what family caregivers want and expect from the health care system is imperative in order to develop programs that will best meet their needs. Additionally, evaluation studies of current programs, such as respite care and home support services, must be conducted to ensure that the services provided are the most effective. In an era of cost restraint, with emphasis on consumer satisfaction, it behooves us to ensure that health care services are meeting the needs of those we serve. In light of these comments and the findings of this research, the following questions must be answered: (a) What do caregivers want and need from respite care, palliative care, home support, and home nursing care? (b) What is the impact of respite care on the family members' ability to get relief from the caregiving situation? (c) What are the consequences to family members of PWHIV/AIDS when health care services do not meet their expectations?

Providing effective care and support for family members caring for those with HIV/AIDS is presently hampered by the lack of adequate research into the coping responses, skills, and difficulties of family members in this

situation. It is important that future research into this area be systematically built upon a sound basis of qualitative findings so that our knowledge of the family members' experience is accurate. Nonetheless, it is imperative when working with family caregivers of PWHIV/AIDS to understand the experience of family members and the work that they are involved with.

Conclusion

While current research explores HIV/AIDS family caregiving, to date, there is little known about the unique experiences that family members face when caring for those with HIV/AIDS who are dying at home. This study contributes to our understanding of family members' experiences by generating a rich description of this experience from the caregivers' perspective.

The dying process itself produces a myriad of fears, family issues, feelings, and concerns. Coupled with the unique challenges faced by HIV/AIDS family members, this profoundly affects the lives of those who provide care and who themselves need care and support. By describing and understanding the experiences of those who care for a dying loved one at home, nurses can better respond in a reflective, critical way. Understanding the experiences of HIV/AIDS family caregivers will provide nurses with the foundation to anticipate difficulties faced by caregivers, plan appropriate nursing interventions to address these difficulties, prevent future problems, and plan care based on theory and research.

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Appendix B

Advertisement submitted to the BC PWA Newsletter

University of British Columbia Master's Thesis Research on HIV/AIDS Family Caregiving

It is widely known that partners, family members, and friends (family) provide the majority of care to persons with HIV/AIDS. Family members often assume heavy responsibilities for care and provide the cornerstone of society's response to the HIV/AIDS epidemic.

As a registered nurse with extensive experience in palliative care and as student in the Master of Science in Nursing program at UBC, I have become interested in the perspectives of family members who care for persons with advanced HIV/AIDS who are planning for a home death or who have died at home. For example, you may currently care for someone or have cared for someone at home who needs alot of assistance with daily activities such as bathing, eating, or moving in bed. In fact, you may be providing all or most of the care for this person.

If you presently provide care or have provided care to somebody with advanced HIV/AIDS who is planning for a home death or has died at home within the last year, your views, perspectives, and experiences regarding caregiving are needed.

You are invited to participate in a confidential, unstructured interview to share your experiences and perspectives on this important topic.

Family caregivers of persons with HIV/AIDS confront issues that are unique and that most people never experience. Issues of communicability, stigma, and multiple and premature losses are common in HIV/AIDS family caregiving. Caregivers of persons with HIV/AIDS may experience a withdrawal of friends and regular support systems, discrimination, and misunderstanding from health care providers. Additionally, when an illness, such as HIV/AIDS, is long and extended, caregivers are at risk of becoming overextended and depleting their physical, emotional, and financial resources.

Appendix C

Participant Information Sheet

The Caregivers of Persons with HIV/AIDS: The Experience of Caring for a Dying Family Member at Home

My name is Kelli Stajduhar. I am a Registered Nurse presently enrolled in the Master of Science in Nursing program at the University of British Columbia. From my work in palliative care, I have become interested in the perspectives of family members (partners, friends, family of origin) who care for persons with HIV/AIDS at home. For my thesis, I am conducting a study to learn about the unique experiences of family members who care for persons with advanced HIV/AIDS who are planning for a home death or have died at home. For example, you may be currently caring for someone or have cared for someone who needs a lot of assistance with daily activities such as bathing, eating, and moving in bed. In fact, you may be providing all or most of the care for this person.

If you presently provide care or have provided care to somebody with advanced HIV/AIDS who is planning for a home death or has died at home within the last year, your views, perspectives, and experiences regarding caregiving are needed.

You are invited to participate in a confidential unstructured interview to share your experiences and thoughts on this important topic. Although this study may not directly benefit you, understanding the unique experiences of family members could help nurses and other health care providers to optimize the care provided to family members in the future.

As a participant, you will be asked about what day-to-day life is like for you in caring for your loved one. In the interview, I will ask you to describe to me what an average day, from start to finish, is like for you.

Appendix E

Sample Prompts for Interview

Opening Remarks

As you know, I am interested in learning more about what day-to-day life is like for you in caring for a loved one who is dying of HIV/AIDS. I think it is important to ask this question so that nurses and other health care providers can understand your unique experience. I think this might help in preparing us to assist and support people like you during your caregiving experience.

Prompts

- Tell me what an average day is like for you from start to finish.
- So the day is
- The experiences are
- Your feelings are
- The changes in your life are
- The similarities in your life are
- Your relationship with the person with AIDS is
- So it's helpful when or if
- So it's not helpful when or if
- So you cope by
- Do you have any questions of me?

Thanks, this has been really helpful.

Appendix F**Demographic Data Collection Sheet**

Code Number: _____

- 1. Age:**
- | | |
|-------|-------|
| 19-24 | _____ |
| 25-30 | _____ |
| 31-35 | _____ |
| 36-40 | _____ |
| 41-45 | _____ |
| 46-50 | _____ |
| 51-55 | _____ |
| 60+ | _____ |

2. Relationship to person with HIV/AIDS

Partner in a gay relationship	_____
Partner in a straight relationship	_____
Friend	_____
Parent:	
Mother	_____
Father	_____
Sibling:	
Sister	_____
Brother	_____
Volunteer	_____
Other:	_____

Loved one is currently in the dying process _____

Loved one has died within the last year _____

3. Status of Residence

Share the same household as the PWHIV/AIDS _____

Live independently of the PWHIV/AIDS _____

4. Level of Education

Less than high school	_____
High school diploma	_____
College diploma	_____
University degree	_____
Other: _____	

5. Employment Status

Unemployed	_____
Unemployed and receiving assistance	_____
Employed full-time	_____
Employed part-time	_____
Retired	_____