AIDS GRIEF AND MULTIPLE LOSS: 
THE EXPERIENCES OF INDIVIDUALS WITHIN 
AN AIDS SERVICE ORGANIZATION

by

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ABSTRACT

AIDS GRIEF AND MULTIPLE LOSS: THE EXPERIENCES OF INDIVIDUALS WITHIN AN AIDS SERVICE ORGANIZATION

This qualitative study identified the experiences of AIDS grief and multiple loss by eight individuals within an AIDS service organization in the province of Alberta. Collaborative, ethnographic, and narrative approaches in research design and analysis were used to connect and analyze audio-taped and transcribed interviews. Critical case sampling assisted in choosing participants who had a minimum of one year involvement with this organization, and who had experienced multiple losses and deaths from AIDS. Participants represented multiple roles within this organization including client, board, volunteer, management, counselor, and administrative support staff. Interviews were analyzed for repeating themes and reconstructed into a narrative life story for each participant. These themes and stories were compared between participants resulting in an ethnographic analysis about multiple loss within this community and culture. The central challenge, woven throughout the individual and organizational history, was 'balancing pain of loss with hope and commitment'. Participants described four core themes emerging from this central challenge: 'layers and cycles' of multiple losses; 'not enough or limited time' to grieve; which creates an urgency to 'fight'; in a setting where there are normative 'complex and blurred roles and relationships'. A cyclical process of coping was identified: tension and emotions build; episodic expressions of grief occur (over reaction and out of proportion expressions, and black humor); numbness develops (due to being overwhelmed); heightened anxiety & catastrophic thinking set in (associated with anticipation of greater loss and especially noted in those HIV positive); efforts to distance oneself occur (temporary to permanent which provide opportunity to integrate, reflect and replenish energy) and protective strategies are created to reduce the impact of multiple loss; memorializing and sharing with the select few who understand occurs; and there is expeditious reinvestment of feelings into a recommitment (which helps to honor those who have died and contribute to those who now need support). Participants highlight the consequences of AIDS grief on individual and organizational functioning, and identify/recommend strategies for resilient coping. The diverse social and organization factors impacting AIDS grief and multiple loss were also identified.
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INTRODUCTION: THE CHALLENGE OF AIDS GRIEF AND MULTIPLE LOSS

Anger and Rage- June 1993

I bring my anger present
my rage at this virus

So,
the feelings won't be lost
and stored inside this
healthy body of mine.

I bring my anger and my rage present.

So,
the vigorous laugh of this
beautiful man won't be forgotten.

I bring my anger and my rage present.

So,
I won't be lost in the sadness
and tears of wasted futures
and lost opportunities.

I bring my anger and my rage present.

So,
I can release the pain of many
losses that seem like one.

I bring my anger and my rage present.

So,
I can create something new and giving.
The above poem was my beginning attempt to express and comprehend the complexity of Acquired Immune Deficiency Syndrome (AIDS) grief and multiple loss. AIDS which is caused by the Human Immunodeficiency Virus (HIV) creates significant impairment to the immune system, and leaves individuals open to a wide array of infections that result in death (Dunkel & Hatfield, 1986). AIDS has been recognized as an epidemic and now pandemic, identifying its global implications (Dane & Miller, 1992). Its consequences are enormous both socially, and economically, and in its wake AIDS leaves enormous grief for us all.

As a lesbian social worker who has worked within an AIDS Service Organization, I am aware of the devastation AIDS has on individuals, families, organizations, and communities. AIDS has profoundly changed me. Often times, I found it difficult to understand what those deep changes were, and how I managed to creatively survive and celebrate life after seeing so much death. I recognized that a personal and professional transformation was taking place as a result of my experiences. I began to see how this work with AIDS was cumulating in my body and spirit. My experiences with suffering, with witnessing people’s efforts to come to meaning in their life, and to see death in its many forms was both profoundly honoring and cumulatively wrenching. My desire to pursue graduate studies and qualitative research grew out of these experiences. I wanted to explore the experiences of a familiar community and my own lived experience with AIDS grief and multiple loss as a lesbian social worker who had worked within an AIDS Service Organization (ASO).

The role of social work has been central in assisting individuals, families, and communities to heal the many losses created by AIDS. Social workers have challenged the social injustices, empowered and supported clients, and have been on the cutting edge, especially gay and lesbian social workers, in providing a response to AIDS (Lloyd, 1995; Shernoff, 1990). Social workers have also played active roles in a response to HIV and AIDS across Canada, and in AIDS service organizations (ASOs) in this country (Clarke, 1995).
AIDS bereaved have not been studied extensively. These bereaved experience additional stresses of prejudice, stigma, confrontations with death and multiple loss, and deaths of considerable numbers of younger people which all have a negative impact on the normal grief process (Dane & Miller, 1992). The impact of these bereavement consequences for individuals, families, professionals, and communities is just beginning to be realized (Dane & Miller, 1992).

Limited statistics are available to estimate the amount of loss due to AIDS that individuals experience. Dane and Miller (1992) in their book *AIDS: Intervening with Hidden Grievers* reference that between seven to ten survivors are impacted by a loss in one family system. Dane and Miller (1992) further suggest that these figures do not include “neighbors, friends, co-workers or others outside the family system” (p. 1).

In my experience, it is also rare to grieve a single death from AIDS. Rather, those diagnosed with HIV disease, their personal support system, and the professional community who care for those with HIV and AIDS experience multiple deaths from AIDS. This occurs in a context where there is fear and stigmatization associated with AIDS. Consequently, people are isolated from their personal communities, and seek support from those already personally familiar with HIV. However, the flip side of this benefit, from this type of reciprocal support of the shared and lived experience with HIV and AIDS, is also greater exposure to AIDS grief and multiple loss. This has been especially true for the gay community, the community of HIV positive people who seek their support from others who are HIV positive and the personal caregivers who may meet each other through ASOs.

Limited statistics are also available to quantify the number of multiple AIDS bereavements experienced by each individual. Cadwell (1994) documented fifteen gay therapists who described each knowing “between 30 to 50 people who had died of AIDS - friends, lovers, ex-lovers, patients, and colleagues” (p. 86). Biller and Rice (1990) also state “because the gay community has been close knit, its members have been known to have buried, 10, 20, and as many as 50 friends with AIDS” (p. 285). Gibson & Plotnick (1997) in their evaluation of an AIDS Bereavement Project in Ontario found a range
of deaths experienced by individuals within ASOs in the province of Ontario. The majority of individuals within this study experienced two to ten deaths, and a range of zero to over fifty deaths were noted depending on the individuals and their length of employment (Gibson & Plotnick, 1997). Participants were also noted to experience deaths of coworkers, and a range of two to ten deaths outside of their workplace. Executive directors were similar in their reports of loss within and outside the organization, and among coworkers. Board members of ASOs in this Ontario study were noted to generally experience fewer deaths than staff and Executive Directors.

Professional caregivers (e.g. social workers, counselors, physicians, nurses, and administrative staff in ASOs) and volunteers also experience considerable AIDS grief. This experience with AIDS grief occurs because of exposure to a multitude of deaths, supporting personal/family caregivers through AIDS grief, supporting those who are HIV positive or have AIDS both personally and professionally, and providing mutual care/support to other professional caregivers. In my experience individuals within the gay community, the HIV positive community, personal caregivers, and professional caregivers describe the struggle to balance their needs to attempt to seek AIDS bereavement support, and also escape the devastating impact of AIDS on their lives.

I have found that AIDS grief and multiple loss within the organizational culture of an ASO are complicated by a variety of factors. Firstly, ASOs are challenged to develop as non-profit agencies while responding to the increasing needs of those with HIV and AIDS. Secondly, these organizations have historically had HIV positive individuals as clients and caregivers, employees and volunteers contributing throughout the organization. Thirdly, many individuals in the organization are motivated from a personal experience with HIV. Many of these individuals are predominantly represented by the gay and lesbian community, which has been most impacted by the effect of HIV and AIDS. Therefore, these social factors both influence and create a climate that exposes all levels of the organization to AIDS grief and multiple loss. These social and historic realities challenge organizations to develop effective coping strategies due to the tangible costs, both personal and organizational, in providing
effective service delivery and maintaining skilled staff. Participants in this new qualitative research study about AIDS grief and multiple loss have been chosen to reflect this complexity and diversity within an ASO.

Few studies exist to document the qualitative experience with AIDS grief and multiple loss. Several United States (U.S.) studies have explored the qualitative experience of AIDS grief on gay and lesbian individuals (Bierman, 1996; Biller & Rice, 1990; Carmack, 1992; Cherney & Verhey, 1996; Fahrenbach, 1992; Rockefeller, 1994; Sowell et al., 1991; Werner, 1992). Efforts have also been made to quantify the extent and impact of multiple loss on gay communities in the U.S. (Dean, Hall & Martin, 1988; Ghuosiski, Fishman & Perry, 1997; Kemeny & Dean, 1995; Lennon, Martin & Dean, 1990; Martin, 1988; Martin, Dean, Garcia & Hall, 1989; Martin & Dean, 1993; Neugebauer et al., 1992), and Australia (Viney, Henry, Walker & Crooks, 1992a). Additionally, Hoch (1997) attempted to quantify the impact in a Los Angeles dissertation entitled The Interactional and Main Effects of Social Support and Stress in the AIDS Service Organization Setting. The methodology was believed to be inadequate and therefore the researcher suggested future researchers employ qualitative methods. Qualitative research and ethnography was also recommended by Ouellette, Cassel, Maslanka, & Wong (1995) to expand our knowledge of community-based AIDS organizations.

Very few Canadian studies exist on AIDS multiple loss, and ASOs. Cain (1993, 1994, 1995, 1997) has focused his qualitative work on the historic changes and challenges within ASOs in Canada. Gibson & Plotnick (1997) completed an evaluation of the AIDS Bereavement Project of Ontario which documented the impact of AIDS multiple loss, and benefit of intervention received by this project in assisting ASOs in the province of Ontario. An exploratory qualitative study therefore appears necessary to understand the experience of AIDS grief and multiple loss from the perspective of individuals within an ASO.

I have felt throughout my clinical social work practice within an ASO that a new paradigm of understanding has been needed to express the complexity faced by individuals, organizations, and
communities in coping with AIDS grief and multiple loss. During my clinical practice, I found traditional grief theory and complicated grief concepts failed to adequately explain the grief processes and coping strategies of individuals, organizations and communities coping with AIDS multiple losses. I have also found that traditional grief theories and grief concepts do not adequately account for the social, cultural and political contexts of the bereaved, and in particular AIDS bereaved. In this way, a new claim is being made about an experience in an effort to understand our human capacities, and name our individual and collective needs (Drover & Kerans, 1983). A new claim is being made from our daily life experiences and as a challenge to inequality and oppression (Drover & Kerans, 1983). Therefore, the act of completing this research is intended to be a form of social action for the individual, organizational, and community experiences with AIDS grief and multiple loss.

Feminist thinking is also central to my experience and analysis. Feminist theory, research and praxis recognizes that the personal is political and through the telling of our private stories we create knowledge of the social and political contexts in which we live (Wisewoolf, 1993). Thereby, through feminist research, analysis, and telling of our private stories of AIDS grief and multiple loss we create a new understanding and claim about the personal, social, cultural, and political truths which inform our experience.

The contributions of feminist writers (Heilbrun, 1988; hooks, 1989; Lorde, 1984; Rich, 1979, 1986, 1993; Wylie, 1995) began my exploration of the meanings within our stories or narratives. In particular, Wisewoolf's (1993) thesis on intimate reflective autobiography, and Houle's (1995) collaborative life writing played key roles in understanding the contributions of our own truths. Wisewoolf (1993) describes the benefit and purpose of this type of process: "our healing is our re/membering: our knowing, creating, and acting" (p. 79). I have come to appreciate over this research process that there are deep places within those in the AIDS bereaved communities and myself waiting to be recorded. It is as Audre Lorde (1984) describes:
a deep place within, where hidden and growing our spirit rises, beautiful and tough as chestnut/stanchions against y(our) nightmare of weakness and impotence...within these deep places, each one holds an incredible reserve of creativity and power, of unexamined and unrecorded emotion and feeling (p. 36, 37).

Additionally, I have found authors writing in the area of trauma (Dunning, 1994; Herman, 1992; Nord, 1997), disaster (Biller & Rice, 1990; Cowan & Murphy, 1985; Dane & Miller, 1992; Nord, 1997; Schwartzberg, 1992a), holocaust (Danieli, 1994; Golberg, 1986; Schwartzberg, 1992a), vicarious traumatization (Bettcher, 1996; Pearlman & Saakvitne, 1995), compassion fatigue (Figley, 1995), stress and coping theory (Benner, Roskies & Lazurus, 1980), and social and political repression (Becker et al., 1989; Comas-Diaz & Padilla, 1990) to be extremely informative.

In the writing and design of this thesis three key ideas have guided and motivated me. These include my intimate experience with this topic, my desire to contribute to those in my community, and my effort to honor the memory of those already lost to AIDS. This document was shaped as an extension of a collaborative research process by creating it as a resource for the bereaved, professional, and academic. The following descriptive study focuses on eight individuals who were interviewed in a semi-structured interview format from within an ASO in the province of Alberta. I have been privileged to be able to create an opportunity for a recording of the experiences and wisdom of AIDS grief and multiple loss from the perspective of individuals within an ASO. This research is extremely comprehensive. It describes the individual grief processes and coping strategies in response to AIDS multiple losses. It also provides description of the current and historic challenges of AIDS grief and multiple loss within this organization and community. It names the organizational, social, cultural and political forces which make being an AIDS bereaved in this community so difficult. Consequently, this research provides a complex understanding of the individual, organizational, social, cultural, and political contexts in which AIDS grief and multiple loss reside. An extensive and evolving literature review follows in an effort to respect that complexity.
Chapter 2 provides a critique of present grief theory, and a broad understanding of potential literature which adds to our current understanding of this experience. Chapter 3 describes the process for this exploratory ethnographic qualitative study. Chapter 4 contains the eight stories or narratives of individuals who participated in this qualitative study and the ethnographic analysis, and Chapter 5 contains the recommendations and implications this research has for social work practice and future areas of study.
CHAPTER 2

REVIEW OF LITERATURE: BRANCHES OF KNOWLEDGE ABOUT AIDS GRIEF AND MULTIPLE LOSS

An Arbutus tree, Figure 1, is used as a visual image and metaphor to capture the branches of knowledge that are evolving in our understanding of AIDS grief and multiple loss. The Arbutus tree is native to the western coast of British Columbia. This particular tree is a very useful image to describe the complex nature of AIDS grief and multiple loss. The tree repeatedly sheds, rust red like layers during the year. A tree may have areas of bark fully intact, areas where it has shed red paper like bark, and other areas that appear raw similar to human flesh. It is an extremely resilient tree that often hangs on the edge of an ocean, and tolerates both wind and waves. This image is a particularly good metaphor to capture the many layers of AIDS grief and multiple loss. At various points those experiencing multiple loss from AIDS may be actively grieving. Previous losses may have experienced some healing, while losses that are more recent may leave us open and raw to the experience of grief. Like the tree itself, I have found individuals, organizations, and communities amazingly resilient to the amount of loss and trauma brought to their lives by AIDS.

This tree image also helps capture the complexity, and evolving nature of the diverse theoretical contributions to understanding AIDS grief and multiple loss. Therefore, the tree branches of an Arbutus tree are also a metaphor of the branches of knowledge about AIDS grief and multiple loss as Figure 1 demonstrates. A discussion of these diverse theoretical contributions follows and these are: social, political, and cultural context; application of traditional grief theory; additional grief concepts applied to AIDS; alternative concepts applied to AIDS grief and multiple loss; new concept applied to AIDS grief and multiple loss – social and political repression; and concepts applied to AIDS caregivers.
FIGURE 1
The Branches of Knowledge about AIDS Grief and Multiple Loss

- AIDS Grief
- Disenfranchised Grief
- Secondary Stress Disorder
- Burnout & Grief
- Social & Cultural
- Secondary Stress Disorder
- Disaster
- Trauma
- Stress & Coping Theories
- AIDS Service Organizations
- AIDS Phobia & Homophobia
- AIDS Activism Organizations
- Social & Political Activism
- AIDS
- AIDS activating community & political organizations
- Social & Organizational Activism
- AIDS Activism
- AIDS Activism
- AIDS Activism
- AIDS Activism
- AIDS Activism
- AIDS Activism
2.1 SOCIAL, POLITICAL, AND CULTURAL CONTEXT OF AIDS GRIEF

Implicit in AIDS grief is the social, political, and cultural context that informs and defines this experience. These contexts impact the efforts of individuals, families, and communities to understand and cope with AIDS grief. The following structures are discussed: societal and organizational denial of death and grieving; AIDS phobia and pervasive discrimination; heterosexism and homophobia; sexism, racism and economic oppression; and AIDS service organizations as alternative service organizations.

Societal and Organizational Denial of Death and Grieving

We live in a society which denies death (Janz et al., 1995, Kamerman, 1991; Rando, 1984; Schwartzberg, 1992a), which creates distance from this experience by relegating it “to formal institutions which remove it from any integrated experience of our daily lives” (Cadwell, 1991, p. 236). This denial of death complicates one’s grieving process. Death and grief are a normal part of our existence as human beings. However, little societal understanding now exists for both these human experiences. Social supports are critical to the healing of losses, yet denial of death, and lack of understanding of the grieving process negate these supports. This deeply personal experience, coping with a bereavement, is embedded in a culture that would prefer to deny death and not hear about the pain associated with grieving (Gray, 1988).

Further, AIDS service organizations and the individuals who work within them work in a context and climate where HIV pervades every role and relationship in the organization (Gibson & Plotnick, 1997; Schoen, 1992). They are grief saturated or grief organizations (Gibson & Plotnick, 1997). The individuals in the organization have a deep personal reaction to the amount of loss and grief they experience in this work setting. There is a verbal and more often nonverbal recognition within the organization of the significance of this experience. At times the impact of AIDS grief and multiple loss is not understood, or is minimized, and denied (Gibson & Plotnick, 1997; Perreault, 1995). At times the impact of grief is narrowly viewed as a personal issue, or an issue for support services (Perreault, 1995).

At the same time, unattended grief can have adverse effects on emotional health (Gibson &
Plotnick, 1997; Perreault, 1995), and organization functioning (Perreault, 1995; Schoen, 1992). Where grief is unresolved within an organizational structure it can severely restrict decision-making, and become expressed in aggressive behavior (Stein, 1988). “Unresolved grief often plays a hidden role in organizational problems such as reduced productivity, low morale, increased conflict, absenteeism, increased turnover, difficulty setting limits, and inadequate attention to positive feedback and informal support” (Schoen, 1992, p. 2). Short term solutions to these problems are ineffective, and building an ongoing strategic response to grief and multiple loss is necessary (Perreault, 1995). However, avoidance, denial or disbelief, feelings of being overwhelmed, lack of resources and adequate time to grieve losses, large caseloads, rapid organizational development, uncertain organizational mission, and insecure and inadequate funding (Cain, 1995, 1997; Fleishman, Piette & Mor, 1990; Gibson & Plotnick, 1997; Janz et. al., 1995; Schoen, 1992; Soos, 1991) have created barriers in the organizational structure to creating strategies for ongoing healthy communities.

AIDS Phobia and Pervasive Discrimination

Irrational fear of HIV and AIDS, or AIDS Phobia, presents ongoing challenges for those living with HIV and AIDS. The presence of contagion or an infectious disease that results in death, the sexual transmission of the virus, and association with marginalized groups of individuals have all fueled AIDS Phobia. These unrealistic fears have also contributed to pervasive discrimination. Considerable literature documents this reality for those HIV positive (Davis, 1991; Doctor, 1990; Huber, 1993; Isenegger, 1991; Piemme & Bolle, 1990; Reamer, 1993; Stevens, 1993). This discrimination has further led to litigation. Law suits have occurred in “disputes over civil rights (privacy, discrimination, confidentiality, the nature of homosexual relationships versus the traditional family)” and “cases regarding child custody, divorce, HIV testing, reporting of HIV and AIDS diagnoses, discrimination, the right to experimental treatments”, and “insurance” (Huber, 1993, p. 224, 225).
Heterosexism and Homophobia

"Heterosexism can be viewed as a form of social control in which values, expectations, roles and institutions normalize heterosexuality" (Spaulding, 1993, p. 231). Additionally, non-heterosexuals are often perceived as deviant, suspect, and dangerous (Glamuzina & Laurie, 1991). Heterosexism can deny the existence of gay, lesbian, bisexual, and transgendered persons. It can further lead to homophobia or fear and hatred of sexual lifestyles other than heterosexuality. In relation to HIV and AIDS, societal heterosexism and homophobia have created significant challenges for those infected with this disease. In particular, in North America where the epidemiological history of HIV began within the gay male community (Cadwell, 1991), heterosexism and homophobia have fueled AIDS phobia. HIV must be seen in the broader political or social context where intense blame and stigmatization are directed at the community infected. HIV/AIDS has become a forum for some members of society to direct their pre-existing hatred at gays and lesbians, and justify their stigmatization, discrimination, and marginalization in a culture that hates gays and lesbians. These societal beliefs are expressed in the following notions: 'AIDS is god's curse against gays' or 'they deserved it whereas children, hemophiliacs and blood recipients' do not. The notions of deserving and undeserving 'victims' of AIDS are pervasive (Franklin, 1993; Sabar, 1995). These social constructs of deserving and undeserving victims, and the assigning of blame to specific groups are powerful social and moral judgments intended to create guilt and facilitate social control. It is not surprising then, that as gay liberation made some inroads, and challenged "norms of the old social order", that "fear of AIDS became a more strident articulation of fear of gays" (Cadwell, 1991, p. 240).

This experience with heterosexism and homophobia is particularly relevant in the province of Alberta, where this research was situated. I have witnessed the challenge that this type of hatred can create for those gay and HIV positive, and the bereaved that by association are judged similarly. The participants of this research speak about the impact of heterosexism and homophobia on their lives, and in particular the lack of human rights protection provided them as gay and lesbian individuals in this
province. Alberta is one of the last provinces to support human rights legislation that will protect gays and lesbians against discrimination (Tanner, 1996).

Over the course of this research two significant court rulings occurred in relation to human rights protection for gays and lesbians in Alberta. These rulings were based on Delwin Vriend's considerable sacrifice and efforts to receive legal protection from discrimination on the basis of his sexual orientation. Delwin Vriend initially launched this legal battle after being fired from his instructor's job at Kings College in Edmonton in 1991. Vriend took the province to court to argue that he was a victim of discrimination based upon his sexual orientation (Tanner, 1996). Vriend won the initial case in 1994 when the judge ordered the province to include sexual orientation in its human rights laws (Engman, 1996). The Alberta government refused to do so and appealed to the Alberta Court of Appeal (Engman, 1996). In February 1996, during the week of my interviews with participants, the Alberta Court of Appeal announced it ruled in favor of the Alberta government. In a 2-1 judicial decision the initial ruling by the Queen's bench was overruled (Tanner, 1996). Vriend and his supporters later initiated an appeal to the Supreme Court of Canada. The decision of the Supreme Court of Canada was announced on Thursday April 3, 1998 during the final phases of this research process.

The Supreme Court of Canada has rebuked the Alberta government for evading its democratic duty to prevent discrimination against all Albertans, including gays and lesbians. In a unanimous decision released Thursday, the court ruled that legal protection must immediately be made available to the province's homosexual community. It ended a seven-year court battle by concluding that sexual orientation must be 'read in,' or assumed to be part of, the Individual's Rights Protection Act as a prohibited ground of discrimination, although the law does not specifically say so. (Ovenden, 1998)

However, the Alberta government decided to wait a week to consider their options and hear from the electorate. Members of the Alberta government conservative caucus were opposed to the Supreme Court decision, and this was one of the most divisive issues faced by this conservative government (Johnsrude, 1998, April 9). There was a strong lobby by right wing organizations against the government support of the Supreme Court Decision. They associated the protection of gays and lesbians from discrimination with legitimizing pedophilia, eroding parents rights', and paving the way
for recognition of same-sex marriages (Jeffs, 1998). Consequently, in the week following the ruling there was a fervor of opinions on whether the ‘notwithstanding clause’ should be used, which would allow the Alberta government to exclude themselves from the Supreme Court decision. There was considerable confusion around what the ruling actually meant. Daily a variety of public opinions were noted in newspapers, television and radio broadcasts. Active lobbies for and against government support led to considerable calls to government officials. Additionally, in the week awaiting a government response a publicly gay Edmonton alderman, Michael Phair, was targeted with a variety of verbal threats of serious harm and injury. This lead to Phair calling a news conference, urging the government to provide public support for the ruling, and political leadership to challenge intolerance and bigotry against gays and lesbians (Geddes, 1998). The following day the Alberta Premier, Ralph Klein, announced his support for the ruling and his intent to use his political clout to have his caucus support the Supreme Court ruling (Geddes, 1998). Premier Klein was noted as saying “opponents of last week’s gay rights are misleading others by suggesting the ruling gives homosexuals special rights” (Johnsrude, 1998, April 8, A1). Given the considerable confusion around the meaning of the ruling, which appeared fueled by homophobic ideas, the Alberta government agreed to publish announcements (“Facts about Alberta’s Human Rights Laws”, 1998, April 15) explaining the Supreme Court ruling (Johnsrude, 1998, April 16).

These legal battles and the vigorous anti-gay backlash, against the support of human rights protection from discrimination for gays and lesbians in this province, provide significant information on the social context in which gays and lesbians live their lives. Specifically, it highlights the evidence of the strong heterosexist and homophobic context in which many Alberta gays and lesbians live and grieve.
Sexism, Racism and Economic Oppression

A variety of authors have also identified how HIV is reflective of the broader social, political, cultural, and economic inequalities in women’s lives (Holland, Ramazanoglu, Scott, Sharpe & Thomson, 1990; Pearlberg, 1991; Struntzner-Gibson, 1991; Worth, 1989). Women, including lesbians, have been largely invisible (Pearlberg, 1991; Stevens, 1993) in the study, reporting and diagnosis of HIV until recently. “Once they are diagnosed, women with AIDS often get sicker and die faster than men” (Lafond, Mensah & Badeau, 1992, p. 24). “The women who are most vulnerable to HIV infection are those who have least control over their sexual decision-making, whether because of drug use, lack of economic power, culturally sanctioned gender-role behavior, racism, or sexism” (Worth, 1989, p. 306). The social reality of violence against women poses an increased risk of vulnerability of HIV infection (Madsen, 1996). HIV positive women must also contend with a variety of social judgments in access to treatment because of their “reproductive potential” (Banzhaf et al., 1990, p. 206). HIV positive women have been denied access to experimental treatments based on their reproductive potential, counseled to abort pregnancies they might want to complete, denied abortions by fearful practitioners, and subjected to societal judgments about all these decisions (Banzhaf et al., 1990). AIDS research about reproductive issues has been low priority (Banzhaf et al., 1990) until recently. We are just now beginning to see some improvement in the quality of information, early diagnosis, and access to treatment for HIV positive women.

Women are also often involved in disproportionate caring of the sick or dying in our personal and professional roles (Baines, Evans & Neysmith, 1991; Drover & Kerans, 1993). This is particularly the case for HIV positive women who are often involved in “caring for (possibly sick) partners, children and/or other family members” (Pearlberg, 1991, p. 68).

HIV disease is not only a reflection of “gender and sexuality”, but also “a reflection of racial and economic disparities” (Pearlberg, 1991, p. 3). Those disproportionately affected are women of color (Pearlberg, 1991; Sabatier, 1988). In Canada we are beginning to see an increasing rate of HIV
infection among, in particular, First Nations communities who are already struggling with racial and economic disparities. Youth and gay men of color are at multiple risk of HIV infection (Lester & Saxxon, 1988). Globally AIDS has effected “the world’s least powerful communities: the poorest, most disadvantaged and underdeveloped groups whose members constitute an increasingly disproportionate share of the world’s total AIDS cases” (Sabatier, 1988, p. 4). Chirimuuta and Chirimuuta (1989), Sabatier (1988), and Stevenson (1994) have written extensive accounts of the presence of racism in this pandemic and the efforts to blame people of color, particularly Haitian and African people, for the disease. The above economic disparities, racism and sexism order the lives of those HIV positive by creating additional blame and/or ignoring these social realities which compound living with HIV, and grieving the losses associated with this disease. “Coping with multiple AIDS-related loss is much more difficult for people with socioeconomic stress because it makes it more difficult to mourn” (Nord, 1996, p. 137).

AIDS Service Organizations (ASOs) as Alternative Service Organizations?

In response to issues of social injustice, particularly created by heterosexism and homophobia, ASOs developed as non-profit agencies. They began as an act of resistance or a challenge by members of the gay community to pay attention to a particular problem. These agencies began in response to an anticipated crisis where “local gay and lesbian activists decided that a community-based AIDS organization was required” (Cain, 1993, p. 668). ASOs as untraditional agencies appeared to present great promise in addressing the broader sociopolitical issues of homophobia, heterosexism, sexism and racism (Cain, 1995). They also carried hope to reach marginalized communities, create empowerment and respond to the emerging needs of those HIV positive (Cain, 1995). Central aspects of these organizations were “the involvement of people living with HIV in the planning and delivery of services”, and their ability to “provide culturally sensitive and flexible support and education services” (Cain, 1993, p. 665).
In this way ASOs are also Alternative Service Organizations, because as community organizations they combine “the radicalization of everyday life with a service orientation that addresses needs of specific populations” (Lustiger-Thaler & Shragge, 1993, p. 168). These organizations act as a form of radical resistance by supporting “a different population” (Lustiger-Thaler & Shragge, 1993), and promoting “social change” (Lustiger-Thaler & Shragge, 1993). In this way AIDS service organizations represented alternative lifestyles within an alternative organization. A more radical model of this collective resistance is the formation of ACT UP (AIDS Coalition to Unleash Power) which challenges government mismanagement, drug costs, and treatments for HIV and AIDS (Kahn, 1993).

The individuals working within these organizations are primarily represented by the gay and lesbian community. The ‘act of being out’, ‘the act of being a lesbian or gay person’ are acts of resistance. Mark Blasius (1994) in his book on gay and lesbian politics describes this experience as follows:

the act of ‘coming out’ to nongays and to other lesbians and gays itself is political since, as I demonstrate, it challenges the coerced conformity, the cultural invisibility, of men who have sex with men and of women who have sex with women ... Moreover, besides the work of the explicitly political organizations, most of lesbian and gay culture is at the same time ‘culture politics’ the activity of calling into question and transforming the power relations that condition how sexuality is conceptualized, represented, and expressed behaviorally at the present time. (p. 4)

Those who primarily work within AIDS service organizations participate in an alternative lifestyle within a larger heterosexual culture. The presence of out gays and lesbians in these agencies indicates acts of resistance within a larger social culture that would prefer to silence or ignore the gay or lesbian person. The activities of working in an alternative organization, which has its beginnings within the gay and lesbian community, and being an ‘out’ gay or lesbian are both politically resistive within the larger social structure of heterosexism.

A more personalized version of this social action work is the concept of ‘border worker’. The work on the ‘frontlines of AIDS’ has been called border work (Gervais, 1995, 1996), a word that Celia Haig-Brown (1990) used in reference to her work with aboriginal communities. Those who work in the
AIDS community are 'border workers', because they work with marginalized, stigmatized and pervasively discriminated against individuals who are HIV positive or have AIDS. They also work the margins as a border worker by supporting those individuals our society would and has cast aside in some way including IVDU (Intravenous Drug users), gay or bisexual men, people of color, and women. As border workers they often work within their own communities most effected by the virus, particularly gay or lesbian individuals. Sometimes there is no border or boundary, as HIV and AIDS impacts, pervades, and penetrates every part of the gay or lesbian frontline worker's life. The struggle sometimes is to find a border.

However, while there has been a radical role that individuals and ASOs have played, literature has also demonstrated a shift in these organizations, and a complex relationship between them and government bodies. Various levels of government have played active roles in “encouraging the establishment of community AIDS groups” (Cain, 1993, p. 666).

“While ASOs were initially started as volunteer-run organizations, local activists who established ASOs typically moved quite quickly to hire paid staff members” (Cain, 1995, p. 85). Paid staff allowed “ASOs to provide consistent services, develop volunteer resources, promote the development of the organization, and to raise more funds” (Cain, 1995, p. 85). At the same time community representation shifted as “volunteers became more accountable to staff members” (Cain, 1995, p. 85). These changes resulted in an increasing dependence on professionals and paid staff in service delivery (Cain, 1997).

Further, ASOs made organizational decisions in their history in an effort to reduce societal stigma and secure funding (Cain, 1994). This occurred through attempts by ASOs to increase social and community legitimacy by appearing “nongay” and “professional” (Cain, 1994). As part of this professionalization and efforts to appear more legitimate board members were chosen from the professional community (Cain, 1994). Board members were chosen for their administrative and technical skills (Cain, 1995). They often lack skills in community organizing, and familiarity with the
issues of being HIV positive (Cain, 1995). Consequently, a shift occurred away from social activism and organizational representation from within the communities most effected by HIV.

Additionally, the reliance on regular government funding has also played a role in the “formalization and bureaucratization of community organizations” (Cain, 1993, p. 666). The rapid growth of these organizations has further assisted in these processes (Cain, 1993; Cain 1995; Cain, 1997; Fleishman et al., 1990; Ouellette et al., 1995). The short term nature of government funding and grants further make it more difficult to achieve longer term social change goals, particularly given the concern for the immediate needs of those HIV positive (Cain, 1995). Further, ASOs find it difficult to pursue political advocacy because of their charitable status role, necessity to accommodate to criteria of funding requests, and maintain positive working relationships with government funders (Cain, 1995). These changes can depoliticize and conservatize ASOs resulting in these organizations looking increasingly similar to other social service agencies (Cain, 1993; Cain, 1995).

Along with these organizational changes there has been a loss of the “familylike atmosphere” (Fleishman et al., 1990, p. 35), a critique of being “out of touch with the people they were intended to serve” (Ouellette et al., 1995, p. 65), and boards of ASOs lacking cohesion, political vision, and skills in leading the organization (Cain, 1995). Additionally, the epidemic has created an increasingly diverse client population who present with more complex social issues (Cain, 1997). Support workers are faced with complex needs, requiring a wide range of skills without adequate training and supervision (Cain, 1997; Haviland et al., 1997). Workers are also faced with issues of excessive workloads, and low pay (Janz et al., 1995). Organizations are attempting to define who they will serve, and what their new role and mission will be (Cain, 1997; Fleishman et. al., 1990). They will be challenged to locate dedicated volunteers as has been the case within the gay and lesbian communities (Cain, 1993). Additionally, most ASOs have now assumed financial roles (e.g. food banks, and emergency trust funds), and spend considerable time in “acting as a small private welfare agency”, because of inadequate government funding in health and social services (Cain, 1995, p. 87). These changes are occurring within a climate
of inadequate organizational funding (Cain, 1995), and in a context of "competitive relationships between community organizations" (Cain, 1995, p. 90).

Despite this bleak context the influence of government funding of ASOs has also provided a means for paid community activists to have influence and direct connections with government bureaucrats (Cain, 1995). There also seems to be "some evidence of a political reawakening", and an increasing desire within ASOs to address the sociopolitical issues which preoccupied their beginning (Cain, 1995, p. 92).

Organizations and the communities they represent have also been creative in their use of alternative resources of ritual, memorializing, and acknowledging the loss and contributions of individuals and communities in this battle with AIDS. Excellent helpful resources to assist the bereaved are also being written (Ennis, Boland & Murphy, 1995; Froman, 1992; Garfield, 1995; Jordan, 1989; Merrifield & Collins, 1995). Additionally, documentation on the impact of grief and multiple loss, and identification of healing strategies in ASOs and organizations are developing. These will be discussed in greater detail in the sections on: Multiple Loss; and Burnout, Grief, Support and Healing Strategies.

The previously noted social, political, and cultural structures all exist to define and inform the experiences of individuals, organizations, and communities who experience AIDS grief and multiple loss. An application of traditional grief theory will now follow.

2.2 APPLICATION OF TRADITIONAL GRIEF THEORY

Human Immunodeficiency Virus (HIV) infection can extend over many years requiring of the person and their support system considerable challenges to cope. The development of Acquired Immune Deficiency Syndrome (AIDS) as the immune system deteriorates brings on new challenges as each opportunist infection can be potentially life threatening. HIV and AIDS have been defined as "riding a rollercoaster" (McKusick, 1993) to depict the emotional, physical, social, and spiritual
adjustments people go through during these life threatening episodes. Inherent in these challenges is the process of grieving.

The concept of grief has been defined as a dynamic process that is highly individualized and strongly influenced by existing norms. “Grief was found to occur potentially in response to any perceived or anticipated loss and to result in the establishment of a new personal identity and view of reality” (Rodgers & Cowles, 1991, p. 454).

Rodgers and Cowles (1991) critique and review of grief and bereavement literature is helpful in understanding the ambiguity and consensus on these topics.

Although multiple studies have been conducted with the purpose of describing occurrences of grief, and theories have been formulated to promote an understanding of the concept, there has never been a consensus, even among authors from the same discipline, on a theoretical or empirical definition of grief (Rodgers & Cowles, 1991, p. 443). Additionally, there has been an interchange of “the term bereavement with grief or grief process, although they also have given specific evidence that the terms are not synonymous” (Rodgers & Cowles, 1991, p. 444). Disagreement exists on the length of time it takes to complete the process of grieving, varying from time limited to limitless (Rodgers & Cowles, 1991).

There is a consensus that grief is: “dynamic and process” oriented; “highly individualized”; “characterized by changes or manifestations that may be categorized as physical, social, cognitive, affective, behavioral, and spiritual”; and is “socially and culturally defined” (Rodgers & Cowles, 1991, p. 448-449). Though authors in the area of grief recognized that grief was fluid and dynamic, they generally divided grief into distinct phases recognizing that individuals move back and forth between phases (Rodgers & Cowles, 1991). Rando (1984) identifies that there are numerous “conceptualizations of the process of grief” but she believes they “can be collapsed into three broad categories” (p. 28).

Avoidance, in which there is shock, denial, and disbelief; Confrontation, a highly emotional state wherein the grief is most intense and the psychological reactions to the loss are felt most acutely; and Reestabilishment, in which there is a gradual decline of the grief and the beginning of an emotional and social reentry back into the everyday world. (Rando, 1984, p. 28)
In summary we have seen a variety of grief theories applied to the experience of AIDS grief. We have seen efforts to acknowledge the contributions or apply traditional theories to our understanding of the AIDS experience (Dane & Miller, 1992; Grothe & McKusick, 1992; McKusick, 1992; Nord, 1997; Perreault, 1994; Sherr, 1995). Applications of Rando’s phases (Biller & Rice, 1990), Sander’s Integrative Bereavement Theory (Cherney & Verhey, 1996; Sowell et. al, 1991), Corr’s (1992) four task based model of grieving (Cho & Cassidy, 1994), and personal construct models (Viney et al., 1992a) have also occurred. However, critique of traditional grief models has developed because they fail to account for the experiences of a variety of aspects of AIDS grief (Werner, 1992). “When we examine the grief of loved ones after the death of a person to AIDS, neither the attachment model nor the psychoanalytic model seems to account adequately for many of the phenomena observed” (Dane & Miller, 1992, p.6).

Critique of traditional grief theories has also occurred because of their failure to incorporate an understanding of the experience of stigmatization and multiple losses/deaths related to AIDS (Carmack, 1992; Grothe & McKusick, 1992; Schwartzberg, 1992a). “AIDS has created an environment in which continual loss has become commonplace, illness is severely stigmatized, and grieving individuals are often facing the possibility of their own imminent death” (Schwartzberg, 1992a, p. 423). They also fail to account for the complicated mourning of AIDS grief.

With the increase in Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS), significant multidimensional stresses arise which engender those known to complicate mourning in anyone (e.g., anger, ambivalence, guilt stigmatization, social disenfranchisement, problems obtaining required health care, and so forth). (Rando, 1992, p. 52)

These models fail to provide insight into the dynamics of self blame, stigmatization, marginalization, discrimination, and social isolation that are an inherent part of AIDS grief in this society. By neglecting these ongoing grief challenges the social, cultural, and political context of AIDS grief is ignored. Consequently, we are seeing evolving efforts to explore other concepts to apply to the experience of AIDS grief. A discussion of the contributions of additional grief concepts applied to
AIDS will now follow. These are Anticipatory Grief, Complicated Grieving, Disenfranchised Grief, and Multiple Loss.

2.3 ADDITIONAL GRIEF CONCEPTS APPLIED TO AIDS

Anticipatory Grief

Erich Lindemann first labeled anticipatory grief in 1944. He described this type of grief as a rehearsal of an impending loss which includes: 1) beginning phases of grief; 2) preparation for the anticipated death, and subsequent adjustments; and 3) the recognition that this could be potentially problematic if grief occurs far in advance of the death, or if the death does not occur at the time expected (Lindemann, 1965; Rando, 1986; Schoenberg et al., 1974).

Rando (1996) further summarizes the contradictions present in anticipatory grief. There is lack of a common understanding of the term anticipatory grief; and conflicting studies on the benefit of anticipatory grieving in assisting with postdeath grief. She, however, does identify that “it has been well-documented that there are problems for survivors when a loved one’s terminal illness persists too long”, and it presents “loved ones with inherent difficulties that eventually complicate their postdeath bereavement” (Rando, 1992, p. 51). This is particularly relevant for HIV and AIDS given that the nature of the disease is protracted, lengthy, and chronic with intermittent life threatening crises. A discussion of Complicated Grieving, Disenfranchised grief, and Multiple Loss follows.

Complicated Grieving

The concept of complicated grief is used to help explain why people do not adjust to a loss. This is also sometimes called pathological, maladaptive, morbid, or unresolved grief. Complicated grief may include: chronic, absent, distorted, inhibited, conflicted, unanticipated, abbreviated, delayed, or exaggerated grief (Sanders, 1989; Rando, 1984; Reeves & Boersma, 1990; Worden, 1991). Historically, certain characteristics have been described to distinguish normal and abnormal grief reactions (Worden, 1991). “Today we find that there is more of a continuous relationship between
normal and abnormal grief reactions, between complicated and uncomplicated, and that pathology is more related to the intensity of a reaction or the duration of a reaction rather than to the simple presence or absence of a specific behavior" (Worden, 1991, p. 71).

Further, Reeves & Boersma (1990) describe various causes associated with the development of a complicated grief reaction. These include: “judgmentalness about the grieving process or lack of support from significant others and/or the community; past unresolved grief which influences the reaction to the current loss; restrictive values or beliefs about loss and/or grief; physiological or psychological illness; and, lack of information about normal grief” (Reeves & Boersma, 1990, p. 282-283). A central concept in understanding the lack of acknowledgment and support for the AIDS bereaved is disenfranchised grief.

Disenfranchised Grief

“Disenfranchised grief can be defined as the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported” (Doka, 1989, p. 4). Authors have extensively documented societal shame, stigma, and social isolation as significant barriers for those HIV positive, their support system, and the communities most impacted by AIDS grief (Alonzo & Reynolds, 1995; Boykin, 1991; Cadwell, 1991; Cain, 1994; Cho & Cassidy, 1994; Clever, 1988; Dane & Miller, 1992; Froman, 1992; Geis et al., 1986; Hirsch & Enlow, 1984; Kamerman, 1991; Nord, 1996; Nord, 1997; Perreault, 1994; Perreault, 1995; Richmond & Ross, 1994; Sabar, 1995; Schoen & Schindelman, 1989; Shernoff, 1990; Sowell et al., 1991; Viney et al., 1992a). The societal sanctions against non-traditional relationships (e.g. homosexuals), and AIDS, a disease associated with moral judgement, create additional difficulty for grievers (Boykin, 1991; Cadwell, 1991; Cho & Cassidy, 1994; Dane & Miller, 1992; Doka, 1987; Nord, 1997; Richmond & Ross, 1994; Schoen & Schindelman, 1989; Sowell et al., 1991, Walker et al., 1996).

Disenfranchised grief creates an intensifying of emotional reactions such as anger, guilt, and powerlessness. Summers et al. (1995) also noted an elevated prevalence of current major depression...
and panic disorder with unresolved AIDS-related grievers. Increased levels of emotional states were noted in specific research on AIDS grief (Gluchoski, Fishman & Perry, 1997; Martin & Dean, 1993; Neugebauer, et. al., 1992; Viney et al., 1992a), which will be discussed in the section on Multiple Loss.

Disenfranchised grief also complicates grief by reducing access to social supports or excluding mourners from roles that will assist with mourning (Doka, 1989). This is certainly the case with AIDS grief whereby individuals are often unsupported, in conflict, or cut off from their traditional families (Coreless, 1997; Nord, 1996; Richmond & Ross, 1995; Rose, 1996), because of an AIDS diagnosis and/or alternative lifestyle. This lack of support or conflictual nature with traditional families limits the support available to assist in healing loss (Cadwell, 1991; Cho & Cassidy, 1994; Dane & Miller, 1992; Richmond & Ross, 1994; Sowell et al., 1991). It also creates ambivalence towards the AIDS bereaved access to grief rituals, like funerals, that play a role in assisting the bereaved to heal the loss (Coreless, 1997; Nord, 1997; Richmond & Ross, 1995; Worden, 1991). Summers et al. (1995) in his study on grief resolution and AIDS discovered that unresolved grief was more likely associated with those who did not attend funeral or memorial services. Furthermore, Bierman (1996) found a positive relationship in achieving grief resolution for gay men who participated in final arrangements of an AIDS related death. Jull-Johnson (1995) found that social support, meaningful participation in social bereavement rituals, and direct acknowledgment that AIDS was the cause of death were helpful in coping with HIV related chronic multiple loss.

The societal judgment within a context of AIDS multiple loss can create or further augment survivor guilt. The experience of survivor guilt (Boykin, 1991; Cadwell, 1991; Nord, 1997; Perreault, 1995) occurs when the AIDS bereaved experience guilt for still living, and self blame when they have lost considerable family, friends, and community to AIDS. The experience of survivor guilt in gay men is associated with deep expressions of grief (Jimenez-Sheppard, 1997). Thus, when we examine the reality of AIDS grief we recognize that complicated grieving is normative (Nord, 1996) particularly given the social judgment, and multiple cumulative losses. A discussion of multiple loss follows.
Multiple Loss

Multiple loss can create complicated bereavement (Cook & Dworkin, 1992; Reeves & Boersma, 1990; Rando, 1984; Rando, 1992; Worden, 1991). Multiple AIDS-related loss includes: “the deaths of important people”, in one’s life, and the “multitude of other losses associated with those deaths, including the loss of social support, loss of future plans, loss of personal history, loss of personality characteristics, and loss of a world that is not constantly overshadowed with death and dying” (Nord, 1996, p. 130).

In an attempt to capture the extent of multiple losses associated with AIDS we see a variety of authors reference the metaphor of ‘war’ (Cadwell, 1991; Clever, 1988; Franklin, 1993; Peloquin, 1990; Sherry, 1993; Sontag, 1989). The words ‘epidemic’ and ‘pandemic’ referenced to AIDS create that sense of urgency, catastrophe, and preparation for action. This language of ‘fighting a battle’ or ‘war’ has many uses. It became a language within the gay community to identify the sense of catastrophe (Sherry, 1993), and expression of social action necessary “to mobilize both government and community itself” (Sherry, 1993, p. 48). Further the language used by frontline counselors in ASOs, such as ‘we lost another one’, expresses this sense of war and catastrophe. There is at times a real war occurring against a virus which attacks the immune system, and creates a multitude of opportunistic infections that are extremely disfiguring, and assault the person in a variety of ways.

Further, Kastenbaum’s (1969) term ‘bereavement overload’, that described the experience of elderly in coping with multiple losses, was applied to the AIDS multiple losses early in the epidemic (Hirsch & Enlow, 1984). The concept of ‘death imprint’, or a permanent mental image of death created by a trauma (Niederland, 1971), was also added to reflect the cumulative impact of being a survivor (Nord, 1997). Rando (1984) states that when multiple losses are experienced it is “too overwhelming to contemplate and deal with” (p.65). “Thus, the AIDS epidemic is producing a situation in which grieving may become an unrelenting process with little opportunity for recovery” (Lennon et al., 1990, p. 483). Where, “despite the rapid escalation in the number of bereaved persons emerging during the
AIDS epidemic, the effects of loss, particularly multiple and chronic loss are not well understood” (Summers, et al., 1995, p. 384).

A variety of researchers have noted a connection between AIDS grief and multiple loss, and increased emotional states. In particular this research has focused on the impact of AIDS multiple loss on the gay and lesbian community. Several U.S. studies focused on the experiences of gay males living in New York (Dean et al., 1988; Gluhoski et al., 1997; Kemeny & Dean, 1995; Lennon et al., 1990; Martin, 1988; Martin et al., 1989; Martin & Dean, 1993; Neugebauer et al., 1992). Viney et al. (1992a) compared the bereavement experience of gay men in Australia. Bierman (1996), Biller & Rice (1990), Carmack (1992), Fahrenbach (1992), Rockefeller (1994), and Werner (1992) completed smaller qualitative studies on the experiences of the gay and lesbian community with AIDS multiple loss. Cherney and Verhey (1996), and Sowell et al. (1991) applied Sanders’ Integrative Theory to their research of bereavement in gay men. Gibson and Plotnick (1997) in their evaluation of a Bereavement Project in Ontario documented the impact of AIDS multiple loss on ASOs in the province of Ontario.

John Martin and colleagues have identified significant emotional, psychological, and social impact from AIDS multiple loss through their longitudinal studies of New York gay men. An evaluation was completed of the 1980 to 1985 results. “A direct relationship was found between the number of bereavements and symptoms of traumatic stress response, demoralization, sleep problems, sedative use, recreational drug use, and the use of psychological services because of AIDS concerns” (Martin, 1988, p. 856). Additionally, “being an integrated member of New York’s gay community puts one at a very high risk of being bereaved due to AIDS” (Dean et al., 1988, p. 57).

Not only is the problem of grief and bereavement complicated by chronic losses, but the issues are compounded by the high likelihood that chronically bereaved individuals are much more likely to be involved in AIDS activism; assuming leadership positions in gay organizations, taking care of other sick and bereaved men, and putting themselves at higher risk of suffering even more losses. (Dean et al., 1988, p. 57).

Lennon et al. (1990) also found “more intense grief reactions were observed among those who had taken care of their lover or close friend during this illness compared with those who did not act as
caretakers” (p. 477). It was also “demonstrated that individuals who are caretakers of people with AIDS and who lack emotional and concrete social support suffer more intense and prolonged grief reactions following the death than do caretakers reporting the presence of reliable support” (Martin & Dean, 1993, p. 95). The “data from the first 5 years of the AIDS epidemic suggested that gay men were not adapting well to multiple personal losses and that there was a direct relation between the number of bereavements and the level of psychological distress” (Martin & Dean, 1993, p. 94). Similarly, Bierman (1996) found a relationship between very high numbers of losses and high grief scores in her exploratory study of 11 gay men.

Martin and colleagues also did a follow-up evaluation of the previously noted New York gay men for the period 1985 – 1991. These findings did replicate the earlier results that noted “bereavement of a close friend or lover who dies of AIDS results in significant psychological distress involving one or more of the following types of symptoms: depression, traumatic stress, sedative use and suicidal ideation” (Martin & Dean, 1993, p. 102). However, changes were noted in contrast to the first period of evaluation.

Bereavement that in previous years was distressing has become less so over time for the men classified as HIV negative. Men who are without major symptoms of AIDS or who know that they are HIV negative may become habituated to the experience of AIDS-related losses. However, men classified as HIV positive (both those who are bereaved and those who are not) continue to experience higher levels of distress. Many of these men seek help for their psychological problems. In this study, men who were bereaved because of AIDS sought (increased or initiated) professional psychological help nearly four times as often as did the nonbereaved group. (Martin & Dean, 1993, p. 103)

Neugebauer et al. (1992) completed a study of New York gay men similar to that done by Martin and colleagues. They found no correlation between increased depressive symptoms, number of losses, type of loss, and recency of losses. However, “men with greater numbers of losses reported more subjective experiences characteristic of preoccupation with and searching for the deceased than did men with fewer losses” (Neugebauer et al., 1992, p. 1377).
Gluhoski et al. (1997) also completed a longitudinal comparative study of multiple bereavement in 610 HIV positive and HIV negative New York gay men. Their study was designed similarly to previous studies and samples of research done by Neugebauer et al., and Martin and colleagues. However, Gluhoski et al. (1997) included a broader definition of AIDS-related deaths, and was “not limited to only AIDS specific deaths” (p. 524). This study was also intended to clarify the different findings reported between Martin and colleagues, and Neugebauer et al. Gluhoski (1997) found chronic distress of the mourner when he had experienced two or more close deaths over a year period. This distress was examined based on quantitative evidence of increased depression, traumatic stress response, anxiety, and global distress. “HIV positive subjects showed higher levels of distress symptoms on all measures, except for intrusive and avoidant thoughts and images” (Gluhoski et al., 1997, p. 521). Gluhoski et al. (1997) found “a single close death will not typically produce chronic psychological symptoms”, and “additional losses beyond three do not significantly increase symptoms” (p. 530). Gluhoski et al. (1997) also noted the resilience of subjects to these losses.

Viney et al. (1992a) combined quantitative and qualitative analysis to assess the cumulative impact of multiple deaths from AIDS. This study compared the experience of two Australian gay communities that differed in their experience with bereavement. The greater bereaved community demonstrated higher quantitative measures of anger, and anxiety, including anxiety related to death, bodily mutilation, and separation (Viney et al., 1992a). Surprisingly, the less bereaved community expressed greater levels of depression and guilt.

Biller and Rice (1990) in their interviews of two lesbians and five gay men explored the qualitative impact of multiple loss. They conclude that multiple loss is different from ‘normal’ bereavement and that there is insufficient time to work through the feelings of the grief process.

Individuals who face loss after loss cannot be expected to bounce back; each grieving process is compounded by the one before it. ... In addition, because of the losses experienced, survivors tend to turn inward, which may have long-term, irreparable effects. ... Interestingly, after each new loss, survivors seemed to further grieve the loss they had identified as most significant. ...
Recent losses were minimized and the grief wounds for the most significant loss never healed (Biller & Rice, 1990, p. 288).

Carmack’s (1992) qualitative study involved interviews with nineteen gays and lesbians who had experienced multiple loss from AIDS in their community. She used grounded theory analysis in an attempt to develop new grief theory. Her research described four ways in which these participants coped with multiple loss. These four ways were on a continuum that she labeled functional engagement, dysfunctional engagement, functional detachment, and dysfunctional detachment. “Individuals in the study who perceived themselves as functionally detached reported acceptable feelings of self-protection against emotional pain and over involvement with others and the community although still caring” (Carmack, 1992, p. 11). Those coping “on a level of dysfunctional detachment reported unsatisfactory feelings of numbness and uninvolved, in addition to a sense that they made no difference to other individuals or to the community” (Carmack, 1992, p. 12). Those describing themselves as functionally engaged appeared to manage and balance their involvement. Those dysfunctionally engaged expressed feelings of “being overwhelmed by other people’s needs” and unable to balance their involvement (Carmack, 1992, p. 12). Individuals in this study identified that multiple loss included the loss of people and lifestyle. Participants described “the inability to finish grieving for one loss before another occurs” (Carmack, 1992, p. 12). The greater the amount of loss the greater the disorder and disconnection from the way of life they once knew. “Continuity was perceived as order or as staying connected with one’s previous life” (Carmack, 1992, p. 13). The experience of multiple losses also created a redefinition of values for these participants. Respondents expressed a need to balance their involvement, which would allow them to still contribute to their community, and yet to protect themselves from being overwhelmed by losses and grief.

Fahrenbach’s (1992) qualitative study explored the impact of AIDS-related loss in twelve uninfected gay men. The men in this study were found to be in a chronic state of grief, and experiencing a great deal of survivor guilt. They also struggle with issues related to relationships, and
are attempting to varying degrees of success to find ways to meaningfully adjust to the loss and change. Also noted was the impressive evidence of psychological resilience, the working through of grief, and the discovery and construction of new meaning in their lives. It was suggested that protracted loss may have significant impact on these participants' abilities to survive in a psychologically healthy way.

Werner (1992) in his qualitative study of twenty gay AIDS bereaved partners noted limited validation for the gay relationship, multiple losses occurring in the gay community due to AIDS, and concerns for the survivor's own personal health status were significant factors in these gay bereaved. There was a high incidence of suicidal ideation, psychiatric episodes, and health problems. However, personal growth and changes in personal values were widely reported. Many respondents pursued professional counseling due to the lack of traditional supports.

Rockefeller (1994) in his qualitative study of thirty-two HIV-negative gay men coping with multiple AIDS related loss noted reoccurring stressors for these men. These included: watching partners, friends and acquaintances fall ill and die; isolation and immobilization resulting from unprocessed grief and bereavement; the complex uncertainty of one's ability to maintain a seronegative status and fear of seroconversion; the lack of personal and communal support systems for HTV-negative men within the gay community; and sexuality and sexual expression in the age of AIDS (Rockefeller, 1994). Various psychosocial adaptations occurred in this group in response to these stressors. These adaptations included: HIV was seen as a catalyst for self discovery and growth; the importance of interpersonal relationships; creating community and social support systems; volunteerism and social activism. It was further noted that personal and communal rituals of grieving were important to assist these individuals in adapting to multiple loss and bereavement.

Sowell et al. (1991), and Cherney and Verhey (1996) applied Sanders Integrative Bereavement Theory (1989) to the experience of gay bereaved. Sowell et al. (1991) completed research with eight gay bereaved men following the death of a lover from AIDS. The lack of social support and social stigma "attached to both the diagnosis of AIDS and the homosexual lifestyle profoundly influenced the
survivor's ability to progress through the grieving process” (Sowell et al., 1991, p. 93). Further, the threat of developing AIDS influenced their “ability to progress through the bereavement process” (Sowell et al., 1991, p. 93). Cherney and Verhey (1996) explored the experience of multiple losses from AIDS in ninety-three gay men in San Francisco who had experienced a minimum of three losses from friends, lovers or relatives to AIDS. They noted an adaptive process of habituation may be occurring in response to these multiple losses. “There was no significant relationship between the number of individual losses reported and the intensity of grief experienced” (Cherney & Verhey, 1996, p. 115). A number of social and demographic variables were significant in this research. Lower levels of rumination and somatization were associated with higher levels of education. “A significant correlation existed between number of losses and the frequency of alcohol and drug use” (Cherney & Verhey, 1996, p. 125). Increased intensity of rumination and somatization was associated with loss of a committed partner. Individuals “not in a committed relationship” reported “increased levels of despair and social isolation” (Cherney & Verhey, 1996, p. 126). Social support was noted to be a critical factor in facilitating bereavement. An inconsistent and surprising finding was that those involved in AIDS caregiving reported lower levels of despair.

Participants in a survey of ASOs in Ontario perceived multiple loss to have effects on concentration, poor morale, apathy, overworking, blurring of boundaries, emotional outbursts, and feelings of isolation, anger, despair, and helplessness (Gibson & Plotnick, 1997). Yet, positive impact was also noted in that the experience was seen as enhancing their “belief in the meaning of and appreciation of life” and “improvement in their spiritual health” (Gibson & Plotnick, 1997, p. vi).

However, while recognizing the above challenges faced by AIDS bereaved, it is important we not pathologize individuals, organizations and communities. This may present a particular challenge when we realize that professional care providers are challenged to assist others with AIDS grief even though they “have minimal training in bereavement counseling” and knowledge of “multiple/relentless loss” (Haviland et al., 1997, p. 16). This is occurring at the same time as societal and organizational
denial, minimization, and lack of understanding of grief exist, as has been previously noted. Theresa Rando (1992) is also critical of the lack of proper diagnosis, appropriate diagnostic categories within mental health, and available treatment for complicated grief. Alternatively, Martin (1989) has suggested that complicated grief reactions are "a normal response to a catastrophic event rather than a maladaptive reaction to a normal stressor" (p.71). Perreault (1995) has acknowledged the continued benefit of this concept. "AIDS grief needs to be understood as normal grief in an abnormal time" (Perreault, 1995, p. 34). Consequently, we are seeing a shift in thinking and attempts to apply contributions from other areas including stress and coping theory, trauma, disaster, and social and political repression to help explain the experience of AIDS bereaved. These areas will be reviewed next.

2.4 ALTERNATIVE CONCEPTS APPLIED TO AIDS GRIEF AND MULTIPLE LOSS

Stress and Coping Theory

Stress and Coping Theory attempts to explain the relationship between external demands and resources available to manage these stressors (Benner et al., 1980). The transactional model developed by Lazarus and associates recognizes "three key concepts: cognitive appraisal, coping, and transaction" (Benner et al., 1980, p. 225). Briefly these concepts are as follows.

Cognitive appraisal refers to an individual's or a communities' ongoing "evaluation of a situation" and "meaning ascribed to this disruption" (Benner et al., 1980, p. 225). Secondly, the concept of coping "represents an attempt to manage stress" by intervening directly with the environment, "or by diminishing the emotional distress resulting from it" (Benner et al., 1980, p. 228). These coping responses can be both positive and negative in resolving the distress. Benner et al. (1980) further recognized the complexity and need to alter one's view of successful coping under extreme situations. Finally, stress and coping involves a transactional process, whereby there is an ongoing and changing relationship in this complex process.
“This process of change becomes even clearer when we examine a long-term, complex stress situation such as bereavement” (Benner et al., 1980, p. 234). Specifically, stress and coping theory has been applied to the experience of AIDS grief by several writers (Cadwell, 1994; Folkman, Chesney, Collette, Boccellari & Cooke, 1996; Goodkin et al., 1996; Martin, 1988; Martin, 1989; Moskowitz, Folkman, Collette & Vittinghoff, 1996; Rosengard & Folkman, 1997). In particular Rosengard and Folkman (1997) focused on the relationship between suicidal ideation, bereavement, HIV status, and psychosocial factors. They found no relationship between HIV status and increased likelihood of suicidal ideation. They found that “suicidal ideation was reported by more than half of the primary caregivers of gay and bisexual men with AIDS” (Rosengard & Folkman, 1997, p. 383). Increased suicidal ideation was associated with those “who experienced many burdens, perceived little social support, felt less socially integrated, and relied on behavioral escape-avoidance coping strategies” (Rosengard & Folkman, p. 380). “Optimism is the one factor that appears to provide some measure of protection against the occurrence of suicidal thoughts among this sample of gay and bisexual men” (Rosengard & Folkman, 1997, p. 381).

Moskowitz et al. (1996) compared the coping and mood of HIV positive and HIV negative AIDS-related caregivers and their bereavement. No relationship was found between the mood and HIV status of the caregivers. Researchers have often examined negative mood. This study highlights the importance of focusing on types of coping that help support positive mood (Moskowitz et al., 1996). Active problem solving and positive reappraisal were two coping strategies associated with positive mood and coping with bereavement. Similarly, Folkman et al. (1996) noted the significance of positive reappraisal and its role in diminished depressive mood in gay male caregivers that were coping with a partner’s death. A discussion of trauma, and bereavement in trauma as aspects of stress and coping under extreme conditions follows.
Trauma

Trauma “brings loss” and these losses “rupture the ordinary sequence of generations”, and defy “the ordinary social conventions of bereavement” (Herman, 1992, p. 188). In particular Kellerhouse (1997) in his qualitative study of AIDS related bereavement in HIV negative gay men found participants’ experiences are similar to those of survivors of traumatic and catastrophic events. These men described themselves as: fighting a battle against AIDS; searching for survivors like themselves; wondering if they would become casualties themselves; witnessing atrocities to the human body and spirit; experiencing multiple losses of their peers; remaining vigilant against infection and the effects of future loss; experiencing intrusive thoughts and dreams; and feeling wounded by the deaths of their dearest and closest friends (Kellerhouse, 1997).

The terms post traumatic stress disorder (PSTD) (Catalan, 1995; Grothe & McKusick, 1992; Dane & Miller, 1992; Martin, 1988; Martin, 1989; Nord 1996; Nord 1997; Perreault, 1994; Perreault, 1995; Richmond & Ross, 1994; Schoen, 1992; Sherr, 1995; Trice, 1988), and disaster (Berube, 1989; Biller & Rice, 1990; Dane & Miller, 1992; Schwartzberg, 1992a) have been referenced as a means to articulate the extreme stress AIDS bereaved are experiencing. A discussion of PTSD and disaster follows.

Post Traumatic Stress Disorder

Post traumatic stress disorder is a syndrome that occurs in response to an extreme stressful or traumatic event (Catalan, 1995; Dane & Miller, 1992, Martin, 1989). The concept of post-traumatic stress disorder is “based upon the prototypes of combat, disaster, and rape” (Herman, 1992, p. 119). It includes recurrent and intrusive distressing recollections, dreams or feelings related to the event, persistent avoidance, numbing, and symptoms of persistent arousal (Catalan, 1995; Dane & Miller, 1992; Martin, 1988; Martin, 1989).
Disaster

Increasingly we are seeing reference to the concept of disaster as a means to articulate the individual, and collective devastation created by AIDS (Biller & Rice, 1990; Dane & Miller, 1992; Nord, 1997; Schwartzberg, 1992a). Biller & Rice (1990) in their own research on AIDS multiple loss in the gay community have acknowledged the benefit of Tyhurst’s (1951) three overlapping phase model of disaster. These three overlapping phases include a period of impact, period of recoil, and a posttraumatic period. These phases “are influenced by time, and psychological characteristics” (Biller & Rice, 1990, p. 285).

Dane and Miller (1992) have also applied a grief model from disaster to AIDS grief. They use Cowan and Murphy’s (1985) six factor model which includes:

1) mode of death; 2) multiple, simultaneous deaths in a family; 3) the appraisal of the death event, that is, devastating, threatening or challenging; 4) the relationship between the deceased and bereaved prior to death, that is, valued or ambivalent; 5) coping skills; and 6) perception of social support (Dane & Miller, 1992, pp. 46-47).

Schwartzberg (1992a) identified the application of Lifton’s (1980) five themes that comprise “the concept of the survivor” (Schwartzberg, 1992a, p. 423.). These include:

1) the death imprint, or indelible mental images of death and dying, which are borne from the enormity of the loss; 2) death (or survivor) guilt, rooted in the randomness of the situation and embodied in the question, “Why did I survive while he, she, or they died?”; 3) psychic numbing, or the survivor’s diminished capacity to feel, due to the emotional overload of the traumatic events; 4) a suspicion of counterfeit nurturance, relating to the emotional extremity of the event; and 5) the search for meaning, which results from living through an experience that shatters, or grossly contradicts, many of the fundamental rules by which a person had previously guided his/her life (Schwartzberg, 1992a, p. 424).

Additionally, Assumptive World theory has also been used to explain the meaning made in coping with a traumatic event (Janoff-Bulman, 1989), in bereavement (Schwartzberg & Janoff-Bulman, 1991), and with HIV positive gay men (Schwartzberg, 1992b). This theory is based on three basic assumptions in which an individual makes sense of and rebuilds their world based on a negative experience (Schwartzberg & Janoff-Bulman, 1991).
While the concepts of PSTD and disaster are used to attempt to understand the devastation created by AIDS they continue to leave out a critical analysis of the social and political context that informs AIDS grief and multiple loss. Judith Herman (1992) critiques the psychiatric and diagnostic category for trauma by stating that the categories are not comprehensive enough, because “the connection between the symptoms and the traumatic experience is frequently lost” (Herman, 1992, p. 118). She states that with “survivors of prolonged, repeated trauma, the symptom picture is often far more complex”, and needs to include a range of responses (Herman, 1992, p. 119). Consequently, I believe the grief concepts from literature on coping with social and political repression may be helpful given the social, political and cultural context of AIDS. These concepts, not previously applied to AIDS grief and multiple loss, may be helpful in understanding the devastation created for individuals and communities.

2.5 NEW CONCEPTS APPLIED TO AIDS GRIEF AND MULTIPLE LOSS – SOCIAL AND POLITICAL REPRESSION

A variety of short and long term symptoms have been associated with individuals who cope with extreme traumatization associated with social and political repression (Becker et al., 1989). The work of Becker et al. (1989) is intended to provide a critical understanding of the grief processes that effect an individual’s, and communities’ mental health as a result of a repressive social and political context. This work is based on Bruno Bettelheim’s writing about his own survival of the Holocaust, and the experience of extreme traumatization in Chile. I believe the following grief processes may provide a more useful working framework in helping us understand the process of grief and healing associated with AIDS grief and multiple loss than present contributions. The grief processes identified by Becker et al. (1989) are: loss and grief, identification with death, guilt, contradiction, equilibrium-disequilibrium, and privatization of the injury.
Loss and grief

“The nucleus of the problem confronting us is constituted by the prolonged experience of death in a personal life situation within a political context” (Becker et al., 1989, p.88).

And then one loss followed another: loss of rights, loss of job, loss of physical integrity, loss of tranquillity, and loss of the family stability of loved one, and the capacity to decide one’s own life. The patient’s specific traumatic situation signals the predominance of some specific loss, but the losses intermingle and accumulate (Becker et al., 1989, p.88).

These individuals “endeavor to maintain the personal and social meaning of the events and this effort has allowed them to tolerate the multiple losses and to survive. In a certain sense, the same survival mechanism impedes real elaboration of the losses” (Becker et al., 1989, p.89). This initial process is able to recognize the grieving process and enormity of loss present in AIDS grief. It also identifies the central challenge in AIDS grief, that being, to find meaning when a way of life has been changed by multiple losses.

Identification with death

Identification with death may be observed in an explicit desire to die, development of rash and self destructive behavior, the appearance of severe diseases ... and fantasies about death and about how the loved one died. Although identification with death can be observed in other kinds of grief, in these situations of extreme traumatization it requires an intense and contradictory quality: the loss is experienced in a social context that continues to engender threats. (Becker et. al., 1989, p. 89)

The description here is consistent with the mental health consequences for AIDS bereaved (Martin & Dean, 1993; Neugebauer et. al., 1992; Viney et al., 1992a). As well, it is consistent with the notion of death imprint (Niederland, 1971) applied to AIDS grief and multiple loss (Nord, 1997). Further, within the stories of AIDS bereaved we see this identification with death through a preoccupation with obituaries, attending memorial services, and attending to one’s own estate planning. Given that many grieving from AIDS cannot escape the experience of death, dying family, friends and lovers, this identification with death becomes normative.
Guilt

"Guilt is a frequently observed dynamic directly related to the necessity of answering the questions why and how things have happened" (Becker et. al., 1989, p. 89). Guilt, and in particular survival guilt is a feature already noted in AIDS due to the explicit socially defined self blame attached to anyone HIV positive or with AIDS, or by affiliation the AIDS griever (Boykin, 1991; Cadwell, 1991).

Contradiction

Individuals attempt to "leave behind" the past by: "attempting to forget the destruction and returning to an integral and unhurt state through a kind of voluntary dissociation" (Becker et al., 1989, pp. 89-90). Efforts are also made to "reorganize their life and affective ties", but these are experienced "as a disloyalty to those who are unable to undertake a similar process (Becker, et al., 1989, p. 90).

It is part of the damage of the extremely traumatic situation that the victims are forced to make unilateral choices to solve the contradictions they are living and that intrude upon every level of psychic functioning. This kind of choice is but another attempt to reduce suffering, in the unconscious illusion that it is possible to eliminate the contradictions. ... The possibility of permitting oneself to be both strong and weak, to lament the losses and to struggle for truth and justice, is not just a reparative act in psychological terms: it also implies asserting a relevant and important political and social claim. (Becker et al., 1989, pp.90-91)

The struggle noted here is also inherent in multiple losses and deaths related to AIDS. The AIDS bereaved attempt to cope with past losses, the changes in one’s community and lifestyle, and the efforts to continue to live in a context where you cannot escape the suffering. The challenge is also to recognize one’s loss is a relevant and important claim about the social and political nature of AIDS.

Equilibrium-disequilibrium

When a person is forced for a long time to undergo deprivation of liberty, ... suffer an unresolved grief, or even the indirect threat of a repressive system, he or she fashions for himself or herself a way of life that accords with the pathological social context. ... Thus, the perversion of social regression becomes an axis around which everyday life is structured. ... To the extent that this situation becomes chronic, the person must confront the paradox of restructuring his or her life and recovering his or her emotional balance on the basis of what has been destroyed. (Becker et al., 1989, 91)
The challenge in AIDS bereavement is to find some sense of balance while coping with cumulative and ongoing losses (Biller & Rice, 1990; Carmack, 1992) in a social context that continues to repress expression of or identification of the loss.

**Privatization of the damage**

"When we speak of 'privatization of damage', we are referring to the fact that extremely traumatized persons end up living this problem as a private problem, dissociated from the social-political character that the event initially had" (Becker et al., 1989, p. 92). These individuals believe they are responsible for the problem and this "individual justification seems to be something between guilt and depression" (Becker et al., 1989, p. 93). "It is necessary that the subjects be able to link their traumatic experience with the social and political context in which it happened and with the meanings and loyalties that make it understandable for them" (Becker et al., 1989, p. 93).

Herein lies the transformative quality of these grief processes that can be applied to AIDS grief and multiple loss. These grief processes are able to incorporate the complexity of losses related to AIDS, account for the multiple losses and disruption/disequilibrium created by one's inability to escape this climate of loss. However, most importantly, this model incorporates an understanding of the social, cultural, and political context that informs, defines, and creates the social structures that make it so difficult to be an AIDS griever. It is transformative through its goal to locate the painful reality of AIDS grief and multiple loss as much more than an individual problem. A discussion of the concepts applied to AIDS caregivers follows.

### 2.6 CONCEPTS APPLIED TO AIDS CAREGIVERS

Various concepts have been used to explain the experience, and impact of caring in this battle with AIDS. Vicarious grief (Kastenbaum, 1987), or the sorrow one feels for a loss suffered by another is an experience many AIDS caregivers can relate to. Secondary stress disorder or compassion fatigue, countertransference, vicarious traumatization, and burnout are efforts to recognize the trauma associated
with witnessing the pain of others. It is important to recognize that these concepts, their definitions, and their applications are evolving (Figley, 1995). A discussion of these concepts follows.

**Secondary Stress Disorder & Compassion Fatigue**

The concept of secondary stress disorder (STSD) comes from the related concept of PSTD. The symptoms are similar to PTSD (Nord, 1997) including reexperiencing the traumatic event, avoidance and numbing in response to reminders of the event, and persistent arousal (Figley, 1995). "STS is a natural consequence of caring between two people, one of whom has been initially traumatized and the other of whom is affected by the first’s traumatic experiences" (Figley, 1995, p. 11). The more friendly term used to describe this experience is called compassion fatigue (Figley, 1995).

Compassion fatigue has been compared to burnout, and is different in that it can emerge suddenly in response to an event, and generally has a faster recovery rate (Figley, 1995). “It’s a condition that shares some symptoms with burnout: depression, anxiety, hypochondria, combativeness, the sensation of being on fast-forward, an inability to concentrate. The difference is that with compassion fatigue, caregivers can still care and are still emotionally involved” (Garfield, 1995, p. 264). According to Garfield (1995) “those experiencing compassion fatigue are able to monitor this decrease in empathy and feeling and remain emotionally accessible” (p. 265). However, survivors may also “experience a delayed onset of these symptoms (Beaton & Murphy, 1995, p. 59), which can “be mixed and slow to appear” (Dutton & Rubinstein, 1995, p. 92), “especially when the traumatization is prolonged or likely to recur” (Nord, 1997, p. 142).

Compassion fatigue has been referenced in application to AIDS by Garfield (1995), Gervais (1996), and Nord (1997). A related concept is countertransference, and a discussion of it follows.

**Countertransference**

Countertransference is “any response the therapist has to her client, positive or negative, conscious, or unconscious, spoken or unspoken” (Pearlman & Saakvitne, 1995, p. 22). Freud first coined this term in 1910 (Pearlman & Saakvitne, 1995). Freud “viewed the therapist’s response as a
hindrance” that should be overcome (Pearlman & Saakvitne, 1995, p. 42). As psychological theory developed, other contributions, primarily from women psychoanalysts and self psychology, challenged this thinking (Pearlman & Saakvitne, 1995). Countertransference began to emphasize “mutuality and authenticity in the therapeutic relationship”, and became a source of valid and useful information about the therapeutic relationship rather than something the therapist must overcome (Pearlman & Saakvitne, 1995, p. 43).

Yael Danieli has also contributed the idea of event countertransference based on her extensive work with Holocaust survivors and therapists. Her notion of event countertransference and countertransference reactions to the Holocaust (Danieli, 1994) further suggests that helpers can have reactions directly to the social and political context in which survivors and helpers live. I believe her notions are particularly helpful in light of the social and political context of AIDS. In the context that surrounds AIDS personal and professional caregivers may experience reactions similar to those coping with social and political repression. “These reactions involve intense feelings of helplessness, vulnerability, despair, overidentification, ambivalence, and fear” (Comas-Diaz & Padilla, 1990, p. 125).

A variety of authors document the countertransference challenges experienced in supporting those HIV positive and with AIDS (Cadwell, 1994; Chachkes, Kaufer, Primack & Ullah, 1991; Dunkel & Hatfield, 1991; Gabriel, 1991, 1994; Garfield, 1995; Gervais, 1996; Macks, 1988; McKusick, 1988; Shernoff & Springer, 1992; Wiener & Siegel, 1990; Winiarski, 1991). In particular these authors identify the vulnerabilities experienced by personal and professional caregivers supporting those HIV positive and with AIDS. Vulnerability to contagion, or infection by the AIDS virus is repeatedly referenced as a stress or fear especially given the exposure to the suffering connected with this disease (Cadwell, 1994; Gervais, 1996; Macks, 1988; McKusick, 1988; Wiener & Siegel, 1990; Winiarski, 1991). Personal and professional caregivers are exposed and vulnerable to experience intense emotions, death and dying, multiple losses, and homophobia or reactions to homophobia. Additionally, given the similarities of age and lifestyle, personal and professional caregivers often identify and overidentify
with those they support (Cadwell, 1992; Dunkel & Hatfield, 1986; Gervais, 1996; Macks, 1988; Shernoff & Springer, 1992; Winiarski, 1991).

A further extension of countertransference reactions has developed under the term vicarious traumatization. A discussion of this term follows.

**Vicarious Traumatization**

Vicarious traumatization, though similar to countertransference and STS/compassion fatigue, relates specifically to the changes in the therapist as a result of hearing painful stories. "It recognizes that the cognitive world of the therapist will be altered by hearing clients’ traumatic material" and there will be "symptoms of secondary stress in the context of profound changes in the therapist’s sense of identity, meaning, world view, and beliefs about self and others" (Bettcher, 1996, p. 23). Vicarious traumatization is the accumulation over time, with numerous clients, of our reactions to hearing painful stories without outlet or attention, which become stored in our body and experience. This accumulation can result in vicarious traumatization, and a reduced awareness to attend to our own future reactions or countertransference to hearing painful stories (Pearlman & Saakvitne, 1995).

Vicarious traumatization was first applied to the experience of therapists counseling sexual abuse survivors. It results in a depletion of the support person’s “physical, emotional, and intellectual energy, thus lessening the resources” the person has available to provide support (Pearlman & Saakvitne, 1995, p. 279). Those experiencing vicarious traumatization may experience shifts in:

1. their identity and world view; 2. their ability to manage strong feelings; 3. their ability to maintain a positive sense of self and positive connections to strong feelings; 4. their sense of meaning or spirituality; and 5. their basic needs for safety, esteem, trust, dependency, intimacy, and control (Bettcher, 1996, pp. 20-21).

Bettcher (1996) further summarizes that therapists’ reactions can parallel those of the survivor and can include “post-traumatic stress symptoms, intrusive imagery, and emotional reactions such as anger and anxiety” (p. 21). Gervais (1996) and Nord (1997) have applied the concept of vicarious traumatization to caring for those with HIV and AIDS.
The final concept applied to AIDS caregivers is burnout. This concept is the most researched of these concepts in its application to AIDS caregiving. A discussion of burnout follows.

Burnout, Grief, Support and Healing Strategies

"Burnout was first described in the literature by Freudenburger (1973), who identified a state of fatigue and frustration arising from unrealistic and excessive demands on the personal resources of health and service workers" (Miller, 1995, p. 19). Numerous definitions and models of burnout have been proposed (Bennett, Michie & Kippax, 1991). Burnout is now being seen as a process rather than an end-state, as was noted in earlier definitions and models (Miller, 1995). This presents hope for earlier identification and intervention (Bennett, 1995).

Research on burnout and HIV/AIDS is in early stages of development (Maslach & Ozer, 1995). However, at this time Bennett and colleagues have completed the most extensive evaluation of burnout from the point of view of AIDS professional caregivers. Their work has led to the development of the AIDS Impact Scale as a means to recognize that AIDS has positive and negative effects (Kelaher & Ross, 1995). They have used Maslach and Jackson’s (1981) definition of burnout, which I will use here.

Maslach and Jackson (1981) define burnout as a combination of the following:
(1) Emotional exhaustion - feelings of being emotionally overextended and exhausted by one’s work;
(2) Depersonalization – an unfeeling and impersonal response to clients; and
(3) Lack of personal accomplishment – a tendency to evaluate oneself negatively, particularly in relation to work and dissatisfaction with personal accomplishment at work. (Bennett et al., 1991, p. 181).

In relation to HIV and AIDS, stress and burnout, particularly in the early days, was associated with overcompensating by some individuals for others who “were refusing to care for people with HIV/AIDS due to fear, homophobia and discrimination” (Bennett et al., 1995, p. 23). It has been noted in some studies that “staff are more likely to report burnout after a longer period of time in their area of work (Bennett, Michie and Kippax 1991)” (Bennett, 1995, p. 89). However, Egan (1993) noted social workers that were in the field longer were “able to find AIDS work less difficult and to burnout less
than younger workers" (p. 121). A similar finding was noted in Oktay’s (1992) study of social workers. Haviland et al. (1997) also noted decreased feelings of depersonalization and emotional exhaustion with age.

It has been noted that the greater intensity of the work in the context of AIDS leads to emotional exhaustion (Bennett et al., 1991; Horstman & McKusick, 1986; Visintini et al., 1996). The heavy needs of clients, the daily confrontations and losing battle with death all create high levels of exhaustion and stress (Bennett, 1995). The intensity of this work is further related to: repeated contacts with clients over an extended period of time; strong identification with clients because of similarities in life style and age; and the development of surrogate family roles where clients are disconnected from their families of origin (Bennett et al., 1991; Bennett, 1995). “It appears that the intensity rather than chronicity of work contributes to AIDS health care worker morbidity” (Bennett, 1995, p. 89). Other unique HIV and AIDS specific stressors include: “youth of patients, multiple problems caused by AIDS, inability to find a cure or solution to AIDS, giving HIV test results, neurological aspects of AIDS, and the unpredictability of illness progression” (Cushman, Evans & Namerow, 1995, p. 125).

“Like burnout, grief is also predicted to have a stronger impact with greater length of time in the area” (Bennett, 1995, p. 89). “Staff who experienced higher levels of grief were those who reported higher identification with people with AIDS” (Bennett, 1995, p. 95). Professional caregivers also experience disenfranchised grief, stigma and discrimination similar to their clients, especially if they are also homosexual (Bennett, 1995). While more study is needed to understand the relationship between burnout and grief processes, Bennett (1995) does express a concern that unattended grief may make staff more prone to burnout. Additionally, the impact of grief in relation to burnout of HIV and AIDS volunteers remains unclear (Nesbitt, Ross, Sunderland & Shelp, 1996). Guinan et al. (1991) found “lack of support network, the coexistence of other sources of stress, the length of volunteer service, and, especially, the number of client deaths experienced” predicted high stress levels (“Stresses and Rewards of AIDS Volunteering”, 1992). However, no significant relationship was found between burnout and
grief in the Nesbitt et al. (1996) study of volunteers. The fact that volunteers controlled the time, motivation, and choice of their commitment to volunteer were seen as factors that make burnout different in volunteers than health workers (Nesbitt et al., 1996). However, informal caregivers within an extended support system of partners, friends, and relatives are noted to experience considerable stress. These voluntary caregivers have not planned or been trained in the extensively demanding physical and emotional tasks of caregiving, have personal and emotional relationships to the person they are caring for; and are likely to have other work responsibilities for which they are paid (Maslach & Ozer, 1995).

Organizational factors leading to burnout have been well documented both within the HIV specific literature and in its application from other literature. These organizational factors include: bureaucracy, understaffing, funding problems (Cushman et al., 1995), and low pay, long hours and high caseloads, excessive paperwork, little opportunity for advancement, powerlessness, no or poor supervision, small and poor office space and location, and unresponsive and unappreciative bureaucratic environments (Haviland et al., 1997; Oktay, 1992). The above issues are similarly noted in U. S. AIDS prevention and service organizations by Janez et al. (1995). Further, Soos (1991) noted concern regarding the potential costs of burnout in the Shanti Project in San Francisco. As well, Guinan et al. (1991) in his study of HIV/AIDS volunteers “found that emotional overload, client problems, lack of support for staff and lack of training were significant stresses in HIV/AIDS work” (Miller, 1995, p. 24). Further, Maslanka (1996) recommended earlier intervention with volunteers, training to help volunteers recognize the signs of burnout, and a more realistic picture of volunteering as strategies which may help retain and reduce volunteer exhaustion. Bennett, Ross and Sunderland (1996) recommended that professional AIDS caregivers “need adequate preparation, training and recognition for this challenging work” (p. 152).

Further, to the theme of organizational stresses, is the notion of traumatic exposure in the workplace environment as noted by Dunning (1994). “Workers who routinely confront wounds,
disease, and imminent death develop their own protective culture, with necessary defenses (intellectual, distancing, protocol, isolation, black humor, and esprit de corps (a form of group spirit) that mitigate against the worker being overwhelmed by such exposure” (Dunning, 1994, p. 365). Further, within an organizational environment there may a variety of reactions between workers which adds to the complexity of response to traumatic event(s) (Dunning, 1994). Dunning (1994) notes that employee performance including demeanor, attitude, and behavior are severely affected by traumatic events in a work setting. Behaviors related to exposure to traumatic events include “difficulties in concentration and decision making, poor memory, and distractibility” which “may effect work performance” (Dunning, 1994, p. 356). However, she notes traumatic exposure is rarely considered in relation to issues of employee work performance, disciplinary actions, and termination. These issues may be helpful in further understanding that grief saturated organizations, like ASOs, create a climate of continual trauma which has significant effects on individual and organizational functioning.

However, while organizational and HIV specific stressors are considerable for professional caregivers considerable resilience is noted (Egan, 1993). Similarly, this resilience has been previously noted in studies of multiple loss in gay communities (Fahrenbach, 1992; Gluhoski et al., 1997). Haviland et al. (1997) found that AIDS care providers experience high levels of personal accomplishment and satisfaction that may reduce a sense of emotional exhaustion and depersonalization. Oktay (1992) also found personal accomplishment helped to balance high rates of emotional exhaustion and depersonalization in social workers working with AIDS patients. Bennett, Ross and Sunderland (1996) found that the rewards and recognition associated with AIDS work act as a buffer against burnout, and assist with retention in the field.

It seems that the challenging nature of HIV work can also provide an opportunity for the professional to develop a sense of meaningful contribution that helps transform the challenge of this work. Therefore, work can be perceived “as stressful, difficult, and meaningful” (Egan, 1993, p. 121). This meaning found in the work was similarly noted to assist in sustained commitment of gay
psychotherapists (Cadwell, 1994). AIDS care providers are noted to experience a sense of self esteem about their work when they view themselves as contributing to small victories in this front line fight of a worldwide disaster (Haviland et al., 1997). Viewing AIDS work as "a personal investment in and dedication to AIDS care" may increase "tolerance for the emotional demands of the work" (Hooley, 1997, p. 763). This personal commitment to HIV and its positive impact on AIDS care providers was also noted by Haviland et al. (1997). Those who recognize and take on the challenge associated with caring can also experience personal growth as psychotherapists (Cadwell, 1994), as staff in ASOs (Gibson & Plotnick, 1997), and as gay bereaved (Fahrenbach, 1992; Werner, 1992).

Hooley (1997) further notes "the use of both individual and institutional coping methods is essential in modulating the intensity and challenge of the work, preventing burnout, and maintaining the emotional and psychological well-being of practitioners" (p. 763). "External coping skills (fatalistic attitudes, negative expectations, and reliance on faith, prayers or miracles), predicted burnout. Internal coping skills, which involve expression of feelings and emotions, patience, and time-out strategies were found to be associated with lower burnout scores" (Bennett et al., 1995, p. 28). Positive coping strategies were previously noted to help gay bereaved (Folkman et al., 1996; Moskowitz et al., 1996).

Additionally, informal support networks assisted in sharing of the intensity and challenging nature of the work. This was particularly the case given the "perception that persons who were not AIDS care providers did not understand the issues they faced" (Hooley, 1993, p. 763). Supervision, collegial support and supportive friendships were also noted to play significant roles for social workers (Clarke, 1995), gay psychotherapists (Cadwell, 1994), and AIDS care providers (Haviland et al., 1997). Political and community involvement also play a role in coping with one's reactions to working in HIV (Cadwell, 1994). Hooley (1997) also noted that for some individuals "self involvement in the AIDS education arena" may serve as a coping skill (p. 762). This was similarly noted as a coping strategy by gay men who experienced multiple losses (Rockefeller, 1994).
Bennett et al. (1995) summarize the following skills as significant in reducing AIDS burnout. These include: "the setting of professional boundaries, coping skills, confirmation of psychosocial successes, and utilization of social and professional supports" (p. 29-30). Additionally, supports for reducing the impact of AIDS and coping with AIDS grief include: humor, ritual, social and collegial support, supervision, spiritual beliefs, psychotherapy, setting limits and boundaries, balancing one's involvement in supporting and caring for others, regular physical care and stress reduction techniques, build in time-outs or time-offs, training, social activism, attending memorial services, bereavement workshops and support groups (Cadwell, 1994; Ennis et al., 1990; Froman, 1992; Garfield, 1995; Gibson & Plotnick, 1997; Haviland et al., 1997; Nord, 1997; Perreault, 1995; Shernoff & Springer, 1992; Winiarski, 1991).

In relation to organizations it is noted that many areas of individual and group functioning and support were noted to improve when a strategic and ongoing organizational response occurred to AIDS grief and multiple loss (Gibson & Plotnick, 1997; Kuller, 1992; Santek, 1992; Schoen, 1992). Perreault (1995) and Schoen (1992) summarize these organizational strategies as follows. Loss needs to be acknowledged in all levels of the organization. Identification of the impact of grief on the organization needs to occur, along with identifying other issues that confound these problems. Board and leadership involvement is critical in establishing organizational strategies, providing an ongoing commitment, and reviewing of benefit packages and policies. Recognition of the unique organizational culture and the mechanisms and resources of support already within the organizations needs to occur. Resources of support, including rituals, already exist in many organizations. Other resources of support such as debriefing, supervision, employee assistance programs, flexible work schedules, individual and group support may need to be identified and implemented. Formalization of staff appreciation, and training and skill building are essential aspects to maintain ongoing commitment and healthy staff.
Ultimately, the goal of developing an agency response to multiple loss is the creation of healthy agencies and the creation of healthy, resilient, creative workers. Just as communities have mobilized to understand and respond to HIV/AIDS, we believe that communities can organize successfully to meet the emerging challenges of grief (Perreault, 1995, p. 37).

In summary this extensive literature review has provided a complex picture of AIDS grief and multiple loss. The experiences with AIDS grief and multiple loss are breaking new ground and pushing boundaries in our individual, community, organizational, professional, and theoretical understanding of grief. Individuals coping with this experience incur significant repercussions on their emotional, physical, psychological, social, and spiritual functioning where complicated grieving, and intensified emotional responses are the norm. Additionally, communities, in particular the gay community in North America, have experienced a devastating impact created by the loss of individuals, lifestyle, and social support. Present traditional grief theory has been critiqued as inadequate to explain the complexity of loss and grief processes of these individuals, and communities. Consequently, we see application of grief processes associated with trauma, disaster, and, in this document, social and political repression. Yet, individuals and communities are noted to be surprisingly resilient in their abilities to cope with such extensive losses that include all aspects of their life, means of social support, and community.

Professionals, including social workers, have taken up the challenge to support AIDS bereaved. This has occurred while there has also been considerable countertransference noted, risk of burnout, vicarious traumatization, and compassion fatigue identified. The professional, peer, familial, friendship, and volunteer supports have experienced considerable grief and pain in their witnessing and supporting others. However, the deep dedication, rewards of personal growth, and sense of achievement have also contributed to the longevity and commitment of individuals.

ASOs are experiencing a form of chronic trauma that is known to effect both the mental health of staff and organizational functioning. This is occurring while the broader community remains unaware and unsupportive of the disaster in its midst. Despite this these communities have been creative, though not surprisingly at times ambivalent, in a response to acknowledge loss in their
organizations while they have attempted to respond to the challenges of HIV disease. However, what is also emerging are the additional new challenges in mission, new client populations, erosion of funding and of social and health services, within a climate of increasingly competitive funding arrangements.

A universal theme in the literature on coping in the context of the devastating impact of HIV and AIDS is the benefit and need for social support. Individuals, communities and organizations while continuing to cope with this experience find significant barriers created for them by the various social, cultural and political structures. The structures of societal discomfort with death and grief, AIDS phobia, sexism, racism and economic oppression remain significant issues for those who are HIV positive, and the AIDS bereaved. In particular within the context of the province of Alberta homophobia and heterosexism are strong negative forces that continue to limit access of the bereaved to support, and create disenfranchised and complicated grieving.

This literature review has provided a broad theoretical background for this exploratory qualitative study about the experiences of individuals coping with AIDS grief and multiple loss within an AIDS Service Organization in the province of Alberta. No research exists on the qualitative experience of AIDS grief and multiple loss within this organizational and community context. This beginning exploratory study will attempt to provide an understanding of the unique grief and coping processes of these individuals and their organizational community. It will also highlight the complex social, cultural and political forces that impact these AIDS bereaved. A description of the methodology used in this study follows.
CHAPTER 3

METHODOLOGY: THE CREATION OF NEW KNOWLEDGE

Introduction and History

This collaborative research process began in 1994. Dialogue was initiated, at that time, to have research completed within an AIDS Service Organization in Alberta. The assets I brought to this study were recognized, because of my commitment to, knowledge of, and familiarity with this community. These assets included my knowledge of AIDS grief and multiple loss as a member of the gay and lesbian community, and as a social worker in the field of HIV and AIDS. The organization was extremely supportive of this research, and saw it as a benefit to themselves and other ASOs across the country. This consequently lead to a formal proposal for myself to complete research on AIDS grief and multiple loss as part of a Master’s Degree in social work at the University of British Columbia. Additionally, on behalf of the organization, the Executive Director provided supportive documentation as part of the application to graduate school, and as supportive documentation for ethical approval of the study. This research project is collaborative, feminist, and insider research, a study of a familiar community and culture. As researcher, these frameworks have guided this study of AIDS grief and multiple loss in this community.

Collaborative, Feminist and Insider Research

Firstly, collaborative approaches to research process are part of a philosophy of feminist research practice, and these were used throughout this research process. Marshall and Rossman (1995) describe the collaborative process this way.

This inquiry should be a mutual and sincere collaboration, a caring relationship akin to friendship that is established over time for full participation in the storytelling, retelling, and reliving of personal experiences. It demands intense active listening and giving the narrator full voice. However, because it is a collaboration both voices are heard. In the conduct of narrative inquiry there is open recognition that the researcher is collaboratively constructing the narrator’s reality, not just passively recording and reporting. (p. 86-87)
Additionally, my role as researcher, was to not exploit or objectify the participants, but to create a partnership that was nonhierarchical in both data collection and analysis (Wuest, 1995).

In addition to the early organizational collaboration of this research process, a teleconference was later established with this organization at an agency staff meeting. This teleconference held on November 14, 1995 outlined details of the proposed study, attempted to address any concerns or answer any initial questions. Collaboration also occurred with individual participants by: explaining the process of analysis proposed; seeking verbal consent again at the beginning of the research analysis; providing follow-up interviews to incorporate their consent and confirm respectful representation and validity of their narrative story as part of the data analysis.

This research is also feminist research. "A feminist researcher is not detached; she interacts and collaborates with the people she studies. She fuses her personal and professional life" (Neuman, 1994, p. 73). A variety of writers (Harding, 1989; Houle, 1995; Lather, 1991; Neuman, 1994; Riger, 1992; Roseneil, 1993; Stanley & Wise, 1990; Swigonski, 1993; Wisewoolf, 1993; Wuest, 1995) have assisted me in defining the qualities that make up this feminist research project. I have defined three central assumptions which characterize this feminist research: 1) ‘the personal is political’; 2) it is essential to ‘understand oppression’ and ‘create empowerment’; 3) ‘value neutrality’ is rejected and an attempt made to ‘incorporate reflexivity’. Each will be discussed in the context of the proposed study.

This research starts with the belief that the ‘personal is political’. It recognizes that our personal experience is embedded in a larger social context.

Secondly, feminist research has as a central goal to understand oppression and to create empowerment (Lather, 1991). It recognizes that the “day-to-day reality of marginalized”, and “less powerful groups” are important areas of study (Swigonski, 1993, p. 175). This research began with a goal to understand the many factors that affect the experiences of those I supported, my friends and colleagues, and myself. As a feminist, and a member of a marginalized gay and lesbian community, I have seen the oppressive nature of HIV/AIDS. I have also observed the explicit societal judgment, and
discrimination experienced by those HIV positive, and those who are gay or lesbian. My goal in this research is to help reveal aspects of oppression that may be present in our private act of grief.

Thirdly, feminist research practice has a commitment to rejecting 'value neutrality' (Roseneil, 1993; Lather, 1991; Harding, 1989). Traditional positivist research on the social world believed it was possible to be 'value free', and by this a researcher could remain "detached, neutral, and objective" (Neuman, 1994, p.61). There has been significant critique by feminists about the 'value neutrality' of science, because it both ignores the social structures that are oppressive and leaves out the voices and lives of women in the research (Harding, 1989; Neuman, 1994; Riger, 1992; Stanley & Wise, 1990). Given that all research is not 'value free' it is important that the researcher position herself in the research (Fine, 1994). Swigonski (1993) states that feminist "research must include explicit reflexivity, that is, researchers need to study the role of their social position as they conduct research" (p. 179). This rigorous reflection on self is central, as I have described here, to feminist approaches to research, many aspects of social work practice (Houle, 1995), and ethnographic (Ayers, 1980) approaches to research.

This research is also insider research. Insider research, coined by Roseneil (1993) has been used in both sociology, and ethnography circles (Roseneil, 1993). This type of research appears more autobiographical in nature (Roseneil, 1993). It is also consistent with life story and narrative methods of research (Marshall & Rossman, 1995), or what Wisewoolf (1993) terms intimate reflective autobiography. This insider research was about researching the experiences of a familiar community, and myself. I am intimately familiar with the research topic, and my motivation to study it was a deeply personal one. The community, organization, and individuals who collaborated with me in this research are mutually known. I reentered this familiar context to study how AIDS grief and multiple loss impacted our lives.
Narrative, and Ethnographic Approaches to Data Collection and Analysis

Given the complexity of this topic and the contextual factors which impact the experience of AIDS grief and multiple loss several approaches to research design and practice were used to complete this study. Firstly, a narrative approach to interviewing and analysis was used in this research study, because the process of healing from loss and bereavement often requires the telling of stories (Rosenblatt, 1995; Tafayo, 1993). Narrative approaches also recognize that “macro- and microforces are intimately interwoven” in an individual’s experience (Gregory & Longman, 1992, p. 334). Narrative analysis is based on the idea that individuals use story telling as a means of making sense of their experiences (Roth & Nelson, 1997), and “other people and the wider community” (Viney & Bousfield, 1991, p. 758). Narratives can also help us maintain a sense of identity, and empower us (Viney & Bousfield, 1991). “People whose narratives are heard within a community may be better able to contribute to constructing how that community sees itself and its problems” (Viney & Bousfield, 1991, p. 758). Therefore, narrative approaches to research data collection and analysis have been used in this study. This approach to research has been used with AIDS bereaved by Gregory and Longman (1992), those with HIV diagnosis by Stevens and Doerr (1997), and recommended as a research tool for AIDS-affected people by Viney and Bousfield (1991). I have borrowed from Rosenthal (1993), and Viney and Bousfield (1991) to provide assistance with narrative approaches to data collection and analysis.

Secondly, an ethnographic approach was incorporated in the interviewing and analysis process. I recognized that the organizational culture of an AIDS Service Organization, the gay and lesbian culture, the HIV positive community, and the larger social and political culture in the province of Alberta may influence people’s experience in this study. “The value of the ethnographic interview lies in its focus on culture through the participant’s perspective and through a firsthand encounter” (Marshall & Rossman, 1995, p. 82). Ethnography has been used primarily in application to HIV in areas of prevention (Bletzer, 1995; Turner, 1995), HIV diagnosis (Roth & Nelson, 1997), and is recommended
in application to community-based AIDS organizations (Ouellette et al., 1995). The ethnographic approaches of Agar and Hobbs (1982) have assisted me in this study.

Through use of narrative and ethnographic approaches I have been able to understand the complex individual experiences of AIDS grief and multiple loss in this organizational and societal context. These approaches have also assisted in identifying the resources of support available and missing in this community.

**Reflexivity and Validity**

Explicit in this study has also been the naming of how my own experience as a middle-class lesbian of British, and Metis heritage informs this study. The purpose of this study was to be reflexive on the familiar experiences with HIV and AIDS grief. Additionally, I recognized the deeply personal nature of this research, and the impact the shared stories would have on me as researcher. Use of journaling, and supportive discussions from my faculty advisor were resources I used to be reflexive of my experience throughout the process of the study. Given that research is a process “whereby subjective and objective knowledge are interwoven and inform” the study it is essential that rigorous self-reflexivity be incorporated (Lather, 1991, p. 68). The above forms of reflexivity were attempts to incorporate this critical self-awareness.

These acts of reflexivity, or critical self-awareness, are also essential in the validity of this study. Rigorous and ongoing reflexivity creates means of maintaining validity and credibility of the study. In addition to these self-reflexive activities, follow-up interviews with each participant were used as a means to verify respectful analysis of the participant story, and validity of the analysis.

**Strengths and Limitations**

As an insider, who is familiar with this community, I am aware that the investment, and support of participants for this study was considerable. My knowledge, shared experiences, and commitment to HIV/AIDS are respected and appreciated, therefore, creating an atmosphere of safety and greater self-disclosure on the part of the participants. Participants of this research viewed me as an equal. That is,
have knowledge of, shared experiences with, and sensitivity about what it is like, therefore, am seen as a 'participant with' them rather than 'researcher about' their experiences.

The strength of my ‘being known’ by participants could have been a limitation, although I worked hard to overcome any barriers in this regard. I have relationships with each that are quite complex and diverse. My role as researcher was a new type of relationship that required discussion with some participants. As well, dialogue occurred with some participants about our shared losses so they could feel free to express themselves fully without concern or protection of myself. Additional limitations include that participants are only able to share what is conscious to them, what they express or report verbally. I am aware that there are many grief reactions that are physical and behavioral which the bereaved may not be conscious of, or are not expressed in verbal ways at a given time.

This study was a beginning effort to explore the qualitative experience of these individuals. The writing of this thesis was created with the intent to have the meaning, experience, grief processes, and coping strategies be explicit through respectful writing and telling of each participant’s story. Quantitative tools were not used to measure the extent of impact of AIDS grief and multiple loss on these individuals, though this may be helpful for further studies. Additionally, participants represent diverse ways of coping with this experience and this study does not particularly evaluate the types of coping strategies referenced in the earlier review of stress and coping theory. This could also be a useful future research approach.

The community and participants of this research are primarily Anglo-Saxon and European Canadian in heritage. The participants of this study were all adults and therefore the experiences of children, and adolescents are not represented in the research findings.

Ethics

Various concerns have been expressed about ethical bereavement research (Cook, 1995; Parkes, 1995; Raudonis, 1992; Rosenblatt, 1995). Safeguards including: explanation of the purpose and method of study; voluntary informed consent; freedom to withdraw from this research project; confidentiality;
consideration of the needs of the bereaved; and collaborative participation which assures respectful representation of participants were all incorporated into this research study.

This qualitative research was approved by the Behavioral Sciences Screening Committee For Research And Other Studies Involving Human Subjects at the University of British Columbia. Additionally, written support and approval by the organization was received and accompanied the documentation for ethical approval. Interviews were held in a mutually agreed space that protected the confidentiality of the participant, and provided a safe comfortable setting for expressions of emotion. A confidential phone number was also provided to participants to reach me during the initial interview process, and means to maintain confidential contact later in the analysis process were also discussed.

Participants all signed a letter of informed consent (see Appendix C), and were again asked whether they wished to participate in the study at the beginning of the analysis process. They were further informed of the evolving collaborative process of this research as it developed. As the research and analysis process unfolded collaborative discussion with participants occurred regarding the extent to which they wished aspects of their lives and stories to be revealed. Participants were consistently reminded of my primary concerns for respecting their confidentiality, and the content and language of their story. As researcher, I reviewed with each participant the content of each narrative story, and assisted them in finding ways to not disclose themselves. However, several participants chose to disclose many details of their life and experience through the writing of the story. Many felt they had nothing to hide and preferred to have the story be written as it was told. Consequently, five participants used their personal name and three participants used a pseudonym. As the researcher, I was respectful of the wishes of all the participants, and collaboratively reviewed drafts of these stories that would become a public document within the thesis.

Additionally, consideration that participants may experience potential grief responses as a result of participation in this study was also recognized. I recognized that the open interview style and the telling of stories may create a type of traumatization for participants as they re-experienced past losses.
Consequently, as safeguards, I chose an agency and community where I was familiar with the counseling resources available to refer participants. I also discussed my concern of potential traumatization with participants prior to the interview, gave clear support and permission to stop the interview at any time, and provided telephone contact following the interview.

Participants of this study confirmed there were therapeutic benefits in telling their stories of loss as has been noted by Cook and Bosley (1995), and Rosenblatt (1995). Many participants, despite expressions of grief, reported considerable benefit at the time and days following the telling of their story. In particular, participants reported enjoying the ‘opportunity’ and ‘time’ to discuss their experiences. Some participants reported never having had the opportunity to express themselves to the extent they did during the interview. Participants repeatedly referenced their familiarity, respect of myself, and depth of sharing was based upon their previous knowledge of me, and our shared experiences. Consequently, there were significant assets as an insider researcher within this community that created comfort, trust and strong motivation of participants to contribute to the study. Additionally, participants also gained reflective insight into their own lived experience as has been noted by Rosenblatt (1995). This occurred through the researcher providing and discussing the narrative story with each participant as part of the analysis process two years later.

Reciprocity

An essential part of all feminist research is the notion of reciprocity (Lather, 1991) or “give and take, a mutual negotiation of meaning and power” (Lather, 1991, p. 57). Reciprocity occurred during this study through the collaborative and participatory manner in which the research was conducted. Participants expressed benefits from participation in this study, similar to what is noted by Cook & Bosley (1995). These include: an opportunity to share feelings, integrate what had happened to them, and assist others in the future through the telling of their story. Additionally, consistent with the norms of this community and in recognition of the financial stress of HIV disease those participants who were HIV positive were offered an honorarium for participation in the study. Each participant was provided a
copy of their written transcript, the narrative summary, and will receive a final copy of the study. The researcher also has planned formal acknowledgment and presentation of the findings with the participants as has been mutually agreed. Presentations locally and nationally will be pursued to share the significance of this study and its findings.

The Participants

This AIDS service organization is similar in structure and history to AIDS organizations across the country. Cain (1993) describes these organizations as having the following:

Its services include individual support and counseling support groups, advocacy, and buddy supports, volunteers providing practical assistance (shopping, cleaning, cooking) and emotional support to people living with HIV. AIDS Network workers also provide support to friends and family members of people living with HIV. The organization provides a community education program through its public speakers; volunteers attend gay dances and bars to educate gay men about safer sex, and provide basic education to public schools and community groups. (p. 670)

Participants or key informants were chosen based upon: a minimum of a one year association with this ASO; having experienced multiple loss and deaths from AIDS; and representing diverse roles and relationships within the ASO. The criteria of a one year association with an ASO was chosen, because my own experience suggests this provides sufficient time to be aware of and to experience the phenomena of AIDS grief. Participants were chosen to represent board, volunteer, administrative support staff, management, counselor, and client roles within the ASO. Participants within this study often represented many different roles at the same time, and had multiple exposure to AIDS grief and multiple loss.

The eight individuals who participated in this research study represent Anglo-Saxon and European Canadian descent. They include Ukrainian, German, Irish, Scottish, French, and English backgrounds. They ranged in age from thirty to fifty-seven years of age. Four participants were HIV positive and four were HIV negative. Five participants were men, and three were women. Five participants identified themselves as gay or lesbian, and three identified themselves as heterosexual. They had involvement with the ASO ranging from one and one-half to eleven years at the time of the
interview, with the average length of involvement being over six years. Collectively these participants represented nearly seventy years of experience with HIV and AIDS both within and outside the ASO.

**Process and Procedure of Study**

The organization and the participants were informed of the nature of this study through the collaborative process of information sharing prior to and following ethical approval of this study. Agreement was made in an organizational staff meeting on November 14, 1995 that I would approach participants to consider participating in the study. Additionally, an advertisement notice (Appendix B) was distributed in the organization to provide potential participants an opportunity to contact me through a confidential phone number. I was provided a phone list of staff members and, given my familiarity with the community, was able to contact other participants confidentially and invite them to participate in this study. This type of sampling technique is called critical case sampling whereby “the researcher is looking for the particularly good story that illuminates the questions under study” (Crabtree & Miller, 1992, p. 39).

Seven participants were approached via phone or personally in a confidential manner to consider participating in this study. The eighth participant requested to be interviewed via a message left on a phone service. An appropriate location and time for meeting each participant was established once I had discussed the potential distress that may occur as a result of talking about AIDS grief, informed them the interview would be recorded, and received verbal consent to meet. All but one participant, met with me in their home. The one exception desired to meet in a confidential location at the agency. The written consent form was reviewed with each participant and signed before the interview proceeded.

In this collaborative, exploratory, qualitative study eight individuals were therefore interviewed, over a period of one week in February 1996, within an urban AIDS service organization in the province of Alberta. In-depth interviews using ethnographic and narrative approaches occurred with these individuals to understand their complex experience with AIDS grief and multiple loss from within this
AIDS service organization. The initial in-depth interviews were audiotaped and were approximately one and one-half to four hours in length. A semistructured flexible interview guide was used to help facilitate these interviews (see Appendix D). These interviews were later transcribed verbatim to assist with data analysis. A copy of one participants’ full transcription is in Appendix E.

Several ongoing and pertinent questions guided this exploratory research process and the analysis in particular. These questions were as follows. What were the experiences of these individuals with AIDS grief and multiple loss? What is the process of grieving of these individuals and community? What are the sources of support and what is needed for these individuals, organization and community to cope? What is the experience of AIDS grief and multiple loss in this multicultured environment? What are the interrelationships between these individuals and environment? What are and how do the social, political and cultural structures impact on the experience of these AIDS bereaved?

As these questions stimulated my thinking processes, an initial trial analysis occurred with one participant. I broke the lengthy text into themes that were later grouped with those from other participants. However, what became blatantly apparent was that the meaning and continuity of the individual experience was lost. I felt it somehow robbed the person of their story, and in effect repeated the sense of hiding and shaming prevalent in the context of AIDS bereaved. Therefore, a decision was made to recreate each participant’s lengthy transcribed document into a readable story. This decision seemed consistent with honoring participants and my commitment to want to contribute to others’ understanding of AIDS grief and multiple loss. I believed that the story form was a more effective way to reach others and convey the experience of AIDS bereaved. However, I also wanted to highlight the shared meaning, coping, grief processes, challenges, and recommendations identified by these participants. Therefore, the analysis emerged as two parts: eight narrative stories; and an ethnographic description of the experience of AIDS grief and multiple loss by these individuals, linked to this organization and community.
The analysis began with each transcribed document being split into two primary columns. The first column contained the transcript of each participant and the second column contained my data analysis. I provided each participant with a copy of the transcript and requested they review it. I would contact them again with an approximate ten page narrative story of their experience. Participants were made aware I would need them to review this story to confirm that it respected the integrity of their experience at that time.

I began my analysis by identifying themes within the lengthy transcript. I listened to the audiotape and underlined key phrases. These key phrases along with my analytical comments were then copied and pasted into the second column. I also began the story writing while the thematic analysis proceeded. I achieved this by splitting the computer screen into two documents – the thematic transcript analysis, and the narrative story. I began writing the story as it emerged grouping similar ideas into sentence structure that maintained the language of the participant. When I reached the end of the thematic analysis and similarly grouped thoughts in a story form I began editing the narrative story. Participants had repeated references to certain themes, and the sentence which captured a particular theme best was included in the narrative story. At times several thoughts which were connected were joined together by collapsing sentences and by creating some changes in grammatical structure. I used my words at times to help connect thoughts, but mostly attempted to have the words of participants create the interconnecting flow of ideas, and personal history. I would then complete a series of editing steps to achieve flow and continuity in narrative structure. As I completed the final version of the story I listened to the audio-tape while viewing the transcript analysis and narrative story on the computer screen. This was intended to assure myself that I had not missed or misinterpreted an idea, phrase, or word in the analysis process. Generally, with each participant’s story small changes were necessary.

I arranged a meeting with each participant following the narrative story analysis. I explained to each participant the process of analysis and asked each participant to read the narrative story once while I was present to get any initial feedback. I left two stories with them for an agreed period of time (one
to two weeks) and a follow-up meeting was arranged. I asked each participant to write any comments on the story. I also asked them to consider if there was any language or other identifying information they wished changed. Each participant was informed that I wanted to assure respectful interpretation of their story and a level of confidentiality that they desired. Additionally, I asked them to provide a second copy of the story to someone they respected as a way to create supportive dialogue with another person who could provide further authenticity and validity to their experience. Finally, I requested participants to consider a title for their story, or a phrase from within the story that stood out for them, which summarized their experience with AIDS grief and multiple loss.

At subsequent follow-up interviews I reviewed editorial changes and received feedback. Many participants were amazed that I was able to so effectively recreate such lengthy text into a story form. Participants expressed therapeutic value in seeing and reading a concise expression of their life experience. It was also evident that participants saw it as an experience that fit with a given period of time in their life. These participants recognized that they had continued to undergo changes in their involvement and coping. At times, participants expressed intent to edit their text based upon their surprise that they felt as strongly as they did at one time. I used the transcript analysis, and audiotape to verify the importance of including certain ideas when participants appeared to want to change their story based upon their present viewpoint. Given my knowledge of individuals I made suggestions to help maintain their confidentiality, where this was an issue. In the end I collaborated with each participant until a comfortable narrative story was achieved which would become a public document within the body of the thesis.

Participants were involved in choosing a personal name of their story and title. For some participants a title was very clear for them, or the alternate person they chose to read their story provided them suggestions. For others, I provided several key phrases that seemed important based upon my analysis and had the participant choose a phrase.
The second step of the analysis process was my written summary. Near the end process of the narrative analysis of each of the eight stories a clear visual image emerged which helped to express the complex individual, organizational, and community experiences of AIDS grief and multiple loss. Finally, I used the thematic expressions of participants to validate this larger picture analysis. The analysis of this study is presented in two parts: the eight narrative stories of individuals within an AIDS service organization, and my ethnographic analysis. These follow in Chapter 4.
CHAPTER 4

FINDINGS AND DISCUSSION

4.1 THE NEW BRANCHES OF KNOWLEDGE

The following eight stories have been organized in a specific sequence to provide the reader both an individual and historic understanding of the experience of AIDS grief and multiple loss within this AIDS service organization in the province of Alberta. These participants provide us a picture of the development of a response to HIV, and an awareness of AIDS grief and multiple loss in the province of Alberta over a ten year period.

Barry's Story: How Many Times Can I Keep Reopening Wounds Without Permanent Injury?

I am a gay man originally from a small northern Alberta community. Like many young gay men I had no role models and support so I repressed my sexuality. This delayed my sexual and emotional growing up into my twenties. I relocated to a larger urban community in the 1960's. My mother's death at that time created a crisis for me, and led to my acceptance of myself as a gay man. The gay liberation movement hit about this same period, and created an atmosphere to deal with these issues. I later began participation in The Gay Alliance Towards Equality, and a gay Christian group called Dignity.

My first contact with GRID-Gay Related Immune Disorder occurred in 1981 at an International Conference of gay organizations. In New York in 1983 I saw a number of people who were visibly ill. The disease was gradually moving north from New York and Los Angeles. We then heard Toronto had cases.

There were all kinds of theories about how it was transmitted. The only information available was through the general media. There was talk within the gay community that it depended on the number of sexual partners. If you had less than forty you would be okay, but if you had more than forty
you were going to get it. The responses from gay individuals swung from one extreme to another. We went from feeling that somehow we were far enough removed that it would not affect us to wondering who we had ever slept with in our lives. We did not know whether we would all get the disease or just some of us.

We formed a small committee in 1984 and started to think about what we might do when it hit our community. We felt we needed to look after our own, because nobody else was probably going to do it. We saw ourselves as pioneers fighting for our lives, and the lives of our friends. We heard about the experiences and fear those with GRID had in dealing with people in hospitals and homes. There was even talk of isolating people in colonies. People wanted to be secretive about being gay. They feared being picked up, forced to get testing, and losing jobs and homes. There was a fear of an anti-gay backlash, and a paranoia presented itself. We were a generation of gay men dealing with losses of lifestyle, friends, and levels of freedom. In 1985 we recognized that we needed to form a new society to obtain the means and resources to address the issues.

I remember the first person I saw in the hospital. He was isolated away from the rest of the patients, and I had to wear a gown and mask. Hospitals were not sure what to do, and were concerned about the risk to their staff and patients. By 1986 we knew that it was a virus, and the route of transmission was by blood. The scientists were sure, but the health care workers and public were not.

The nature of the disease was short term with a crisis period of a few months before the death of an individual. Five or six individuals became ill and were diagnosed. Others died and were diagnosed after their death. The first individuals to become ill were either activists or members of organizations. Consequently, there was a sense early on that we were under siege, and a fear developed about who was going to be next. The thought that we were all contaminated and going to die played a role in my decision to leave my government job, and become the first Executive Director of this local AIDS Service Organization. I wanted to be sure services would be in place for members of my gay community, and when I became ill.
Our small AIDS service organization began in 1986 as a social service agency which educated gay men, and provided support to them and their families. As drugs like AZT became available testing was recommended so people could begin treatment earlier. We educated health and social service agencies to respond and provide care. We also mobilized the gay community to do something positive rather than ignore it or be paralyzed by fear.

We were seen in the general community as a gay organization, dealing with a disease people were afraid of, and therefore we would not operate in a typical fashion. We did not have the resources to build a structure like other agencies, and so we looked to other AIDS service organizations for models. As clients became involved they had expectations and experiences which prohibited us from working with typical existing models. Our clients and their needs challenged us to remain flexible and open. We needed to have a certain amount of organizational structure, but a comfortable enough environment for people to get services, and accommodate for salaried and volunteer staff. The individuals, board members, and clients who participated early on shared a similar vision, and were often mavericks who were active in community causes and gay rights. Consequently, within the organizational environment there was a level of freedom, a comfort with issues of sexuality, a flexibility in using both humor and sadness as coping mechanisms, and a belief that the place would evolve as needed. We created a climate where people did not have to hide parts of their lives, and could be fully who they were.

It was challenging early on. It was scary, but also new. In the newness of this fight we had the strength to cope with it, and were able to respond and absorb the loss. The grief was more visible, would come and go, and you could rally support. I think we were also naïve, and could not fully understand the long term impact loss and grief would have on individuals and the organization.

Rituals developed within the organization as a way to deal with the losses. Sometimes we pulled people together to talk about the person who died. Other times people talked to support services staff, or went out of the office for a walk. It was important to just let these happen and develop, because
they had meaning for people. I am not sure what other AIDS organizations have done. I have not seen that information gathered up and documented.

Early on we started using a candle in the office as a way of alerting people that someone had died. It helped explain why people were feeling the way they were, and provided a way to remember the person. We now have a lamp as well as a candle to memorialize a person. Individuals who have been around the office for a while want a candle lit that will burn out that day. A real flame seems to be important to them as opposed to a lamp light. For others the lamp is just fine, and at times both will be lit.

We started the practice of memorial services for a number of gay men, because they had no family in town, and were totally isolated. Volunteers also expressed a need, because they did not or were unable to go to regular funeral services. In some cases the funerals were too awful to go to, because of the way they were conducted. Our memorial services allowed families, caregivers, volunteers, and staff to remember the person in the way they felt most comfortable. We began by doing individual memorial services for people, but by the third and fourth year there were too many people dying to continue this practice. We evolved into having regularly scheduled memorial services twice or three times a year. The services became a way for people to officially say their good-byes. I do not think staff make use of memorial services like they used to. I do not know why that is? Our first volunteer coordinator was instrumental in starting the memorial services, and Support Services and volunteers have maintained that practice.

The first volunteer coordinator also began the agency memorial quilt as an important way of remembering people, which was also used at memorial services. At that time individual quilts were made and sent off to the National AIDS Quilt, but nothing remained at the agency. A group of volunteers designed, and sewed the first agency quilt. I believe that started in the second year of the agency. We had an inaugural display of the quilt at our first memorial service where stars were sewn on to remember the individuals who had died.
Organizationally I think we acted out our grief including feelings of loss, helplessness, frustrations, and anger in a variety of ways that were not easily recognizable. People typically got angry about other issues, and their expression of anger was out of proportion with what appeared to be the issue. Staff and volunteers seemed to lose interest, or did not feel good about coming in to work, because they have been unable to deal with the loss and anger. It was a challenge to deal with people who are either depressed, short tempered, and cranky about a task that needed to be done today. However, what was really bothering them was an accumulation of people being ill and of deaths. People who were previously able to suppress their feelings now are feeling and acting it out. People have been particularly uncomfortable with their feelings of anger and helplessness, because others are sick and dying. I am not sure why they cannot express their feelings around this issue, yet are able to do it around other areas. Why is it that we are not able to accept the reality that these people are dying?

We tried to use the tools that were available to respond and provide support. We brought in Kubler-Ross and had a couple of workshops. We also recognized some people would burn out and leave. People would come and go, and the length of time they stayed with the agency would probably vary. I do not think early on we could assess what it meant in terms of an ongoing culture and effect on the staff. I think we felt that staff would somehow cope, or we just never thought about it. We were too busy dealing with all the activities of a small agency of finding resources, developing programs, and delivering services. We never stopped long enough to think about any long term stuff.

Organizationally, I did not see any other models that would assist us. I heard more about inadequacies of support as opposed to good programs. In about 1990 we began having discussions between organizations about this issue. We felt a real inability to actually do something constructive about it. We recognized that we were good at helping clients and volunteers through resources, follow-up, and support groups. We thought by telling our staff to get some counseling this would do it. However, we realized we were in new territory, were not knowledgeable, did not have the resources, and were uncertain how to deal with it effectively to assist our organizations and staff.
Organizationally we did not recognize the impact working with those HIV positive would have on the added stress and culture of working in this environment. We have tried across the country to get people with HIV to be in charge of their lives, and become involved with the issue in all parts of the agency as Board, committee, staff and volunteers. They are not just clients they are coworkers, or volunteers and we seem to deal with them differently. We start seeing them become ill and go into hospital. We see them go through the various phases. We pretend this is not happening, and spend part of our time trying to convince ourselves this is only a temporary set back, and they will be back in next week. There have been many cycles with generations of people living and dying with HIV over the past many years. I have found it harder with each cycle to get as close to individuals. I remind myself sooner this is a person I am going to lose. This is our circumstance until we get to the stage where this is a chronic illness.

The cycle or period, over the years, that I dislike the most is around Christmas. It is generally before or after Christmas that we lose a bunch of people. This also happens just before summer. I think the period around Christmas is more difficult to cope with, because of our expectations around Christmas time. There have been traumatic periods where we nearly shut down, because we lost several key people who have been connected with us for many years.

My role as an Executive Director can also be an isolating place to seek support, because you are caught between the Board and staff level. The organization is pretty good at recognizing and looking after the impact grief and loss has on parts of our staff. However, with another part of our staff we seem to think that somehow it is not going to affect them. I think the accumulation of loss and grief on non-support staff, administration, and volunteers is more insidious.

As an Executive Director the losses are also around the overall climate of uncertainty and loss of funding and resources. The hardest part of my job was having to fight all over again for access to drugs, health and social services. Non-profits today experience greater stress in locating funding, and finding Board members and volunteers prepared to make the same kind of commitment. I have found it
an increasing challenge to establish relationships with new Board members. I have needed to draw on my reserves to recreate what I have lost. Today the battles are tougher, because they are not about individuals treating you decently, but are about policies within organizations, and the fact that social services have been cut. Today the problems are more complex and insurmountable, because the solutions are less clear. I feel that today there are a lot more layers of problems to cope with. This is discouraging which leads to a sense of impotence, depression, and of being overwhelmed. I have felt at times that I am the only person carrying that burden, though that burden is not mine to take on. I have had feelings of resentment and anger that board members, agencies and funders seem able to walk away, but I cannot.

The battles ten years ago were about fighting prejudice, homophobia, insensitivity, ignorance, and fear. While I see a growing level of support and involvement from the general community I also see a polarization in society around sexuality, the disease of AIDS, and civil rights for gays and lesbians. As the pool of support broadens there is loss of solidarity with the tight little group that was fighting this battle alone. This has been a normal evolution around the issue.

There has also been a body of information that is now helpful to us in understanding the impact of loss and grief. I no longer believe that organizations should assume people will somehow be able to look after themselves. People give lip service to it at the Board level. I think the present grief interventions proposed for staff have been at times simply remedies. For example, taking off a day here or there is not sufficient when most organizations do not have the time to accommodate it, and staff are too overworked to delegate their responsibilities. These remedies often come too late when early on they may have been helpful.

I think grief and loss needs to be built into the daily business and planning of an organization. I think there needs to be a written statement or a personnel policy that recognizes that issues of grief and loss are going to affect all the staff and the organization. I think it certainly can be part of the screening when you hire people. However, I think it is hard to anticipate what may happen over the course of
working. Therefore, I think ongoing training with staff on grief and loss are necessary as a proactive response to what will happen. I think it should be part of a person’s annual review and evaluation. I think we need to ensure that people take their holidays and get breaks. I think we need an employee assistance program or access to mental health services. I think we should be proactive by encouraging individuals throughout all levels of the organization to access peer or professional support and workshops.

Organizationally we have a formal bereavement policy. A committee of the Board is looking at finding and implementing ways to do grief loss support, such as Employee Assistance Programs. The personnel committee of agencies should be the body responsible to recognize and provide staff assistance with the constant grief and loss. Organizations need to get more information and research on how grief affects the agency. I think we may even be able to get acknowledgment from our funders that this is part of our situation. As well, I think the Board Chair or Human Resources Chair should be responsible to look at the needs of the Executive Director of an agency. There should be an appointed person from the Board who has an understanding of grief and loss who the Director can talk to safely about some of these issues.

Directors may also have other areas of potential support. Some of this support has happened informally, but directors are often too busy or too stressed to devote time specifically to grief and loss work. Locally, they may have meetings with other non-profit Directors where you can talk about common issues typical to non-profit social service agencies. They may also have their peers from other AIDS service organizations. There is a history within AIDS service organizations where you can be far more open about your feelings, issues of sexuality, and death and dying. I think specific workshops should be designed for Directors. They should be encouraged to attend grief and self care workshops, but these would be best with Directors from other ASO’s. It would be difficult to attend a workshop with the staff you supervise, because of the leadership and disciplinary role of a Director.
As I look back now there is a ten year span of emotional and social experiences which are hard to remember and capture. The greatest loss for me was losing a whole generation of gay rights leadership. These were individuals who I have known in the community both locally and across the country through my civil rights work. It was tough going to meetings and places to find out who was either ill, had died, or was going to be next. I guess I just absorbed it. I may have been angry about it. I was certainly sad about it.

1986 was a real breaking or changing point in my life. I can separate my life pre-AIDS and after AIDS. I have always compared this experience to some kind of war. I crossed this border into fighting AIDS, and nothing was the same afterward. I did not worry about the future, because I was not sure that there was even a future available. Everything became very urgent and immediate. I submerged my life in AIDS work. It became all consuming at the expense of other parts of my life. I put other parts of my life on hold including a social life outside of AIDS, my family life, and my own personal self. An imbalance occurred, but I did not recognize it at the time. It was probably not untypical of how some people reacted to the disease and the work around it.

My family were initially uncomfortable with dealing with me fully as a gay man, and as a Director of an AIDS Organization. Their ignoring of parts of my life was not supportive, and created distance between us. This has changed as their comfort level increased, but it did contribute to my isolation for many years.

I received a tremendous amount of enjoyment from what I was doing. I had never felt so worthwhile, because we were doing things that were helpful to the community, and encouraged the community to respond and be helpful. The best things happened around community development. Some members of the gay community coped by withdrawing, but there has been a consistent number who continue to respond. I developed a whole bunch of new friends. There was a solidarity and comradeship with a group of people right across the country.
There were those who became burnt out emotionally. Some burnt out around the organizational issues. Some became sick and died. It has been rare that a director has stayed ten years in an agency. The average was about four to five, and some stay only one to two years. I can certainly move out of this work and do something else. I cannot ignore that ten years of the most productive part of my life have been involved in this issue. I think people need to recognize when this work has gotten to be too much. I think there comes a time when you need to separate yourself from it in order to be healthy. I think people should leave for healthy reasons as opposed to just collapsing or imploding. I have seen too many people lost, burnt out, and leave with their lives partially destroyed.

I went through a period thinking I was successful in being able to handle the issues of loss. I believe I had the maturity, training and skills that I could take on a lot of the work and leadership of the organization. I coped for the ten years by using some coping mechanisms in my earlier life. I put some things on hold, and told myself I would deal with it later. I would take little bits of holidays, and do social things I enjoyed. I would seek out and get support from Board members and personal friends. I made decisions that I would continue to be a friend to individuals who were sick, but would not be a caregiver. I withdraw around the final period of illness, and was not involved in very many deaths. I knew I could not handle the emotional turmoil that went with it. I did some grief and loss acknowledgment through the funeral process and sharing with friends. Earlier on I was emotionally healthier, could stand the battering, and absorb the grief and loss and go on.

With clients and volunteers of the agency I adopted a pattern of being helpful and supportive, but not becoming personally involved outside the office. This did not work with everybody, because I naturally became closer to some individuals. I realized I had limitations in drawing upon personal supports because of my personality, and the caregiver and leadership roles I played within an organization. I believed I had to role model that we could not stop to deal with some of the losses, because there was always the next batch of clients, and piece of work that had to be done. There was no room or time to stop and personally shut down.
I am finding now because of the wear and tear of the year in and year out cycle of this work that I have allowed myself to be worn down. I have complicated my ability to cope by not having regular holidays, and looking after my personal life. I had thought if I just keep on going that I will get around to dealing with other things in my life. I have found out that I got into a merry-go-round and stopped doing the things necessary to look after myself. I fooled myself into thinking I could continue in this pattern of always coping, and that things will look after themselves or will go away. I think I became numb for a while. I have realized like other people when you get into this kind of pattern you’re going to become unhealthy and ill.

One of the things I was able to do was to leave work at the office. I can still do that, but I cannot always leave the experience and feelings of loss. I do a little bit of socializing, but there are times on the weekend when I have to shut myself away from people. Sometimes that has been healthy. Other times I have submerged myself into escaping into a book for ten hours so I do not have to think or feel about how bad I am feeling. I have felt totally exhausted, and have not had the physical and emotional energy to have fun. Social activities do not provide me a recuperation, but only allow me to put my feelings on hold for a couple of hours.

I have also had losses in my family life. These became just another layer of loss which I was going to deal with later. However, I can no longer compartmentalize and suppress what I am feeling. These personal losses opened up wells of feeling that I had kept buried. It allowed me to start feeling some of the accumulated losses. They are like wounds that are not healed being reopened again. I have asked myself how many times can I keep reopening wounds without permanent injury. Today I get a lot angrier about another round of losses. I feel the pain of loss more, and not just as a personal loss, but as an overall loss. At present I feel loss physically. It is no longer just a mental thing. I am actually carrying and wearing the grief in my body. I feel it inside my chest as a lump of sadness.

There is a piece of this work that is painful and tougher than it was four or five years ago. It has caused some depression several years ago which I did not recognize until I started to come out of it. I
think that experience made me aware I could slip back into that again. I did not seem to recognize I was shutting down emotionally. I knew emotionally I just could not come in and deal with one more thing. It had affected my whole mental health including my stamina, and need and ability to plan to get away. I had to get over feeling I was a failure, and feeling guilt about my need to stay away from the office. I’ve tried to change some of my coping strategies by trying to recognize the losses, and how I feel. I am not sure if what is happening right now is a phase or a normal cycle. I recognize I am not dealing with it, and my coping is not very good behavior. This tells me I am not managing it the way I should manage it. If I am not managing it then the disease, and my unhealthy behaviors are managing me. I can accept intellectually I need to do something, but I am unable to make that happen.

I realize I need to seek some time off to look at these issues. I recognize if I do not, then I will become useless to myself and the organization. Somehow I cannot walk away or take the time to go away long enough. I see that there are too many things that are happening that need to be looked at. I feel I am the only person who can look after it. Somehow in the last year I feel I have got myself trapped.

I have stopped tallying up the number of individuals I have lost. I stopped doing that because there are just too many people, and it was too overwhelming. We have a book of names of those who have died. I have gone through it, and when I see the full name that is when I remember. I have been amazed at how much I do remember of them. I guess I would have to say on a yearly basis there has been seven or eight people that are significant enough to me to feel a sense of personal loss. Certainly every year there have been three or four people I would classify as friends. There are some people, like Donald who come back often.

I can understand why older people are more cautious in investing emotionally, because they know what it is like to lose friends. I have a small core of personal friends, but this has gotten smaller over the past ten years. I have felt lonely at times, because the generation of people I should have
grown old with are not here. As I have lost my peers I have lost some of my history, and the history that
should have been made.

I can accept that death happens to all of us. Sometimes I get angry and want to rail against the
injustice of how people die, and whatever god is. I can cope with it, because I realize that the majority of
people in the world die miserably not peacefully in their beds. It helps to see how well people do die, and
cope with this disease. However, I do not understand the afterlife or justice in this life any better. It seems
like a huge mystery. I can really only make sense of my own desire to still fight the fight, and be involved
to help those with AIDS have the same opportunities, access to care and support that others in society do.

Annette’s Story: It Is Hard Being A Survivor

I had been married for several years in the 1960’s when my husband, Siegfried, told me he was
gay. I did not know anything about the gay life. It belonged in books at that time. I had no one to talk
with, and felt very alone and very embarrassed. He finally moved out and we sort of got on with our
lives. He had a few partners. A few of them I knew. Then in the 80’s he moved to Toronto, and was
there until he got sick with AIDS.

My daughter and I went to an AIDS Organization support group in ’86 when we first discovered
he was HIV positive. It was a very small group, and we kept in touch outside the group, as well. At
first, I knew individuals who were HIV positive, but later knew their mothers. I volunteered with this
organization till about ’88.

In the 1990’s, I began working at the AIDS Service Organization. In the past ten years I have
been associated with the support group, volunteering and working at this organization. I have certainly
tried to listen and share my experiences. I have tried to be there for somebody who feels that they need
a shoulder. One of the staff at the STD clinic seemed to recognize this and several years ago asked if I
would get together with a mother who had just found out her son was HIV positive. We met downtown
and shared our experiences and emotions. There are also other families where we continue to keep in
touch. I feel that the families need someone, as well, as the actual person who is HIV positive. It is essentially letting them know that I am there if they ever need to talk. I still feel that we need each other. It has not really completed or ended yet.

Working at an AIDS organization has helped. It is a comfortable safe place. Everybody understands what you have been through, and might be going through. It is very therapeutic working there. I would not feel as comfortable crying in a government office. Of course, in another office we would not experience as much death as we do there. It is a different environment. The homosexuality part is quite obvious to me. The environment allows them to have physical touch with each other, and be open about their experiences being gay. I am perfectly accepting of it, but I do not think it would be as accepted in any other office. It has made me more accepting of the gay life. I probably would not have been if it was not for my husband and working at an AIDS organization. It has made it easier to handle death or accept other deaths in my own life, because of what I have been through in the past, and working there.

I think AIDS has come a long way. AIDS seems to be more prominent in the way that we are remembering them even though there are more people dying of cancer, and heart disease. Cancer and AIDS are similar in that they are both terminal illnesses and you go the same way with weight loss, and so on. I guess the way it is contracted is different except where you are a hemophiliac and have no control at all. With AIDS there are choices people make about being a drug user, being promiscuous, and not practicing safer sex. AIDS is a newer disease, and it was labeled at one time as being a gay disease and now it is not. It is like homosexuality. It is out in the open now. You do not have to hide it.

There has been judgment about dying from AIDS. A good majority of the population probably still feel it is a gay disease. I think certain heterosexual groups have not experienced anybody dying of AIDS. They believe it is not going to happen to them. In the beginning with Siegfried not many people wanted me to welcome him back to live with me. However, my family and friends were supportive once he was here. Several years ago a girl I used to go to school with asked me where I was working. I
told her I was working at an AIDS Organization. She asked me if I was scared to work there. Recently a couple of people have said it is a great thing I am doing and how do I handle it. I am finding that Alberta attitudes are more accepting.

I have experienced quite a few deaths in my own family. With someone dying of AIDS I do not relate it to myself. I had a girlfriend die of breast cancer. It is not likely I will die of AIDS, but when someone dies of cancer I begin to question this for myself. Most often with AIDS the person is quite young, and this seems very unfair. If we could see an end to it, if there was a cure, but you know there is going to be more. There are still quite a few that come around the office and you see the progression. It is not easy to watch them. I feel so helpless. I know their time is limited. They come to the office and all of a sudden they do not come for a while. The next time you see them there is a drastic change in their appearance, and then others you do not see anymore. It hurts when you see all these different people going. This is not the end of it, and that is the whole problem.

There are so many AIDS related deaths. I have experienced probably twenty personal and twenty acquaintances who have died of AIDS. It’s hard to be a survivor. All these people are gone, and you are left to cope with the loss. When there have been multiple deaths of these young men I feel it should have been someone older like me. I feel sad that they are young and have had no life yet. I experience a lot of anger. Why have they not found a cure yet? With AIDS there are drugs that prolong your life, but there is no real cure. They have been doing research for years. They are making so much money on the drugs. Sometimes I think that there is a cure and they do not want to release it. All these thoughts go through my mind.

During the bad times when there has been a lot of deaths I think about the fact we will not see them again, or be able to talk with them anymore. I wonder who is going to be next? I find I need to talk with someone. I was quite comfortable talking with one of the counselors in Support Services, but he is not there anymore. I talk with my daughter. We are good friends. There was one time, when I had to go out of the office for a walk. I just had to leave. I did not want to be there for a while. Maybe
I was running away. It was hard to face at the time. There had been seven or eight deaths that summer when Dana, John, and Ernie died. It seems that they wait for each other and go together in groups.

It helps to cry. I have an Elizabeth Kubler-Ross book, and a book called Embraced by the Light, which are little stories of how people have had near death experiences. This book comforts me. I think for me, I try and make sense of all the pain and suffering by remembering the person in the happy healthy time of their life. I think of the moments I had with them, and the time I shared with them. I try not to think of how ill they were when they died.

We have informal groups at the office where we all meet in the drop-in center to remember someone. It helps to know that we are there for each other, and we can cry there, and we can give each other a hug. It sort of helps to laugh, if you can joke about it. There are times when you feel why are we laughing, but it does help to get through that particular moment or day. At staff meetings, I feel it is helpful, in a general way, to let staff know how clients are doing. It helps to prepare us for when they come into the office. It is not as shocking, because you can visualize that he has lost weight, or is looking poorly. Other times, when someone was well known, one of the counselors talked to us individually. They prepared or forewarned us that the person was very ill and likely to die soon.

We also light a candle in the office when someone dies. Back in'88 when Siegfried died I phoned the office to let them know. They said they would light a candle for him, and it would be lit all day. This was very nice. However, I do not know how this ritual got started. Now we have a lamp as well. The lamp is nice and it is decorative. However, there have been times when people are sitting in the waiting room and they just turn on the lamp switch. They did not realize what it really means. So, I personally prefer a candle. It is more real. It is an actual flame. When the candle is lit everybody seems to come to the front of the office, and wants to know what is happening. Why is the candle lit? Who was this person? How old was this person? Where is he from? A lot of times I do not have these answers. I do not know the person at all myself. A week in January when Sherry died there were three or four deaths. The candle was lit almost every day, but that is common around there.
I have been to the candle light walk a few times and to the prayer vigil. The first few years the candle light walk was quite important to me. I enjoyed walking in a group with a candle, and remembering the people who have died.

The memorial services are a closure. You can say goodbye. It is very touching when everybody lights a candle, and talks about their remembrances of the person. I think it is very appropriate, and very comforting. I feel very close, and safe.

The quilt started after I had been involved with the organization. It was an outstanding way of remembering people who have died. It is frightening seeing all the stars on those quilts in the office. I volunteered when the Canadian quilt came to town which was quite emotional. When I go to see these quilts I feel a big loss, so many people.

At Christmas time we hang memorial ornaments on our agency Christmas tree. It is a very special, wonderful tree. It is a remembrance and each ornament is so different. I put all of Bob’s, Clark’s, Siegfried’s, and Ernie’s ornaments up. I look forward to looking at each ornament, touching it, feeling it, and putting them up each Christmas. It seems we need another tree pretty soon.

There have been times when I needed to do something about how I was feeling at a particular time. I try to put it towards the back of my mind and keep on doing what I am supposed to. Though it would have helped to go out of the office with someone for a coffee or a walk, and talk about and remember the person. I do not feel the same closeness with support services staff anymore. I think because there are more clients now, there is more of an overload on them. I feel I do not want to take up someone else’s time when they need it more than I do. The clients come first.

It would be helpful to have a grief counselor, the staff knew, available at the agency on the day someone died. Maybe someone from one of the mental health agencies, they have done some incident debriefing with us before. I am aware that we are allowed so many days off for a death or going to a funeral, but otherwise I do not know what is allowed for any type of counseling. I do not know what our bereavement policy says. If I really needed some type of grief counseling I would probably seek
someone outside the office on my own. I am familiar with a few counselors who have been connected with the agency. I am sure some of the other staff would like to talk to someone on an individual basis. There has been a lot of grief around our office and some of the staff have found it especially so, because of recent family deaths.

The major thing is the organization has expanded and grown. We began with one little office and now it is quite a change. Many people have passed through, not only staff but clients. The closeness is not there. The change has occurred for a reason, but I do not think that the closeness is there with the personnel. Early on we did not have that many people in education, all the resources, and the support people we have now. I think the function is making money, because we know our funding has been cut. We are doing so much fundraising now, which we never did at that time. The atmosphere and people are still very caring, giving, understanding, and comforting. Though, a lot of politics goes on there. I think there are just more people around, more meetings, and more organizations. I feel lost in the shuffle sometimes. I still enjoy going to work every day. I do like it there.

I do not know clients as well as I did earlier on. It has not been as emotional for me. With Dana, John, and Ernie their deaths were probably the harder ones, because I knew all of them. Of the group who died in the beginning of the year, Sherry was the only one that I felt closest to. In the past I would have had more opportunities to form relationships with them, because I would see them more in the office. The clients mostly come in the evenings now for support groups, and clients who come in the daytime go and see one of the counselors. I do not see them as much and we do not seem to talk. Maybe I do not have the time or maybe they do not have the time anymore? Maybe I do not want to make the time anymore? I feel like maybe working at an AIDS organization that we should. But, there are times when maybe I do not want to get too close. It has been very touchy at times. I do and I don't.

I do not let people in as close as I used to, because I do not have the energy anymore to deal with anybody very close. I could not see myself going to the hospital every day or visiting very often. I go to visit one of the guys at the hospital maybe three times a week and that is enough for me. I can see
he has good support. I do not think I am needed. I feel I am needed more for his mom. I also chat with
certain people I know who come into the office. I phone Bob at home once in a while over a weekend
to see how he is doing. There is a notice on the white board asking for visitors for someone else. I do
not know if I even want to do that right now? I will ask how a person is doing, but I do not know if I
want to see him. Maybe I want to remember him when he was still in the office.

I went to see one of the guys yesterday. He is not talking anymore. He is comfortable. He has
talked about death. He is ready to go. I am okay with that. Let him go. I guess this is how I deal with
it. There is not any more we can do for them. They are going to a different level now, and a happier
place where ever they may be. I guess I feel helpless and wish I could do something. Now I feel I have
to be there, or I do not have to be, but I want to be there for his mom.

I think I have chosen not to become as involved with the organization. For example, I have
chosen not to go on the candle light walk in the last few years. They are not as important anymore. I
feel I can only do so much. The older I get, I feel I have to make choices now. I think my feelings or
views changed when my granddaughter came along. The time we spend together is very important to
me. I want to be part of her life.

David’s Story:

I Remember The Dead, But It Is The Living I Still Have To Fight In Concert With

I started working with an AIDS organization in ’87. I was surprised when I was accepted. I
was not sure the organization was looking for a straight man at that point in time. In the beginning, I
remember feeling uncomfortable that I had to prove myself, be visible, and fit in. However, I found it
exciting working in something that was struggling for resources. I have always had an opportunity to
work in situations on the edge. When it came to this organization, it was working on the edge. We
were working on something very new which carried a lot of suspicion, and disdain in the general
community. Especially in Alberta, where we were and continue to be challenged by basic human rights around lifestyle and illness.

It was the first place where I had worked for eight and a half years. This was fairly significant in my life. I had come from a number of years of experience as a social worker when I started at this organization. I saw this as the greatest challenge that I thought I was ever going to have, probably ever will have, as a social worker. I think working with this organization was a freeing experience. It allowed me to become involved in some areas where I could function with safety, and live out a particular ethic as a social worker and human being. Working there has been a constant reminder of who you are number one as a human being, and number two as a social worker. It was an opportunity to be reminded almost every day what suffering, loss, human misery and laughter are all about. There are so many basic levels of human interaction that we see on a daily basis. These challenge me to think about who I am as a human being, the opportunities I have, and what I need to be thankful for.

When I started with the organization there was a great sense of commitment and ownership on the part of the gay community, and a sense of solidarity with people who were HIV positive. We all had different jobs we did in that office, but there was a connectedness to the people who were infected and affected. There was a sense of communal support. We are all in this together with even the few other community organizations that were involved. There was more of an opportunity to get support and to feel comfortable in accessing other people. We all got together on a fairly regular basis. We put a lot of effort into creating that sense of communal support. Everybody in the organization had to go through training, which zeroed in on your role and contribution to the organization. What you were about? Why you were there? What is going on for you that might impact your ability to function in the organization? In the early years the communal support was very apparent, it was accessible, and it was part of our survival.

I remember struggling with what my relationship was going to be with people I supported. There were some whom I would count among my close friends. Whom I was privileged to have been
their true friend, to have been that close to them in their dying and death. These were men who I knew very well. Men who I joked, laughed, cried, and talked with on sometimes a daily basis. Men who I would say I really loved. There were also other individuals I supported who were part of this bigger community that was experiencing something, and I had a role to play along with others in the community in supporting this individual. I always felt that no matter what circumstances brought them to having HIV that they deserved the very best that we had to offer.

Three individuals stand out in my mind when I think of my experiences over the years. The first was a sad soul, a really isolated gay man who had a very difficult life living in Alberta. He had a lot of internal struggles as a gay man, a lot of internalized homophobia. I remember seeing him when he was in the hospital for the last time. The only people visiting him were one of our volunteers and a priest from some church. Here was a person who seemed to have shut everybody else out, who both relied on us and did not want us. I remember sitting with him in his room and feeling very lost, feeling totally incapable of doing anything. I felt both a great conflict and very sad that this guy was pretty much gonna die alone.

The second experience would be Alan. Alan and I clicked. We became really good friends. It was really tough when he died, because I knew it was one of the few opportunities I would have to connect with another person on that level. I think dealing with his death was made easy, because of the closeness of our relationship. It was not so much grieving a loss as remembering a special friendship.

The third experience would be with David. I was surprised by the degree to which I was hurting and knowing that there was nothing I could do. These three represent such a range of emotion and they capture quite a range of years and experiences. At one end it would be a sense of being held at a distance by an individual who wanted us but did not want us. At the other end, I felt totally incapable of doing anything and felt the weight of what was coming. I experienced the loss but also the fear that they’re going it alone and I can’t go with them. You’re at the end of the road, you’re left behind, and they go on. It’s the finality, the ultimate separation from a connection with another human being that...
makes it both scary and sad. It's sort of like reaching a climax and coming down with energy physically, emotionally, and mentally draining. I never believed that they have been wasted lives, but that they were unnecessarily shortened.

It's not that I haven't thought about the cumulative total of deaths. I do not feel particularly raw. I know that when I look at the total I do feel a weight. I do feel tiredness. If I were to put a number to the cumulative total, whew god, it would certainly be over a hundred. Can it be that many? I guess it is. It seems amazing that there are that many people, that I have known, and with whom I have had a connection. However, I would say the number whom I really felt the loss was probably well over thirty people, maybe closer to fifty people.

I remember, during those times where there were a number of deaths it was as if we saw it coming. Once it started we got to the point in realizing that here we are again caught up in another wave. We are going along this wave with everybody else. Other times it was just boom, boom, boom, boom, boom. There was this overwhelming feeling of these cumulative deaths. Some of the deaths were unexpected. Some of the deaths were very tragic, suicide or a drowning. It was the combination of the circumstances around the deaths, the significant individuals involved, as well as the deaths being part of a circle or a wave of deaths, that made it so impactful.

I think it's probably very similar to what happens with critical incidence stress. During these events I experience an adrenaline rush. I get pumped up, apply lots of energy, or lots of resources to deal with this situation. However, it's after it's over that some people fall apart or are deeply emotionally scarred. During these multiple death periods, I am not sure if it's just a numbness that I have felt at different times. I have never been able to identify it. I hate to say it, but there is a certain detachment I have felt particularly in those periods when there's been multiple deaths or deaths and other losses. There are other times when I have felt bummed out, overloaded and fairly overwhelmed.

I do not know that I ever despained, but I know other individuals have despained. It's the impact of other's despair, someone else's struggle, or really connecting with someone in a very special way that
cannot help having an impact on me. There were a lot of times when I would experience tremendous sadness and a flooding of memories. At times I felt very angry. At times I felt energized, or fulfilled. This depended on the people and how much they let me into their life, shared with me, relied on me, or how much they have given me.

I never in my wildest dreams ever thought that I would be this close to death or have this kind of experience. The common denominator is that everyone we have dealt with is going through an experience that is terrifying, filled with all kinds of anticipation, and they also lose their identity in the process. That’s had the greatest impact on me. It’s a recurring theme time, and time, and time again, and a constant struggle to help people hold on to some piece of their identity as it’s slowly being peeled off them. In a large degree it’s a lonely road that those people gotta walk, and it’s lonely for us too, because we know we can not walk it with them. We can be there with them but we really ain’t experiencing the same thing that they are experiencing. We struggle through our stuff to figure out how best to help and support them, and they struggle against this tide that is ever so slowly or rapidly moving them along to death. I believe that before a person dies that they come to this realization that everything else is gone and that their essence is. Maybe they have not really lost all of this identity. Maybe it just becomes part of their essence, and that’s what they die with their essence. It’s having to go through that process, and that struggle of losing it all to be able to realize it all at the end. I think it’s watching, and seeing this realization of people being stripped away of everything that they are and being reduced to a common denominator and that is a human being, you know, flesh and a soul inside.

I can remember discussions with individuals where they really talked about their own struggles, hopes, dreams, and accomplishments. I know, at least, as they go through that pain and suffering, I can see this whole living human being who has either dealt successfully with pain at this time and not at this time. When you saw the whole person with pain and suffering in it. It helps to make sense of pain and suffering, by really viewing how they see their life in the scheme of things. People with HIV have
eloquently humbled and shown me that they have come this far in their life, and so they’re capable of taking themselves through the rest of the journey.

I do not believe a lot of people really understand the cumulative toll. I pretty much, privatize a lot of my feelings around, multiple loss, grief, or bereavement. I do not have the energy to educate someone to the point of being a support for me. I am fairly selective about what I share, with whom, and when I share. It tends to be more episodic, that I would need to sit down and unload with somebody else. I do not rely on a lot of other people, except some of my colleagues. I talk with my wife about some of my frustrations, but I don’t want to walk in the door and unload on my family. I seek out those folks who affirm what I am feeling at a particular point in time, who energize me or who get energized by me. I do not want to sound snobbish but it’s like an elite club, because there is a ‘common understanding’ about what we are feeling and experiencing.

As well, I go to church, and church creates an atmosphere for me to get into my own thoughts. I have a belief in God, and church gives me a place to struggle with some questions. I do not always walk away with answers. I use it to catch my breath, and to feel confirmed in what I am doing.

I need to talk with other social workers. I need to have a philosophical type of debate or discussion. It helps ground me as a social worker, because what we deal with on a daily basis seems really horrendous. These discussions put what we are experiencing in some kind of perspective or within the greater scheme of things. I have had the privilege and opportunity to contribute provincially and nationally. For example, I have participated in an adhoc committee of the Canadian Association of Social Workers. We have worked on a policy statement on HIV and AIDS, a booklet for people who have never addressed the issue, a psychosocial care model within the Comprehensive Guide For Care of People with HIV, and a special edition of The Social Worker. I sat on a national group that looked at the training needs for social workers, and made recommendations to social work programs for colleges and universities across the country. Provincially, I contributed to the first action plan for prevention and care of HIV by the province of Alberta. I was manager of the second half of the Caring Together
Project which provided me the opportunity to become involved in the issue on a community development level. I have seen all these opportunities as forms of advocacy and reaffirmation of the lives of people.

There were times when I was sure that I was not up to, when I believed this was way beyond my skills and abilities. As I look back over eight years I think two things are clear to me. One is that I have had numerous opportunities to have an impact. I had a responsibility to make use of those opportunities, because some of them were handed to me almost on a silver platter. Secondly, I had a responsibility to use these opportunities to ensure that as a social worker I did something good. As well as, really representing what I perceive the needs of people who are infected and affected. They always had to be forefront, and that if this community and I had this opportunity then I really could not screw up.

What continues to help is knowing I can still make a difference. It’s just not that I am impacted by all this, but I’m able to somehow use it to help somebody else. I made a difference not because of my own ability alone, but because of the accumulative experience of other people. I mean there have been times when I have thought about leaving the organization. However, it’s never been because I felt overwhelmed by the losses or the deaths. It’s always been for other reasons. I have come to accept the losses and deaths. It’s not that I am resigned to it, but I accept this as part of the process. If I ever got to the point where I no longer accepted the deaths, then I would say, I have to get out. As long as I’m able to accept it and help other people then I have been able to contribute something. This makes everything else seem worthwhile, and it helps, at least, makes sense of it all. It’s a way of continual giving, and losing with at least a purpose.

I have used the opportunities that have come along as ways to draw strength and support, to do a little healing, and to reinforce the experience of those infected and affected. I have seen all these opportunities as healing processes as well as reaffirmations of what I am here for. Including, the reaffirmation of the lives of people like, Dana, and Sherry. God, I cannot even begin to name them all!
The difficulty for me is if I look at the context of eight years, it’s really tiring. I feel very weary. I remember walking through when the National Quilt was here. I felt tired, like a really big weight with all that life experience, all that pain and all those deaths. I go back to this phrase, I remember the dead but it’s the living who I still gotta fight for, fight with, fight in concert with. If I’m gonna survive, if I’m gonna stay sane, I have to think about the here and now. It’s not that I forget all those names, and stars on those memorial panels. I will never forget them. I need to stay focused, because the people who are living right now need my energy.

I notice in myself that I become more aggressive about HTV and AIDS when there are a number of losses. I translate my feeling of anger into a need to be more radical or socially aggressive about the issue, or what I perceive as a social work ethic of becoming angry with the system. I believe it is my duty to some how speak in anger for the people who are experiencing these losses. It’s that old phrase that comes back in my head pray for the dead and fight like hell for the living. Some how the fight still goes on. I cannot do anything about the deaths, but maybe I can do something about those who are still living. So, it’s the fight, the fight that comes back time and time and time again. It really forces me to continue to look at what am I doing about myself? Can I do it any better? Can I do it any different? Can I make the experience any more tolerable for people who are going through it? It’s knowing that I still have something to contribute, I still can make a difference, that helps me make sense out of the losses, dying and deaths.

There have been times when a lot was going on in the office and deaths were occurring. I remember as a way to cope with the demands I would have a deliberate mental process of saying I gotta deal with this here. I will need to come back to my grief later. During other critical periods, I find I need to get some quiet time, unwind, reflect, and think about people and experiences. In the process of clearing my head I’ll do a lot of reminiscing, thinking, self questioning, and remembering. I walk a lot, partly to get fresh air and partly to have some quiet time, to reflect and to remember. Sometimes I do
that self care well and sometimes I do not do it well. However, I know that for some folks the struggles gonna be over, but my energy will be needed for the next person coming through the door.

I realized early on that I could not rely on the organization to provide grief support. We recognized within the organization we needed to look at it, but we had fits and starts in our ability to get some help on a regular basis. I realized I needed to find it within a network of support outside the organization. When I look back I am not sure that we have organizationally tackled the issue. Our approach seems to be this little bit and that little bit. I suppose there are other organizations that do it better. I suppose there probably are other organizations who do it not as well. I guess we are some where in the middle in our organizational response to staff bereavement needs. I think it is a real challenge from an organizational level because of the range of job responsibilities, staff motivation and expectations, and staff skills in dealing with personal issues and emotions. However, over the years the organization and the community have created a number of rituals which have been a means of taking care of ourselves, and both providing and acting as a vehicle for others in the broader community to come together.

The first memorial panel was started by a group of volunteers in about '88 or '89. These volunteers felt a need, in a very visible way, to remember the people who were dying here. They also realized there were folks who would never have a panel in their name added to the national quilt. The memorial services were created as a response by the organization to create a vehicle for folks in the community and staff in the organization to come together to remember individuals. At that time there was still a sense of isolation about the issue, and family services were really a whitewash. We also have books with individuals’ names in it which had the same purpose, and started around the same period as the memorial services. There are a number of times when I pull out one of the books with the names in it and start paging through just as a memory, as a reminder, of whom we have known.

In the office we have also used a number of things to inform people that someone has died. It was important for us to immediately write the person’s name on the white board, and light a candle.
The lighting of the candle as a ritual goes way back. I do not remember when that started. In the last few years we also have a stained glass lamp to memorialize a person after they have died. So now, we have the lamp lit, and then we also have a candle. It seems powerful with both the candle and lamp lit. It is like double light. You look over in that corner that is dedicated to people who have died, and what you see is brightness.

Each year during AIDS Awareness Week we have a candle light walk. It has been a very significant healing event for me. And then there is the prayer vigil around the same time. We have informal gatherings of folks in the office when someone really significant has died. We have bereavement workshops for service providers. All these provide opportunities for people to come together to do a little healing and remembering.

What has helped in support services was being able to collectively express our anger. Working with an expressive woman helps turn the key. It was easier to get in that groove of sounding off when you need to. Though, I think the best time for me was when four of us were together in support services. I think that we were a good functioning unit. We met weekly, and I never realized how important it was to dedicate time to talking. We balanced off each other. Each of us played a role which naturally followed our personalities as part of a team. It really allowed me to feel very supported and connected. Support Services also tried to play a leadership role within the organization by encouraging people to attend to their grief. At times that leadership role was valued, and other times it was not valued. It always felt strange that it fell to us to help those in the office deal with their stuff. I think it was very difficult, because we felt the need to attend to both the emotional health of clients, as well as everyone else who works there.

I think the first five years was the real growing process or period of evolution of this community into recognizing how it was going to respond to HIV. It was what I consider the developing process of the professionalization of HIV. I think, to some degree, that’s been good and to some degree it’s been very negative. I think the professionalization of HIV has been bad, to the degree that the organization
has lost its sense of mission. I think it's been good to the degree that others in the community have recognized a role that they need to play and are developing their skills in playing that role. Only time will tell whether the professionalization of HIV in this community and Alberta, has been a positive or negative experience in the long haul.

I am less comfortable with where the organization has moved, but not where the issue has moved within this community. I think there is certainly a lack of community ownership particularly from the gay community. I think to some degree it's been very much special issues or interests which have taken over, and therefore the roots of the organization, to some degree, have been forgotten. I think maybe that's part of the problem. A lot of the people who work at the organization now are fairly new, and do not have a sense of some of the early struggles. I think at the same time there are opportunities to accomplish something really neat, and also to fall into traps of mediocrity or lose our direction altogether.

I am struggling to make sense of what has changed in the organization. There has been an evolution. We moved into a big office. We turned the corner, and it has been a slow process to where we are now. We are becoming very much like other help-focused organizations. Maybe that takes away some of the uniqueness and the expectation to attend to self care stuff, because this is where you work and this is where you live. I think this change has occurred to some degree, due to numbers. I mean in the beginning they were named individuals, now we're dealing with 120 people a month. The change has come about because of the issues and needs of the personalities who now occupy this space. As well as, the kind of environment that has been created in this office. We are a big office, with more organizations, and people. We are having to deal with less public funding and more reliance on fundraising. Therefore, we need a Board who is focused on fundraising, but a board who really do not know the experience of people with HIV. So, I guess, as we need to maintain a certain level of income in order to function we gotta give up a sense of connectedness with people who we are here for in the first place.
We have become much more segmented, and compartmentalized. I hate to say it but it’s professionalization of HIV. We have professional staff, we bring in special people to organize the walk, and we bring in special people with special skills to sit on the Board. So there is less of the experience of the people who are infected and affected, because you are there for a specific job. What’s becoming clearer is support services for people who are infected or affected needs to be separated out from whatever else goes on in that office. Therefore, I see more and more two camps within the organization. If we’re not here for the people who need us, those who are infected and affected, then we have no business being here at all.

As we have become more segmented and compartmentalized it is much more difficult to rely on a communal type of system of grief support. At the old office when we dealt with concentrated stress or grief it didn’t seem to throw us out of whack. Our response to critical incidents now is very different. I think people express their futility, frustration, anger, or grief in inappropriate ways. There is an exaggerated response at critical times, an over reaction, to a crisis, major loss, or death. It’s like a volcano that blows and then simmers, very episodic, without any kind of healing or processing. I do not think that people use the opportunities that are available to them and therefore it comes out in very inappropriate ways. Opportunities like attending funerals or memorial services, talking with a counselor, are not used and there is not a lot of self care. For myself, I think it’s very subconscious, I survive now by tapping into a smaller group of people who really understand. I guess it’s that elite club, I mentioned earlier, who understand the experience of AIDS grief, and of those infected and affected. I think our experience here is traumatic enough. I am not sure you can get through it any other way than just feeling constantly committed, to solidarity, to a mission, and to struggling along together.

If I was going to start an organization over again I would try to capture some of what we had in the beginning. I would recommend that before they start hiring people for specific jobs, that everybody go through a targeted process of self reflection including staff, volunteers and clients of the organization. This would give people an opportunity to understand: what they are there for; what they
need; what they expect out of the organization; what they expect to bring to the organization; what their expectations are in dealing with stress, loss and grief; and what ways they can help others in the organization through difficult times. I would also recommend developing the sense of communal effort, and that we all bring varying degrees of expertise and experience to the organization. Organizationally, I believe it is important that we identify: concrete ways of dealing with stress, loss and death; rituals we might put in place; norms that are visible identifying what the organization is about; policies that will respond to situations that occur; space for staff to have quiet time; and finally acknowledge and attend to the emotional needs of people who work there.

With Support Services, I would hear from people who were infected and affected about what support could look and be structured like. Hiring support staff not just on professional qualifications but on maturity, honesty around their emotions and experiences, and ability to work as a team. It's identifying on a very human level what that unit is going to do, what it's going to look like, and what message it is going to give to the community about the humanity of the people who work there.

When I look back over eight and a half years I see that Alberta attitudes remain quite varied. The personal attitude and support towards the disease depends on whether a person has any connection to others who are in pain, and struggle. HIV is showing up in every nook and cranny of this province. However, I think there are still folks who will deny it. I also think a lot of human service professionals still do not like homosexuality, have very traditional views of family, and have difficulty caring for those with a history of drug use. They deal with someone around HIV only because it's a professional responsibility. These professionals will not address their own discomfort, their own anxiety, and will not feel challenged at all.

Over the years I have become heartened by some individual responses. Ministers, for example, who talk about acceptance, and inclusion provide me hope about organized religion. I think generally women are most supportive, and heterosexual men feel extremely threatened. I think a lot of people on the surface are very uncomfortable, but inside have struggled with their inability to talk about HIV, their
gay son, or their family member who is an IV drug user. I think these individuals secretly support everything that we have been about and have done over the years. So I view the supports and attitudes within the broader community as really mixed. Though, there seems to be more people who, when it strikes home with them, are more responsive.

For myself I still walk proud. I still feel proud to work where I work and be connected with whom I am connected. I never felt I had to hide. However, maybe now more than ever I feel like I don’t care, and I use the opportunities to educate people. I have grown over eight and a half years in my understanding of myself and other people. My god! I have such admiration for what people can tolerate, and for what people can go through. I still got fire in my belly. I still feel fire in my soul. It’s the collection of experiences, the accumulation of deaths and losses, the experience of these people’s lives and my connection with them, that has helped me feel that it is still worth the fight.

**Allison’s Story:**

**I Learned A Lot About Multiple Loss And Human Courage**

My first contact with individuals who were HIV positive occurred in a rural hospital in Alberta. In 1983 a man got sick going home to Vancouver. He and his partner had to stop in our hospital emergency. He decided he was going to discharge himself, and head to a larger urban setting. I remember the nurse on the floor was very angry. She said, ‘good get that faggot out of here’. That was my first encounter with that kind of discrimination and vehemence.

Then in 1987 a gay man required invasive procedures following a suicide attempt. The physician would usually wash his hands, but he would never wear gloves. This time he was wearing gloves. I said to one of the staff, ‘What is going on the Dr.’s got gloves on?’ She said, ‘this guys got AIDS’. I had no idea, none of us knew, how transmission occurred. I just knew you were supposed to wear gloves because this guy had AIDS, and that bug was going to jump out and get somebody. The doctor kept reassuring me he is got going to be my problem on the unit. All the staff did not know what
to do, or how to set up isolation precautions for someone with AIDS. Within 24 hours he was breathing and conscious, and within 48 hours was discharged.

I knew very little about HIV when I first moved to a larger urban community in 1988. I was at a social function and was introduced to this gay nurse who was working at an AIDS organization booth. They were looking for volunteers, and so I took a brochure. I filled out the application, was interviewed over the phone, approved to be an acceptable candidate, and went through volunteer training. They needed hospital volunteers so that is what I started out doing.

The first fellow I went to see did not want me there. I was used to working in a hospital system where patients were compelled to communicate with the staff. I was there as a volunteer. He did not have to look at me or like me. The next week I came back, and there were two people to see. So, I went and saw the new person first. He asked me a lot of questions that I really struggled with. Why are you here? Why do you want to come and see me? What is your purpose? I was a volunteer. I wanted to make a difference. I wanted to do something nice. They needed people to come to hospitals and I can do that. Retrospectively, those were pretty shallow reasons, but I think a lot us start out not knowing why we are there.

I also went back to see the fellow that I saw the week before. I think he was more ill and less able to blow me off. He let me sit there, and challenged me in the only way he could. ‘Get me another blanket’. ‘Get me another pillow’. I went away thinking, ‘God these people with AIDS sure are rude, nasty, and demanding folks’. I still had no concept about the disease at all. However, as a home and hospital visiting volunteer I started to learn about HIV.

Around this same time I went through the experience of my brother dying where there was sickness, grief and death. These were all people experiences. At that time I was working in a part of the hospital system where the sickest of the sick were. Circumstances where individuals were dying who had family members. However, everyone who worked there focused on the machines, and not on the people. Despite being a health care professional for almost eleven years I did not really understand the
experience of being ill. It was not until I started working with people who were HIV positive that I really understood what being sick was all about.

I was also developing my sense of being a gay woman. I was able to identify with being badly treated, because of my own life experience. I watched AIDS deaths and began knowing these young men. I saw what they were going through. I was appalled by it. I was appalled that nobody knew anything about it, and appalled by my colleague’s comments. “It is their fault! This is self inflicted! They knew better, and who needs them anyway!” No one in the health care organization I worked for understood it, or wanted to understand it. I thought if no one else is going to do this, and take care of them then I will. It is not hard to figure out how to keep myself safe. So it became my raison d’etre (reason for being).

Over the years it has been a journey I have cried through, and raged at. I remember this one gay couple. The parents of one of the one men parachuted in, said you can not take care of him anymore, and took him away. They literally, physically took him away from his partner. I do not think I have ever been that angry. I was at work and I was pounding my fist, and crying in the middle of the afternoon. My colleagues are looking at me, and wondering what the hell’s the matter with her. There has always been much more than a professional impact for me. I never purposely came out at work, though I think staff knew I was gay. They made the assumption that AIDS death had more impact on me because I was gay. It was my community. These were people who have shared what they have gone through in being gay in red neck Alberta.

I have watched people lose who they were. Individuals who at times have been rude and horrible. However, if you put that in the context of who they used to be it makes sense. I had worked with people long enough to understand all the anger belonged to the disease, and what had happened to them. If you look through the picture albums you see stunningly gorgeous young men. Men who five years later now look eighty. A person who has grey hair if he has any hair at all.
The experience is raw. It is ugly. It is totally unjust. Then it happens again. It has seemed like carrying a child for nine months, and giving it up. Then getting pregnant and carrying another one for nine months and giving that one up. Then all of a sudden you are pregnant again and carry that for nine months and lose it again. I can not parallel how gut wrenching it is. It is not something I can sit down and describe to anyone else who has not been there.

I know there were times when the deaths started stacking up. There were periods where there have been five or six deaths in a few weeks. I can remember I had to take some time off work. I took a whole half day off work once, because I just could not do it. I think I had been to four funerals in about two weeks. Over a five year period I can say that there have been over a hundred individuals I have known who have died of AIDS. I had never looked at it collectively before, and when I did it was devastating. I had coped with it by viewing it as just one more person. One more notch on the stethoscope! The impact was enormous when I saw the names, remembered each person, and what they had gone through. A lot of days I would start to think about it, and then consciously choose not to.

What I remember most acutely about those multiple death periods is being so angry at the virus. I was angry at this microscopic thing I cannot see. I cannot take it and shake it. I cannot hit it and spit at it. I was angry at what had happened to some people who were really special to me, and that were now gone. I did not have an understanding of what was happening for me. When I look back now the information about disenfranchised grief makes a lot of sense. I could apply it to others. However, I never sat down and recognized it was happening to me.

There has been something unique in this experience with AIDS. HIV has been about a young population who are stigmatized, and marginalized. Individuals who have a stigmatized and marginalized disease. It does not matter what the source of infection the stigma is there. This stigma comes from fear and from ignorance. It impacts people grieving. I have known parents and families who years later struggle with grieving, because to the world the AIDS death was a cancer death. Gay
partners who have tried to attend other bereavement groups, and were treated horribly because their spouse died of AIDS.

I think it is all the intensity, multiple loss, and anticipatory grief that goes with AIDS that makes it particularly difficult. With AIDS, families or couples are often also infected. Other types of terminal illnesses rarely have the survivors sharing the sickness. Consequently, AIDS survivors often do not look forward to life, but look forward to going through the same hell. This is why I have seen men contemplating suicide after they have lost their partner.

I know my coping skills were okay for the first little while. In the beginning deaths would happen intermittently. One fellow would die, and then a couple of months later it would be someone else, but there were not multiple deaths. When I was stressed I would go to the gym and work out, or go for a huge bike ride. I would do something physical to get rid of it.

It was somewhere in the middle period when I first started to see those multiple deaths. I did not cope well. I felt very alone. I would not allow myself to cry. I grew up not crying as a way to cope with my family history.

I did not have anyone at home who understood what I was going through. I think my partner worried about me. She wanted to understand, but could not comprehend it. My partner did not have much contact, or do very well with grief. I think a lot of my grief, and emotion turned into creating arguments. I needed to be really angry. None of it was conscious. Looking back now, I probably needed my partner to hurt too, because I was really hurting. There was a lot of pain. It had an impact on my relationship which was already falling apart.

I would go home, change my clothes, grab a beer, sit in front of the television with the remote control, and shut down emotionally. I was immobile. I could not do anything. There would be other times when I would avoid going home till much later. I would sit in the living room in the dark with the fireplace and stereo on. I would sit there and have a scotch or two. I went through quite a few bottles of scotch coping. This is when I would allow myself to cry. However, it would soon turn to anger.
Other times I would cry because I was so angry, or that would be the trigger for me crying. I did not identify it as my own pain, because I was healthy. I was taking care of these people, and so their pain was important. However, my pain came through as anger.

No one in the health organization I worked for understood. I was not allowed to be angry or express it at work. Others would ask various questions. Why do you keep doing this? Why don’t you work with something else? I would become angered by these comments. I always perceived their comments as being prejudicial against working with gay people, drug users, or street involved women. Especially, given comments made by staff in the past. I did not associate it with them caring about me, and that I was allowing this stuff to eat me up. I do not know whether their intent was truly caring or prejudicial.

My coping was not very healthy. I physically was not well, but not in any definable way. I had a lot of headaches. My gut was experiencing a lot of my stress for me. I do not think at the time that I had much physical awareness of what it was doing to me, because I had to bottle it up, stuff it and get on to the next one. I can remember feeling pretty numb at times, almost sleep walking through work. I can remember trying to be there with clients who were coping with something other than AIDS, and knowing I was a mile a way. I can remember not having any regrets. Whew, got through that one! That one will be okay till tomorrow! However, not allowing myself to wonder if I was going to be okay until tomorrow. I had denied the expression of pain in me all my life. Therefore, denying, stuffing, and putting away pain till it is safe I could do.

I remember being aware I had to do something differently. I had a choice to let it eat me up or the opportunity to grow with it and from it. At first I knew this intellectually, but then more of a whole body awareness. I knew I drank to much. I knew I could not keep doing that, because it was not working. I was also making other decisions that were a lot healthier for me. I knew I had to take better care of me. I did not relate it to how I was coping at work. Though some of the guys I was working with taught me to be gentle with myself, and pushed me to acknowledge that I had value. I could not
survive the old way I had functioned, especially when there were multiple deaths. I could no longer keep things bottled up, and tried to be tough through pain.

Around this time I also saw a counselor. The therapy process taught me that it was okay to cry, and that I was worth more that what I was doing to myself. I also remembered that I had the talent to write. I started writing a journal, and would rant and rave on paper. My fishing rod and I also spent a lot of time together. These were healthier ways to cope.

I am healthier in my response now. I am not totally healthy. I am not sure you can be. If I was in the thick of things I probably would at times revert back to those self destructive behaviors. There would be times when I would feel things so acutely. Times I would feel so defeated that I would say why the hell not. Especially, given the lack of support systems, and individuals available who I connect with. I can not imagine working with people who are dying from AIDS in isolation. I do not think it would be possible. I do not know if other people can, for me it would be just so huge. I guess that is why it was so hard working on the front lines in the health organization I worked for. There was not that shared experience, and shared grief. I have felt angry that others do not get it. I have judged them because of that. They have expressed a willingness to work with those HIV positive, but they still do not seem to understand what is happening for these people. There is one person at work who has a little bit of an understanding, but I don't think she would need all of her fingers to count the numbers. Even those whose work is focused around HIV do not seem to get it. They work with numbers, and not with the people.

I honestly did not think there was another soul walking in this city that could understand. However, there was this one person who worked at the AIDS service organization. We worked collaboratively together. It was part of our employment, but it was more than that. I have tried to understand what is different about my relationship with this person, and the way we both connected with those HIV positive, and each other. It was more than both being gay. It was also more than both approaching people with HIV disease from a totally non-judgmental point of view. We connected
because of our sense of injustice, and our shared understanding of how larger systems work. There was a level of empathy, because of our shared experiences of going through several deaths, and our shared pain and grief. We had been in the pit with these people. We were both willing to get in there, and be there. Willing to feel it, touch it, taste it, smell it, and experience all those deaths. I think more that anyone else I knew at the time, and since, this person really understood the pain we were all going through.

I used to and I still do, go to funerals to see if there is some way to get some closure. Even though we have already said goodbye in a number of different ways. Sometimes it works and sometimes it is horrible because the funerals are not about the person who died. I used to tell those I worked with that I was going to the funerals to get some closure. However, the services rarely meant a lot. It was the people who were there. It was to get the hugs. It was to talk about who was gone, share the tears, indignity, and anger. It was because I knew that other people who were sick were going to be there, and specific individuals who worked at the AIDS service organization. These people really knew what we had gone through.

There have been various attempts by the AIDS service organization over the years to acknowledge grief. The three large quilts have a lot of meaning to me. Especially a couple of quilts, because I know every star on one of them, and most on another. There are some names on the quilts I do not know, and I feel a pang when I see it. Here is someone who died of this ugly thing who I did not get to know. It seems foreign, because there was a time when I knew every star on those quilts. There are also individual quilts of remembrance which hang in the office. As I go in and walk around these quilts have a huge impact on me. They slap me on the side of the head every time I go in.

The bereavement workshops were very significant, because we all had permission to acknowledge the pain. It was a really safe environment to express it. Especially, when it was just those of us who had been in the trenches for a long time. It was like a slow leak in a propane tank where stuff had been, and finally it was okay to let it out. At the first workshop I did not know what I was getting
into. The second one I happily signed up for it. I knew it was a good thing. However, the first morning it was really hard to motivate myself to go. I knew it was going to hurt. I knew it was going to get rid of all the superficial stuff I had dusted over on top of it. It was like going to the dentist with a toothache. Geez it can hurt, but you know you are going to feel better when you are done.

The burning of candles is a wonderful tribute to those who have died. It is something I have taken from my experience with the AIDS service organization. I did not use candles to memorialize or focus my thoughts before. I use candles at home now, and have personalized it in a number of ways.

I have seen a lot of changes in this organization over time. The initial office was like a street front clinic. There was a gay presence, and humor about sexuality. It was homey, and a comfortable place to hang out. It was a people place, and seemed to more closely connect to the people who were sick. However, the space did not have an elevator, and it was not accessible for some clients. I do not think I ever went to the old place purposely to deal with grief. However, I would go there and it would happen. I would sit on the lounge in the back and start talking. Pretty soon I would start crying, and hugging someone.

The office environment since seems more like a business operation. The people are still very genuine, but I do not feel the same connectedness with people. In the new place I have needed to seek out particular individuals in order to get support. It is not built into how the place is set up. I do not see or seek out the AIDS service organization as a source of support for me. I go there to look for literature, and use the resource room. I have always had a sense that I am accepted there, and there is a sense of belonging. However, my greater sense of belonging was with the people who were HIV positive.

I have volunteered on the AIDS service organization Board. The board members did not understand grief. The board had the accountants, and the humanitarians. The accountants were winning in a big way. The accountants did not want to understand grief, because they would have to be people instead of being accountants. They spoke of a willingness to raise money so workshops, and support can happen for people. I knew that fighting for money, fighting for grants, and writing proposals were
in the end a positive thing for people who need the support. I suspect the board members got a good feeling about their ability to raise money for a cause that is not a nice thing in society. However, I did not think they wanted to know what was real. This was something the frontline staff were hired to do and deal with.

Sometimes they seemed to miss the point. I think they forgot about addressing the priorities. We were here, because there were people who are sick out there. This board was unwilling to provide real advocacy for those HIV positive. I think in a lot of ways I felt impotent to make changes on this board.

AIDS had become a very trendy cause for corporations to sponsor. Those who support AIDS were seen as being more liberal thinking, compassionate, and humanitarian. It was like the flavor of the week. It certainly did not speak to any kind of dedication, or continued support. I may be really unfair, but there were some people on the Board I wondered if it is not the flavor of the week for them too.

Maybe we need one Board of Directors who are the corporate finance group. However, there has also been a need for a collective of people who are dedicated to working in an ongoing way on real issues that face those HIV positive. Individuals who know what it is all about, and are willing to work in partnership with those HIV positive. This group of people needs to have a much stronger say in this organization.

Bereavement support also appears to be lacking at the ASO. It was not built into the organization. It was built into two individuals in particular who worked there. These two individuals brought the importance of bereavement support to the organization. So, when these individuals left, the focus on grief support went with them. In the everyday operations I do not know what the organization does. I do not see the same support for those who are dealing with the constant grief in living with the disease. There are so many other things that are happening that grief support does not have importance anymore in the organization.
I would recommend as a way to organizationally cope with AIDS grief that bereavement workshops happen more often. Particularly for those infected with HIV. I think there is real value in groups, but you have to work hard to reach out to people and break down those barriers to help them connect with others. Any kind of group work provides that shared experience and community. I think creating opportunities for those HIV positive to get together and have safe trusting environments to share would be really valuable for people who are living through this disease. I think it is hard to actively seek out the support one needs when one is coping with grief and loss. I know in the past I did not, because I was too tired to go out and find it. It would be helpful to have someone organize and attend to every detail of planning workshops, and creating follow-up.

The organization also needs to work on its image. The perception that the network is only a gay organization is still out there. It needs to improve its comfort level, and invite people in. It took a lot of work for a small group of dedicated women to get support. There are people out there who are disenfranchised both by society, and this disease. They also need our support. We need to coordinate our outreach to them. There are an awful lot of people who continue to live through this disease alone.

There remain a lot of challenges ahead. I think the epidemiology of the disease has made some people more accepting. This is because there are currently in Alberta more and more of those innocent victims emerging. The hard work of individuals like Sherry have softened some of the judgment around heterosexual women and children. I do not think there is any more tolerance or acceptance of the disease from the point of view of it affecting injection drug users, people in prison, or gay men. I do not see an acknowledgment of the value of individuals that have been lost. There has not been an acknowledgment of the suffering so there can not be a lot of learning from it.

Politically we have been in a climate where the perception is not going to be changed. Delwin Vriend lost his provincial appeal to have sexual orientation included as a form of discrimination in Alberta. One of the judges used morality six or seven times in this dissertation. This reflects the political climate we have lived in.
I have seen some really positive changes in some of the medical research and medical treatments. The way the system works has changed a little bit, which is not very heartening. Over the years I have taught and challenged my colleagues to learn about HIV. However, despite years of teaching it was the same three or four of us doing the work. No one truly acted on what they had learned. There continued to be right wing, gay hating professionals who I would not want to be caring for those HIV positive. I do not think anyone can really understand until you’re willing to get in there, work with people, and see what they go through.

My colleagues saw changes in me over time as well. At first, I wondered what this HIV work is all about, and later recognized it fits who I am. I was then on to the evangelist stage. From there to the screaming, crying, and leaving work really sad and ripped apart. I think some of them understood the grieving part. However, I do not think they ever understood the intensity and repetitiveness.

When I look back over the years my family and friends were accepting. I did not come home to a family that was homophobic, or afraid that I would bring home the virus. I have also chosen to not tell my elderly mother that I am gay. My children have been aware, and this was not a big deal. I have been amazed that my mother did not say anything derogatory about working with people who are gay, or had AIDS. Her concern was that I not become infected. Over time I think my friends understood the work was important to me. They recognized and respected that I was contributing to the gay community. The individuals closest to me tried to offer support in whatever ways they could. My new partner has experienced pain and futility at times in her efforts to help me through some of the rougher periods. I think it is still hard for others to understand unless they have lived through it.

The people who are able to work in this for an extended length of time are the ones who really see value in it. Those who truly care about the individuals and communities it is impacting. I have been here long enough to see almost a generation pass. I have seen a layer of people become diagnosed, live through this, get sick, and die. I am not sure I can be here in this community for the next generation coming up.
Maybe I am fortunate to not be as immersed in it as I was before. My old support systems are not available anymore. Most of the HIV positive individuals I used to connect with and share hugs have either gotten sick or died. It would be difficult in this community to find anyone else who has really gone through the number of AIDS related deaths. The health care community is still not an area where you get a lot of that kind of support. There are not enough people who have done it. It would be difficult to find anyone that could really empathize. Individuals who really acknowledge the pain of grief. If I had to go out and find that support, it would be a lot of work.

My experiences with HIV have taught, and challenged me more than any other life experience. The experience made me a more gentle and whole person. I learned a lot about multiple loss and human courage. It taught me about the human spirit that keeps people going. It taught me about anger, and a lot of injustices. It forced me to learn to grieve, and give myself permission to grieve. It allowed me to acknowledge that grief can be part of life without destroying it. It opened up dimensions in me, and brought them into focus. It forced me to accept my spiritual side, and discover rituals that provided me a symbolic way of dealing with grief. I learned to cry, praise the day, and keep going.

It was hard to make sense out of all the pain and suffering. At times I have thought of Victor Frankl's book *Man's Search for Meaning*. He talked about there needs to be meaning in suffering for suffering to be tolerable. If anything made sense out of all this pain and suffering it was being honored by so many people giving of themselves. I have seen people make miraculous changes in their lives. Individuals who have talked about how HIV was a gift in a lot of ways for them. I found a place where I could have a positive impact. I was there with individuals. They could trust that I would accept them, not reject and abandon them. I did everything that one individual could to help them get through this in a better way.

I think everyone has a passion. I found that passion in my work even though it caused me a lot of anguish. Passion is intensity, whether it is positive or negative. It does not need to always be ecstasy. It can be pure hell. It has taught me how to feel in ways that I have never known how to feel
before. I am a better person for it. I feel privileged to have done it. There was real joy in being
honored and privileged to know individuals and their families. It is the people not the disease who have
had a really positive impact on who I am. The individuals who have gone through it with dignity really
amaze me. I mean everyone had different degrees of dignity. However, there were some who went
through it gently, and who found good in it. I can sit back and think about all these men, and a couple
of women I have known. This journey which is horrible in so many ways with all this anguish, grief,
pain, and anger. Yet, I remember the good times of laughing and smiling. I guess good memories are
not always happy ones. I suspect that the partners and families have the same kind of memories. This is
why I did it again and again, and hope to and want to in the future.

Dennis' Story: It Is Important To Focus On The Positive In Grief And Loss

I remember first hearing about HIV in '85 or '86. It was something that was going on in New
York, San Francisco, the big centers. Even though there was information about safe sex and low risk
behavior it was in the back of my mind. It was happening there. It is not happening here. When I stop
and think of it, boy was I really stupid. We are not so separate from everyone else, because I have
traveled to San Francisco.

It was not until I became HIV positive in 1990 that HIV and an AIDS organization came into
my life at all. I realized then how many people had been afflicted, and had passed away. Especially in
Alberta, the gay life is very transient. People move to Vancouver, Toronto, or Montreal, the bigger
centers. People just disappear and you think, oh well they moved on. It was not till afterwards that I
realized that, yes they had moved on, they died.

When I was first diagnosed with HIV everything seemed to fall apart at that time. I had very
irrational thoughts. I gotta quit work. I gotta sell my house. I'm gonna be dead within the year. It did
not take long to realize that I had to get out of that rut. I soon discovered that I can still be a
contributing member of society. I can still live a good life and have fun.

It has not changed my lifestyle all that much. I still work every day. I tend to take better care of
myself. I tend to eat better. I exercise, or go to the gym three times a week. I try to develop positive
attitudes. I try to look at the good and positiveness of it. I think something developed after my
becoming HIV positive. It is such a negative thing that I was bound and determined for it to have a
really tough battle with me.

My family does not know. They know I have a chronic illness. I gave them various scenarios
of what could happen, one of which included death in five years. I let it stand at that, and if they wish to
think it is AIDS fine. I get support from the support groups I facilitate within an AIDS organization run
by people who are HIV positive. I also get support from a very small group of friends, and other people
in the gay community.

Shortly after I was diagnosed, I had contact with an AIDS service organization. It seemed like a
struggle to get connected at that time, and it took a while to get into a support group. I realized later that
there are other organizations and support groups. Over time I have contributed in quite a few different
ways. I took a peer counseling course. I have met individuals on a one to one basis to talk. My greatest
enjoyment has been facilitating support groups. I have participated in volunteer training, and talked
about my experience living with HIV. I sit on various committees, and a couple of Boards of AIDS
organizations. However now, I look forward to a break from the committees, boards, meetings, the
politics and bureaucracy of it all. I have seen people in the AIDS movement who have been there for a
decade. They have no energy any more. They are there, because they have to be there. I want to do
things because I want to do them, not because I have to do them. For me, it is time to move towards
more positive energy.

Living in Alberta and this community is where we get into the politics of the whole thing.
There are some good things that happen, but there is so much crap to put up with. It costs a lot of
energy to get to that point. Right now there is a question of whether anti-retrovirals will be covered here in Alberta. The new drug that I am on is not as yet. The coverage only exists because of a surplus in the funds. There have been instances throughout the years, like court trials, that make it extremely difficult for an HIV positive person to have a healthy view of oneself in this community. Now we have the Delwin Vriend case, and the Alberta Court of Appeal Decision. It does nothing to strengthen the community. I think the ruling denies gay people for what they are. Now you are gay and HIV positive, which are two things or two strikes against you. There continue to be barriers as an HIV positive person in getting support in this community and province.

In terms of impacting my life, I have seen a lot of people die. Most of my loss has occurred through the Monday Night Support Group that I facilitate. It still affects me to this day. I have five people who are consistent now. I had twelve people who were consistent a year ago. Most of them have passed away. Last year there were thirty people who died. It has made me realize my own mortality. As a whole, I would say for myself, I have experienced probably one hundred deaths to AIDS, and of that about seven are personal. I cannot make sense of all the pain and suffering. I think it is unjust. All I can hope for is that people will have a better time elsewhere.

When there has been a death someone from the AIDS organization calls to let me know. They do not want me walking in there and seeing the candle lit. When I heard the news of each one I would go through a recollection of them. I felt numb, particularly during those periods where there were a number of people who died at the same time. I think the numbness is there because it is hard to take. I have felt sadness. There is some bitterness that comes through, the unfairness of it all. I think part of it is the way the system treats the whole affair of AIDS. I have heard many times, they are faggots and they deserve to die. This is God’s retribution. I get angry over the insensitivity, and the disregard for human beings basically. I mean how can you not care for someone just because they are different. I believe that the best world would be a tolerant world, and that includes treating AIDS people with tolerance. I also go into introspection. I look at why I do feel this way. I acknowledge the loss. I also
look at how I can move out of feeling this way. I look into myself and think well it is time to move on. I wonder sometimes if I am callous and hard. However, that is my way of coping. I think I have a hard exterior at times, but life goes on.

At the same time, facilitating the support group is hard. It is a most difficult thing seeing the loss of faculties, and of weight. It is always in the back of my mind. I just had a young man come in who reminded me of a previous fellow. This other fellow was around for years and I knew him from university. I watched him deteriorate in front of my eyes, and he experienced nothing but loss. That was extremely difficult. So, when I see these similarities, I question my ability to deal with this new fellow losing things. At the same time, he has so much energy and is so much fun. He is very upbeat which is kind of infectious. You cannot help think that maybe this one will beat it. But, I know I cannot watch him deteriorate. Number one, I do not want to, and number two, I have to move on for myself. I think I need a break, because I am going to end up burning out.

All the little issues are harder to deal with. I need a break to stand back, look and reflect. A holiday is not enough, because I know I will be back there. It takes energy. There were maybe two days this year that I did not want to facilitate, but I did anyway. I get exasperated, or feel inadequate sometimes when I deal with intravenous drug users in support groups. A lot of times their issue is not the HIV issue, but the drug issue. I feel exasperated because it takes more energy, and is such a hell of a lot of work to keep them on track. It is not as rewarding for me when I have to work that hard in the group. I am putting out more than what I am getting back. This tells me that I need to check on what I am doing. Most of the time it was all right. If it takes that much energy to get there and to do it, then it is time to stop. I can see myself in six months coming back into the AIDS issue somewhere. I do not want to get to the point where I am of no help to anybody. If I am not giving them something, I should not be there. At the same time, if I am not getting anything, I should not be there. I realize that time will be coming, and so I need to stop and change before that happens. Negative energy is worse than no energy.
In all of this I cannot help think about myself. I personally do not fear death. It would be some of the losses that came before it I would fear. I have heard that issue many times. I do not mind dying, but I do not want the pain, not the pain. I just have to think of my coping skills, and how others have coped. I hope I have the resources emotionally, mentally, and physically to deal with something when it attacks me. I think all three have to be pretty balanced or in harmony with another. Sometimes I think, what if I lose my emotional capability, or my job. Seeing people lose their eyesight is always in the back of my mind. I will fight it, and I hope that I will win. I see promising things all the time. It is just a question of time whether those promising things will be there for me, or whether my time will have run out. If there are promising things on the horizon then I have to make sure I am there to see that. I will work myself, my whole body to that degree. My medical doctor and I believe that it will become a manageable chronic illness. In some ways it is becoming more and more that every day, but you have to want it. It is partially up to you.

People ask me, why I keep going to these support groups. It is because I think I still have something to offer. I still get support and strength from them. One of my defense mechanisms as a facilitator is to create a wall between other people and myself. Though I have a few friends from the group, I do not allow myself to get personally involved with the majority of them. Sometimes I wonder. Am I wrong to do that? Am I right to do that? But, I know it works for me. I think part of that defense mechanism is that I know that these people may not be here. So, I have to protect myself. At the same time, it stops me from doing things, and finding companionship sometimes. There have been a couple of individuals where we were very interested in each other. I just could not let it happen. Now there is a procedure for that as a peer counselor. Though, I think grief played a role in my not becoming involved with somebody very personally, because to lose them would be much harder. It is a real dichotomy. I think life would be so much easier if someone I dated was positive, because a lot of the issues about being HIV are out of the way. The community is so small here that the only connections that I do make are within the support groups. I think it is one of the reasons I am ready for a change.
Another way I deal with all the grief is to look at new faces, new things, and get new energy from them. I remember the good times and some of the really good energy that has left with people passing away. That is my method of survival. I cry sometimes, but generally not in the group. My role there is as a facilitator, and as a role model. Not that a role model should not cry. I am there as a source of strength to the people. The crying happens in other places. I cry at sad movies and sometimes when AIDS specials are on TV. I cry for all those people that have gone. I cry for them more than for myself. I guess I always wonder about the next person's grief before my own.

I read the obituaries every day, but now I pay special attention to people who die young. I want to know why they died. Some I read, and I know they have died of AIDS. They do not come out and say it. There are underlying things that are said, survived by such and such, his lover, another fellow, and the person is between twenty and forty. I try to look at them and get a perspective that it is still happening in this community.

I think grief is a very personal thing. The one person who really affected me most in grief, and not to do with AIDS, was my grandmother. For years after her death I had a lot of anger. It was not until many years later, that I realized that she had been in considerable pain with arthritis. Death was good for her, because it freed her. That was a positive aspect of her dying. It took me many years to get over that, because she was just so close to me. I felt cheated. However, I learned to look at the richness, the positive of that life. I think it is basically within each individual, depending on whether their make-up is more of a positive or a negative one. I have shared the majority of this with a lot of other people. Maybe that's a good thing. If you keep things bottled up, maybe it is negatively bottled up there.

Travel and holidays have been very helpful. I can go away and not think about AIDS or HIV at all. Well, I mean it is not foremost in my mind. I always seem to pick up literature in my travels. It is the excitement of doing new things and meeting new people that really helps me cope with loss and
being HIV positive. I like treating myself to a good meal with friends. This may seem like a small thing, but at times of loss I like to be around individuals that give me support.

The ASO memorial quilt I find very important. All the stars signifying a person who has been lost to AIDS is overwhelming for me. At the same time, it bothers me because it is so anonymous. When there are five Kens' on that one memorial quilt I wonder is that the Ken that I knew? I understand the anonymity is out of consideration for the family. At the same time, it is just like being a statistic. Why don’t you just put numbers up there, because that is what you are doing when you got ten Kens’ on that one quilt. I would like a better way of remembering people, a picture or something like that. One of the gay newspapers puts a face to a name in its ‘In Remembrance’.

The AIDS organization memorial services are probably the same issue for me. They are not well attended, and they are not the best closure for me. Half of these people I do not know. I think the best services are ones that talk about the individuals. I sometimes sense I am going to them because of duty more than anything. What has helped is really remembering that person for what he was, and meant to people. It is important to really talk about the connection with that person, and maybe have a picture of that person present. Otherwise, with so many deaths they just become another statistic.

The family or the person’s memorial service is the end of closure for me. A couple of them I wish I had gone to, and a couple I wish I had not gone to. I wish I had not gone to the ones where they did not talk about the person. They were just this religious diatribe. You've sinned, you've paid for your sins and now you're going, and we'll meet you on the other side of the gate. What kind of memorial is that? So ones that are not personal, or do not have anything about the person in them, are the ones that I felt uncomfortable being at afterwards.

Most of the funerals I have attended are those that have a connection with me in my past. I do not think I intentionally meant it to be that way. These were people whom I knew at university, or worked with previously. Individuals with whom I felt a kinship. I attended some which do not fit that pattern. These were people who left a real positive impression upon me. For example, Russ was so
positive about things even though he was very ill. He always had some words or gems of wisdom. Things were bad for him, and yet you could not keep him down. He was at peace with himself at the end. At the same time there were some I did not attend because they were too close. Others, where I have not gone, because I did not have the energy at the time.

We have both a candle and a lamp, which light up a corner of the office after a person’s death. There is an interesting debate going on in this office about the candle and the lamp. Some people were very upset with the lamp, because a candle burning does have finality when it is out. I agree that the candle has more respect or awe to it. It is something that ends! It is gone when it is gone, and so there is more of a sense of closing there. With the lamp you turn it off with the light switch and you turn it back on with the light switch. It is sad that a picture cannot be put with the candle.

Most of my dealing with grief has been helpful when another HIV positive person is there to help. I don't know whether it is because we are in this struggle, or the same wagon together. They understand. I find more help from the Monday Night Support Group. One of my closest friends is HIV positive. He knows the struggle that we are in. He has gone through his grief. I have gone through my grief. It is easier when the both of us go through it together. He knows I go to services and stuff like that. He has said, 'Listen if you need to talk, if you wanna go out for coffee, call me'. I do not get the same from other people who are not HIV positive. Some of my friends still cannot understand confidentiality. They call the support group the Monday Night Secret Society Meeting. However, there are a few people at the AIDS service organization who understand. I talk with one other person who works in reception who has dealt with the issue. I used to talk to two support staff, but they are not there any longer. I do not think some of the support staff there, now, deal very well with the death issue. I think for me when dealing with grief it helps talking to a person who is HIV positive. Or someone who understands the issue, who has had grief, who is genuine, and who creates a zone of being comfortable.
I think this AIDS organization and the environment there is resilient. It is the resilience of the place to all the hard issues, times, and deaths that has amazed me. I mean there have been people there for as long as I have been there and longer, and they are still there. I believe the new energy, by new people, was needed. It is very easy to get lackadaisical about the whole thing. It is important to always have fresh input or fresh energy to look at ourselves and how we do things.

The climate and culture in the office is changing. It think it used to be more open to gay people. It is an issue that has never been fully addressed. I mean there is more diversity coming. It is happening in all the organizations. I do worry, at times, that the whole thing will flip right over, and it will not serve such a gay clientele. This is great if gay people are not needful of the services, because the infection rate has dropped right off. I do not want them to drop off, because they cannot get services there anymore.

The office spaces have not always been accessible to clients. I remember in the old space there was a Board meeting occurring on this particular evening. It was Monday Night Support Group and I was trying to get into the building. The direct passage to the Drop-In was blocked, and I had to go past the Board room. There were people on the Board whom I knew in a social setting that did not know my status. They had to know my HIV status after seeing me. It made me worry a little bit, and it took courage of me to go in there. This is a barrier for some people. In the space we have now, we do not have a Drop-In. In some ways that has harmed support networks that people have found. So, if I was to redesign the space I would create a Drop-In. It would have the most direct passage to a comfortable room, without ever having to go through reception or past all the offices.

I think some of the staff deny death. I think with so many deaths a shell develops. Unless they have significance for the organizations it is just another number. Though, I think it is a reflection of our community as a whole. It is hard to separate the community from the organization, because there are always connections there. There is always a solemnness, or the energy is really down when somebody passes away. The people there get very somber the closer, or the more impacted they are by the
person’s death. I mean that is understandable, but they need to remember that they are there to provide support for clients. There is a nothingness at times there, and it is difficult to find support in atmospheres like that. I tend to use my other support systems to seek help or get comfort during those times.

As a board member, I do not know if everyone really understands the impact that it has had upon people. The Board has seen the quilt with the stars on it, but it is just like putting numbers up there unfortunately. There are the humanitarians of the board, and the pragmatists or the financial aspect of the board. They are about fifty/fifty. I do not think they have any concept of it unless they know somebody personally, and have dealt with grief. The humanitarian side of the board understands grief, because they work with AIDS organizations or AIDS clients. They are very much aware and are always questioning. Is this the best that we can do? Which if you cannot question you cannot be an AIDS organization, because grief is a vital role or aspect of the organization. The question is how do we deal with it?

I have sat on the human resources committee and we have looked at this issue, mostly with employees. It always comes down to dollars. If we had unlimited resources it would be great to always have grief counseling available for the staff. I guess grief and loss falls under the Employees Assistance Program. I guess for some it means going to a psychologist. I think we have to deal with, and work through the grief through whatever resources we can get. I think, at the same time, if you are coming into an organization that deals with grief it would make sense to have some workshops or seminars dealing with anticipatory grief. You are going to run into it, and it is far better to deal with it beforehand than afterwards. I guess this is something that we should be looking into.

Everyone grieves in their own way, but the commonality is that there is always a richness and a positiveness of somebody's life. Does grief so overshadow it that people forget that part? I know that it is hard to do, but I think you have to deal with grief through looking at people's positive influences. I mean are there not workshops to deal with grief, and look at the positive aspects of a contribution of a
person’s life? When a person passes away, let’s look at their contributions and their strengths. The physical body is just a shell. Try to remember that, and look at the positive aspects. I think more work is needed in this area. It is not denying the negativity of death, but let’s look at the positive passage of life of an individual. I find it healthy to do that. I do not think anyone with a real negative make-up would survive in an AIDS organization very long. It is probably the resilience of the positiveness of people's energy that helps one survive.

Bonnie’s Story: It Seems Like It Is All Loss Especially When There Is One After Another

I thought AIDS was a gay disease until my test came back positive in 1990. I had an HIV test as part of a series of tests, because I was having health problems after my son died. My doctor told me not to worry, because I did not fit any of the categories. Neither my family doctor nor the specialist knew anything about HIV, and they had never told a patient before.

My doctor told me I was HIV positive on my birthday. I freaked! I thought I was going to die. She locked me in her office and phoned the STD clinic so I could talk to someone who knew some answers. A counselor I was seeing for grief about my son got some information for me. My doctor phoned me every day for a week. She did not have any other information other than you cannot ever have sex again. A few months later I relocated to Alberta. I did not want my family to find out, and I had nothing but bad luck with hospitals in Ottawa.

My father was the first one to actually guess my diagnosis about 2 1/2 months later. I told a few friends, and my adult daughter. My mom knows. She lives in a little hick town and has not told anybody. If anyone asks she always tells them my diabetes is getting worse. So when I die it is going to be that I died of diabetes. I was mad about this for the first year, but I got over it. I know the small town. It is safer for her not to say anything. I will never have to go back there until I am ashes in a little box.
My son, Tyler, died three months before I found out my diagnosis. He died of AIDS in May 1990, though we did not know that at the time. They knew he had some kind of viral infection, but they did not come up with anything conclusive even from the autopsy. Who knows what would have happened had they actually checked for HIV. His diagnosis has never been confirmed. My diagnosis has answered a lot of questions. My mom says she is not prepared to handle that Tyler died of AIDS.

I really crashed when Tyler died. His death made me suicidal. It was scary. I do not want to ever be there again. I had lost a child previously and had been unable to get pregnant. I was diabetic and high risk to have a baby. It was hard to have him born a healthy preemie, and then to lose him over something we did not know about. I asked myself. What did I do wrong that I am being punished for? I did not understand grief, nor why I was still feeling the way I was after a year. I wanted to make it go away. Over time I have moved past it and put it in different places. It still comes back every once in a while. It took about four years to get over his death. I can now get to his birthday and not fall apart. His death helped me prepare for other losses yet to come.

My first contact in Alberta occurred with a nurse and social worker who came to my home from the hospital. I was really panicking and terrified. I was doing the denial thing. My diagnosis must be wrong, and this was not really happening. I kept looking over my shoulder to see if anybody could tell or knew.

I started going to a support group at the hospital as a way to connect with others who were HIV positive. It took a month of going to the group and talking on the phone with a support worker before I actually went into an AIDS service organization. For the first few months, I would look around and watch to see who was looking before I would go in the door of the ASO. I was scared initially, because I was coping with all this new information. I also felt I did not belong. I was also the only woman with all these gay guys.

However, it was these gay guys, and the folks at the ASO who protected and got me through rough times. A canoe accident occurred with myself and another man, while I was on a retreat with
others who were HIV positive. He drowned. When I got home the media were after me. I would not talk with them so they threw my name on the front page of the paper, and practically told the city I was HIV positive. After this incident I was to fill in at a work place for a friend going on holidays. A man in this work setting said I could not work there. He said his wife would never forgive him if his kids got AIDS, because he worked in the same room with me.

My community of support has totally changed since I was diagnosed. There were individuals where I live who would not eat anything I cooked for Potluck dinners. They would double bleach their wash, because we used the same washers. Some of these people who were not supportive are friends now. There are others who I am no longer friends with in part, because of HIV. There are people still out there who are afraid to drink out of a cup or use your washroom. Individuals who are ignorant and are not interested in learning. I laugh, because I probably was one of those people ten years ago. I go out of my way now to make them nervous. I do not have the patience anymore to deal with people’s discriminatory comments, whether it be about AIDS, gay, or race. The people I hang around with now are not quite so narrow minded. My community of support is very mixed, both gay and straight. I have gay friends that are more my family than my family is at times. I seem to be around people that are involved with HIV in one form or another. The ASO had become my home away from home.

I met Mark at the hospital support group. He was real obnoxious in a group setting when I first met him. However, sitting talking with him alone he was so quiet. He had built up this whole facade of Mister Tough Guy to keep people out. It took a year to get past some of that behavior. I realized some of it was due to his drinking and using. I did not know anything about that lifestyle, but I learned real quick. He ended up in an alcohol/drug treatment center, and seriously got off the stuff. It was a battle at times, because he was determined to prove I was like everyone else and would walk away. I was stubborn and determined too, and because of this we made it.

We were a lot more alike than people saw on the outside. We were both kind of loners. This was the part where we were the same that we never let anyone see. We got married which shocked a lot
of people. It really blew me away that people could not see that we would want all the normal things
even if we were HIV positive.

Mark and I experienced a lot of stress dealing with his family. We got married, partly, so I
would have the authority to deal with his family and follow his wishes. I had a lot of anger especially
with his sisters, because they never heard what he wanted. When I first met him they were arguing over
who was going to get what when he died. They were insisting they were going to be present at his
death. He did not want that. It was hard watching what he went through with his family, and that he
could not have what he wanted of them. So he wrote out a will, informed them of his wishes, and that
his wife will take care of all of it. They were not happy and created trouble even up to the moment he
died. The sad part is they could have been there all along if they stopped to hear what he wanted. One
of my friends helped intervene with his family and protect me during those last hours of Mark’s life and
at the memorial service. I found out later that his mom also helped keep them away. The dealing with
him dying was made worse by all the background stuff of constantly fighting with his sisters.

We had several episodes where Mark almost died. As he got sicker we became more isolated.
Mark was not well enough to go anywhere. I was not prepared to leave him alone too long. He was
angry that things were changing. He knew he was not getting better this time. His moods changed from
one extreme to the other. First he was going to find someone else for me when he died. Then he would
be in a panic when I went to the store to get milk, because I had met someone else and was not coming
back.

We thought he was going to die long before he did. He cheyenne stoked breathing for hours.
Whenever I would step past the door frame, even though I had not said anything, he would start fighting
again. The nurse had never seen anything like it before. I decided I could not go back in the bedroom.
I felt guilty, but I realized he could not die with me in the room. I went to sleep and remember waking
up at 4:10am. I almost fell off the bed, because I heard him calling me. My friend said that he had not
said a thing. He died at 4:11am. I know now that it was him that woke me up. He waited till
everybody was asleep or out of the room before he died. They are more aware than they appear to be. I did not know they had that kind of control.

I slept a lot the next several days. I was totally exhausted from six months of him being that sick. I was zombie like and really miserable for a while. When he died it was hard, because of the isolation we had created by hiding behind the four walls and shutting off the rest of the world. It made it hard for about six months afterwards to go back out that door. My best friend did not let me slide too far. My daughter knows my moods and could tell whether it was a crisis day or not. The people at the ASO helped by phoning me when I was not going in to the office. I have learned it is important to connect with someone who you can talk to, and not worry if it is four in the morning. I reached a point where I did not want to bother my friends anymore, but I still needed to talk to someone who knows what I am talking about.

My father was also really sick. I told my dad he would have to be okay. I was not prepared to say goodbye to him yet. I just could not deal with two at once. He died in September two weeks before I had planned to see him. He died the day before my birthday, the day of Mark and my anniversary, and two months to the day after Mark had died. He was the one person who I talked to and kept me sane at that point. It was too much all at once with Mark, Dad, and some friends who were HIV positive dying all within a few months. I was a habitual basket case.

The first Christmas was tough, because it was the one holiday that was a holiday for us. I did not want anybody around, but my daughter was there. My poor kid. Here I was making turkey stuffing, and throwing things. I am blubbering and angry. We tried to carry on our Christmas rituals. Everything bombed, because I was just mad at the world. The second Christmas I got back into doing some of my crafts which helped me feel I was accomplishing something. We began spending it at a friend's. I want my daughter to be used to going over there so when I die it will not be so strange. We are trying to change things and set things up for her. She has begun her own connections at the ASO which has helped.
We have done various ritual things over the years that anybody else would think was crazy. One year we planted tree seedlings in a local park before Mark had died. We planted them for my daughter so she would have a place to visit after we were gone. His tree did not do very good. I believe it was a sign he was not going to see the end of the year. I plan to go back and see them after the snow goes. I will panic if mine is dead too.

I go look at the ASO memorial quilt where Mark's and now Tyler's names are written on stars. I know most of the names on the quilt. It is kind of scary considering the number that is on there. A friend was recently shocked to find out that there are two other agency memorial quilts packed full with stars. It is important to have them displayed.

One of the support workers at the ASO got me involved with a project which helped me vent some of the anger. I have continued with volunteering at the ASO on various Committees. I went to a bereavement support group that was not specifically AIDS related. I also went to an AIDS specific support group. I still keep in touch with some of the other family members I met at the support groups and the ASO. This has helped.

Mark got me a dog for my birthday and our anniversary. He got her as company for when he was no longer here. When I do not want to get up in the morning she makes me. She climbs up on top of my head and washes my face. I have to get up to feed her and get the paper. She barks at me until I do. She also seems to know when I am depressed. She does not leave my side which helps. She brings in the ball when she gets bored. It is like she is saying, okay you have slept for two days now I want to play. Looking after Tiffy has kept me alive.

I have experienced a lot of loss, because of AIDS. I notice more things as loss. I notice every little thing like my body's ability to do things, my ability to work, and my loss of friends. Sometimes, it seems like it is all loss, especially when there is one after another. The period after Mark died, and this last January were like that. There is so many all at once. I cannot take anymore. I tend to close myself in when that happens. I pull over the covers and disconnect the phone. There is part of me that has built
a wall and will not let anybody get past a certain point. This is partly self protection, because I am not going to be left again.

Every time someone else dies I wonder who is next. I wonder when it is my turn. Oh God it is getting closer! This thought never leaves. I just bury it. All the people I knew are not here anymore. A lot of them who even came after me are already gone. God everybody's dropping and here I still sit! I notice now the senseless things. What possible reason would there be for someone having to die a certain way? Why am I here? What did I do? What is left? What crap do I have to go through now? There are days I would rather be in their shoes and trade them places, but that thought passes.

It is still awful going to an ASO memorial service and knowing half the people on the list. It is probably over fifty people that I am at least acquaintances with who I know that have died of AIDS. Maybe half of those people I was close to. Sometimes I run into people and we will be talking about a person who died four years ago. I kick myself for not saving pictures of people. I do not have any visual remembrance of them. I fight to maintain not losing who they were, and what they look like. I can see the face, but I cannot put the name to it anymore.

It seems when three or four die all at once it is harder, than when they go staggered. It seems though they go in groups and bunches. I do not have time individually to deal with each one of them. It is just too many all at once. It overwhelms me, and I start to spin. I want to yell stop already! I cannot separate them individually at that point. It is just all these people dying. It is not just about the ones you know it is about all of them. If there was ten people who died and I know only four, because they have died together you grieve ten people.

The ASO memorial service helps during these multiple death periods, because I cannot do the individual funerals. I have not gone to funerals of some of the people I was close to. It was just too many. It makes it too close to my reality. Going to the memorial services every few months makes it more tolerable. It is a way of keeping in touch. I cannot ever let go of that. I sit there and blubber at every one of them. I am still remembering all these other people who have died. At the services they
play one thing or read one thing and it connects for me with every single person I have known. The next few days after a service I need to get involved in something as an escape.

During these periods I experience a lot of anger though I notice that has diminished over the years, or maybe I am getting used to it. I get frustrated quicker by little things. A lot of the anger is around that I am always the one left behind. I have a lot of problems with depression since Mark and everybody else has died. I have spent more time on anti-depressants. Some days I can talk about stuff and not react and some days all I do is cry for days. It comes and goes. I do not necessarily know what triggers it. It seems the severity of grief gets less than it was particularly after Mark died. Grief does not go away it just changes. It is not every day, but I might have three or four bad days. The depression never goes away totally you have to make it pass. I know now when I start to get to the point where I cannot do it alone anymore.

I have trouble watching a lot of AIDS movies. I used to watch all of them. I avoid them now, because I have had enough. I am also trying to do the will thing. I am starting to do stuff like that, but it is hard. I have the forms to write it up, but it is still sitting in the package. I keep telling myself I do not want to deal with this today. I am trying to leave letters for certain people, and I have a file which I add to every once in a while. I can do that for a day then I need to escape into something else for several days.

I use different things at different times to help me cope. Most times rearranging furniture is therapy for me when something is bugging me. Other times I get in the car and just drive. I tend to watch a funny television show or movie now more than before. I find Super Nintendo relaxing. I can focus all my attention and shut out everything else. I write things out when I need to deal with things. I also do slushy parties with one friend. They started after Mark died. They entail strawberries, lots of ginger ale and cheap bubbly wine. It has become our ritual. A kind of a wake after some big event or a death. I plan to start painting and drawing again, which I have not done for ten years. There are several
different things I use to cope depending on my state of mind. I just keep trying things until something works.

It is getting harder to go in the ASO, because everybody’s gone. Even the volunteers and support staff have changed quite a bit. It has been important to have a lot of support around so that if one person is not around the other one is. I get involved with all of these AIDS oriented things, and then I need to take a few months. For a while I had no life at all except HIV. I had to find some other corners to get involved. I have to shut it off and do something else. This is why I have got off a lot of the committee work I was doing at the ASO. I am now more involved in the housing co-op. It helps to give me balance. I need to be able to have something else I can do which I can totally immerse myself in so I am not thinking about HIV. Sometimes this works and sometimes it does not. I cannot seem to hit a happy medium. It is either all or nothing. I think it will always be like that.

The first ASO office I went into was a homey drop-in kind of place. It has become more organization-oriented in this new space. I miss the way it was in the other building. I tried to get the new place reorganized, but it never happened. I think support services staff should be up front. The waiting area should be relocated, because the new people coming in are intimidated to wait up front for a support worker. In the old place we used the Drop-In. However, the Drop-in is no longer there. The connection among the people who are infected seems to have got lost. The Drop-in was a place to just hang out for a while. Now I run into more people at memorial services than I do there anymore. We need a Drop-in that is ventilated to allow both smokers and non-smokers to go.

In the last five years the infected people seem more divided. It used to be we were all there for the same reason. It did not matter whether I was a woman or they were gay. Now it is very much individual groups of those who are straight, gay, and addicts. There is no longer the common support from individuals. I still get it from the staff, but it is not the same with the clients. Maybe that is the way it has to be, because it is more diverse.
The ASO is still my safe place when I am feeling vulnerable. I am not expected not to feel grief. In the general public after a few months you are expected to be over it. The hardest part is putting on this front for everybody, that because I have had so much time I should be feeling better. I can go there and deal with grief, whenever and in whatever way I need to. I go in there, come home and feel better. People can challenge me there to stop wallowing in it. I will take it from them, because I know they understand.

Sometimes there was a lot going on at the ASO. Everybody was in there needing to see someone for support. They only have so many hands. I generally stay home on those days. I feel those people who have been there less time need it worse than I do. I will get through. I know it will pass.

I think there are people at the ASO who deal very good with grief. Humor has been an outlet. I also think a lot of people there are terrified of it. It is not a bad thing, but some staff tend to run and hide from it. I can see with new staff they need to learn all over again like the rest of us do. It would be helpful to have something for the people who are new going through grief.

I would not want to be a support person. They are getting the worst of it. They are close with everybody. They are not only dealing with their own grief, but also having to fix the rest of us. Here I am falling apart, and getting them to pick me up. I know they are not in any better shape, but they are just holding it better. I am sure come the end of the day they are going home and having a nice stiff drink. The same as we do.

There are parts of the community more accepting, willing to get involved, and not afraid to talk about AIDS. There are some changes. However, something will happen and I think we have not accomplished anything in five years. I still find places in the hospital and medical community where the attitude towards HIV positive people and comfort level of staff has not changed. It is a little terrifying that these are the people I count on to stay alive. I have been recently trying and frustrated in accessing my medical records and proving my HIV infection occurred through a blood transfusion. However, my biggest fear is the impact that cutbacks in health and social services will have for me when I am sick.
Will I just die sooner, because the services are not there anymore? I am afraid of being sick and not being able to take care of myself. I am more afraid of the politicians than I am of any doctor. I do not believe we have any greater political support. There is not a lot I can do about it if the community does not want to change.

I think everything happens for a reason even if I do not know why it is for several years. HIV has been the best thing that happened to me, because I know who I am now. I might be physically sick, but I am probably mentally healthier. I have had to really look at and figure out what is important. I have become much clearer about what I am responsible for, and what I am willing to put up with from people. I do not have the patience for fighting over petty things. I pick and choose what is worth arguing and fighting for. I also no longer look for something missing in my life. I found what I was looking for with Mark. I am content now to be by myself. All the grief has made me stronger and taught me self preservation.

Different things have happened that have strengthened my spiritual beliefs, and made me no longer fear death. I saw Tyler's spirit leave his body when he died. Mark had control over the timing of his death right up to the second he died. He started to let go, but I told him we need fourteen days to move in to this place. One of the last things he asked me was is everything done. He died on the fourteenth day. Events like that keep me sane. I know I will see them again. Otherwise I am not sure it would be worth fighting for.

Perry’s Story:
I Do What I Do Now, Because I Want To Be Recognized For Something

I have been gay the better part of twenty years, which I was not sure about earlier in my life. I was married and had three kids. I have been divorced, and separated since the kids were small. I decided it was just too much to deal with my lifestyle, my partner’s illness, my ex-wife and kids so we
have not had contact in many years. They do not know about me being HIV positive, and I am not sure whether to tell them.

My first contact with HIV occurred in 1987. I met a friend's brother who was gay and HIV positive in Vancouver. I met my lover, Peter, who was HIV positive, a few months later. He had set a precedent human rights case in British Columbia which made it illegal to discriminate against those HIV positive. We spent a week in AIDS Vancouver learning about what you can and cannot do. This was how my AIDS education started.

Peter and I were together eight years. Our relationship was a physical and emotional one, and we had an open sexual relationship. I knew my lover so well, that I could tell you what he was going to say and do, and how he was going to do it. People were amazed.

We lived in a rural Alberta community for a while. There was no formal support for those HIV positive, and we met others who were positive through my lover's doctor. At this point in Peter's illness he was really scared to be left alone. He wanted me to stay at home and look after him. We went into the Social Service office to apply for social allowance. Peter told the worker the situation. She told him he was lying. She said we do not have homosexuals in our rural community, and therefore we do not have an AIDS problem. She lost her position because of her comments.

My parents also live in a rural area in Alberta. There was also this nice respectable family who was considered highly in my home town. However, they lost a lot of support when several individuals within their family became HIV positive. Half the town was behind the family and the other half was not. Consequently, I am careful who I tell because of the impact it may have on my own family.

Peter and I began our first involvement with an urban Alberta AIDS service organization in 1991. I was reluctant to become too involved because I thought it would make my partner depressed, and sicker. We began contact with a support worker, accessing an emergency trust fund, and getting some reading information. There were times, because of our drug habits, that our accountability and credibility were questioned especially when accessing the trust fund. However, once the support worker
checked us out we got along okay. Later on as my lover got sicker we had contact with a buddy volunteer. The support worker would visit us and help get things set up so that when he did pass away everything was in place.

We had a lot of turmoil in our relationship because of our drug use. There was an incident where I had cocaine related assault charges, and Peter had a restraining order against me. He was sick then, and in and out of hospital. He did not want me charged, and wanted to see me. He went to the crown prosecutor, and demanded the charges be dropped.

We got back together and left on a trip to Vancouver. At that time, I thought Peter was going out to Vancouver to die. I think it was during this trip that I became HIV positive. I think I got mine from an IV drug dealer in Vancouver. We were doing cocaine in the hotel room with this man who was Peter's friend. I asked this man. Are you positive? He says No! So away we went. I saw him at AIDS Vancouver the next day.

We came back to the community we were living in, and I missed my court date. I was picked up at home and taken to jail. I needed five grand for bail money. I sat there, and pondered where I was going to get this money. I finally broke down, and my parents helped me out.

As Peter got sicker I would have to clean him up. It was not easy, but I just did it. I remember feeling so guilty, because I left him home one day and went to a friend's place to use the phone. He was bed ridden. I accidentally locked the keys in the apartment. I could not get back in. I had to get the caretaker to let me in. Peter, by then, had crawled across the floor and lost all of his body functions. I never left him alone again. I wore my keys around my neck.

Toward the end of his life I thought I would leave. It was too much for one person to go through. I was looking after Peter, and trying to deal with the fact I was diagnosed just prior to him passing away. I had no other support other than Home Care, and a friend who would come over once in a while. I thought I cannot do it anymore, but I stuck it out. At the end I had to encourage Peter to let
When it was over I did not cry. I could not do anything. I was glad he was dead, and that it was over. I lost it after he was gone, and tried then to deal with the stress.

My family support has been good. Early on it took my mom several years to get over the fear and come and visit us. I did not think she was very supportive when I told her about my diagnosis. However, I have seen a big change in her over time. I also tend to back down from conflicts with her, whereas before I would fly off the handle. My parents now know everything since my court appearances. They have been supportive the whole time, both financially and emotionally. My dad had no problems with people being gay, or HIV positive. We have always gotten along good. However, my sister and I have not had contact in several years.

Peter and I went through a lot of problems with his family in Ontario. Once they found out he was sick and gay the door was closed. His mother and sister came out to see him once when he was really sick. His father sent him a note saying we should move to China, because they knew how to take care of our kind there. When Peter passed away they could not be bothered. I held up the funeral quite a while waiting for them. My partner’s sister gave me the run around. I thought she would come for sure.

When Peter died in 1994 I had the ashes couriered down to his sister. I had to remind her that he did not want anything to do with his parents. She had to stick to those rules, though I knew it was hard for her. They were not there when he was alive so why should they be there now. I videotaped the memorial service. It took me about a year and a half to send them a copy of the tape. I had one contact with his sister since, but there is nothing there. I am done with them. I got the very best from my partner.

The assault charges against me were dropped after Peter passed away. However, I had to go to jail, because of charges related to my cocaine habit, and failing to appear in court. He died on a Thursday. I went to court on a Monday and the judge let me out for the funeral even though I was already sentenced. I went home, but could not stay there. I wondered where he was. I began this
unreal cocaine ride. These cab drivers I knew followed me around for two days. They watched me all night, the day of the funeral, and got me to the courthouse the next day to turn myself in.

There was a two week period where nothing really made any sense. The support worker from the AIDS service organization came to see me a lot, which was really supportive. I saw a psychiatrist and psychologist at the remand. They provided me information on the stages of grief, loss and bereavement that was designed for seniors in Florida. They were also concerned I was suicidal. I know it was a lot to bear. It was difficult when I found out I was HIV positive, but life goes on. I saw my lover live for eight years when I thought he only had six months. I had unprotected sex in an eight year relationship, had been an IV drug user, and been an ex-prostitute. I had accepted the odds that if I do not have it already I will have it.

I got through that period after Peter died by doing a lot of talking. I cried. Sometimes it was rough talking about certain stories or events that happened. I had big waves of emotion all the time. Sometimes it was so overpowering I would almost black out.

I was relocated to a prison for a year to complete my sentence. It was while I was in prison that I realized that there was a real opportunity here to educate people about HIV and AIDS. There is a society in prison that you do not get a chance very often outside to educate. Most of the guys in prisons are going out to their girl friends or wives who are into prostitution and drugs. By educating these guys in prison you have gotten into crack houses, and a lot of other places.

When I first went into prison the nurse there did not believe I was HIV positive, and insisted I go for another test. The nurse finally called the clinic where I was tested, and then announced where others could hear that my HIV test was positive. I was really upset that my confidentiality was violated. Lawyers and AIDS organizations all agreed my rights had been violated. I even took it to the Ombudsman and the Warden. No one was able to do a thing about it. The prison got me quieted down by having the Ombudsman show up.
Initially I was in protective custody which took a lot of stress off. I was later segregated with two other guys who were HIV positive. The staff would relocate anyone who came into the area we did not like. They did not want any trouble. The prison staff had written on the bed boards HIV positive. They even tried to give me AZT without my consent.

One of the eerie things that happened in jail was two guys approached those of us who were HIV positive. They wanted us to give them the virus. I gave them a lecture. I told them you have no idea what you are going to go through. It is easy enough to get access to drugs and a syringe in jail. You can buy one for a buck from someone. So if you want to go to the shooting gallery it will not take long to become HIV positive. I had a lover while I was in jail and everybody knew. It just shows, that anything's possible in there.

I created a lot of static in prison so they let us start a support group, and provide AIDS education with the help of the prison health care, Salvation Army, and an AIDS organization. I saw really tough convicts break down and cry over an AIDS movie. I taught inmates the grief, psychosocial, and emotional concerns of those HIV positive. They asked me how we coped with my partner's illness. They were really intent on listening, because of my unique experience. I was able to use what I had gone through with my partner, create an understanding about HIV, and really connect with those in jail. I was initially fearful of people knowing I was gay and HIV positive. However, I was amazed how supportive the inmates were even those who were pretty red necked. Some would actually hover around and protect me. Some of the guys introduced me to their families even after they found out I was sick and gay.

In our support group we used the Living and Dying - Dying at Home Manual from Casey House in Ontario and started teaching inmates. Health care staff in the prison initially taught the course, and then afterwards the inmates started teaching inmates. They took the manual and designed it for inmates to teach other inmates. I believe this is the first time this has ever happened in an institution where we started, and took over the course. The Program Director had to pick it up, because there was such
enormous pressure from the inmates. The center really went out of its way to accommodate to what we were doing. As far as I know it is still going on. In the time I was there over 200 inmates had gone through the course. Now, a lot of the guys I knew are getting released. Some that are Aboriginal are going back to their reserves to start up organizations. So, I think my time in jail was well spent. It helped others and I think made an impact there.

The Salvation Army chaplain was the one in prison that really listened to me. He was not too keen on the gay issue, but this guy let me dump on him. I would get angry, scream, holler, and jump around his office. It was so good to let it out. He seemed to recognize that I was grieving Peter, and other things.

When I got out of jail I spent a lot of time at the AIDS organization. I made a promise to Peter before he died to become involved. The support worker kept me busy there with various things. The environment there was organized, professional, yet casual. The people were there because they care. They have had to learn to adapt to different emotions, lifestyles, and cultures. The volunteers there are tremendous. There were various possibilities of getting support from both peers and professionals. The people there tried to help me clean up the garbage I had been packing around. I was using prescription and non-prescription drugs to get through this period of my life, but they all beared with me. It took a while for me to be accepted in their circle. They saw me as the typical street punk at first, but by trying to do something they have come to accept me.

At times I wish I would have had more time to talk with a support worker. There would always be an interruption when I was seeing someone. I think it took a longer time to deal with my grief because of this. I liked the idea of talking with other people who had lived through the experience. It was not till much later that I was able to really connect with someone else.

I have gotten my support from all over. I never really lost my immediate family support. I have support from the gay community, and all the different people I have seen and worked with in the prison inmate community. Even now when I am out, I see a lot of inmates that are coming out and have met
them and their families. I do not think the gay community is as forceful behind HIV issues anymore. I
am getting a lot more support from mixed groups of heterosexuals. My main support is from the
survivors club or families of people who have passed away. I talk with other gay couples about how
they cope with caring for their sick partner. It helps to share our common issues and experiences. Like,
oh you did that too! You had to put up with the depression! You had to sit and hold him all night! I
understood how important it was to finally get a four hour break from that home situation where they
are dying, and feel guilty because you are not there. Talking with the survivor club helped me put my
experience in perspective and realize that I did everything I could. I could not have done anything
different.

However, heterosexual men do not understand how two guys could have a relationship, hold
one another, cry together, or show emotions. Only another gay man seems to understand what it is like
to lose your partner. I get my emotional support from gay men. I can sit and cry in front of a gay man
where I can not do it with the heterosexual. People see the lifestyle as being different, but there is not
much difference at all.

The only reason I am living in Alberta is because of my family. If I had a choice I would move
to British Columbia, it is no big deal there if you’re HIV positive. Here there has still been a stigma,
even in the gay community. Though, I have found professionals from various agencies who have been
really supportive and encouraging for me. They have a positive attitude that things will change, and
have helped me during difficult times with the prison project.

When I first became involved with this issue, there was a group that was dying. Now the next
group is dying. Individuals who a few years ago were pretty healthy, that now are not looking good. It
is getting closer. I am in the third group that is coming up. I have noticed now it is my group of friends
dying. Out of twenty of us that originally met when I first came to this community in 1985 there is only
one who is not HIV positive. I know eight that have passed away. There has been three deaths in the
last three months. It has been boom, boom, boom since Christmas. I know twenty-five who have died
in the last four or five years. I think it is probably a lot higher, but I do not realize that others are gone. Some I have discovered have died by going to the clubs, and talking to friends. Others I notice are missing, and no one has heard of them.

With some friends I know their death is coming, that they are going to die. I try to talk to them before they get that sick. Sometimes it bothers me afterwards. I feel guilty that maybe I should of went over there last week. I tell myself to stop kicking myself. It would not have made a difference. Other times, I get really angry at the fact that I do not know when to be of help. I do not know when I could have been there, or could have made a difference. I wanted to make others feel better even for just an hour. Sometimes, I feel a lot of loss and anger more than anything. I feel mad at my partner and my friends for dying. My old friends are all dead. The new ones are there, but the ones that were there from the beginning are not. It is a lonely place.

It is hard to believe they have died. I wish it would stop. I feel detached. I have to start all over again. It is hard to lose good lifetime friends. It is impossible to start new relationships. It is hard to get out and meet somebody new and try to explain to them you are HIV positive. Sometimes I feel like I do not want to tell people, but because my partner was so good with me it has become an obligation.

I recently tried to get to this friend's memorial service, but I just could not go. I am tired of putting my friends to rest. I can appear to be pretty up about it. I cope with all this dying by thinking. Well, I have to go someday! Sometimes I am overwhelmed, and go on a drunk. It seems like every time one passes away I am sliding into a bottle for a while. I wake up the next day, and I feel okay. I look at it that they are always happier when it is over.

It is hard knowing it is going to happen to me one day. I know for me it is important I not be alone, and that I have my friends around me. I do not want my parents around when I die. I will talk with them before, but I do not want them to have to deal with the end result. I have told my friends that I have made the choice to not live if I am unable to make choices for myself anymore. I will be dead.
will have a whole bunch of booze and stuff there for a big party. Call the morgue, and have them take my sorry little butt out. Keep partying! I will be happy to be dead, because I do not have to deal with any more of you dying. It will be my turn to check out.

It has gotten to a point that I do not go to memorials anymore. I have my memories of that person. I do not need to go to memorials and see a picture and urn sitting there. I decided there would be no more after seeing my partner in the coffin. I have never crumbled at a funeral like I did then. I will not allow myself to be that vulnerable, or lose that composure again. I do not think I would ever attend another one, unless I had another partner who passed away. I do not want to go to memorial services and put up with the natural family fighting with the adopted one. I have seen so many of these. The person that died would never want it. I do not like the turmoil that comes after the person’s death. I have had enough. I do not want to go to anymore.

So now I use the rituals at the AIDS organization instead of going to services. I see the candle, that burns when someone dies, when I go in the office. I go and find out who it is, what happened, and when the service is. I tell myself maybe I will go to this one. However, when it comes time to go to the memorial service there is not a chance I will go. I prefer to listen and support others by having them come and talk about what it was like to attend the funeral. I like to hear about it afterwards. I find keeping busy and helping others helps me deal with people passing away.

It is the talking, telling stories, and helping someone else that helps me deal with the constant grieving. Sometimes I go in to see a support worker. I tell the person to not say nothing, just sit, and listen. Let me scream for a while. I usually feel better after I dump.

The memorial quilts in the place are comforting. Seeing them sometimes is pretty overpowering, because you get all the memories at one time. You see a person’s life there. I have seen partners try to make those, and really struggle through it. I like to see people bring in the panels, and display them. The stars on the large quilt are another way people are remembered.
When there are multiple deaths and losses the tension around the AIDS organization is really high. People are edgy. They are talking about the person who is going to die, especially when the individual is familiar. There is compassion and understanding because everyone knows others are getting edgy. People are putting up barriers, because of all the deaths. They are trying to figure out how to cope. They are trying to deal with the grief on their own. Then, I see people sneaking off, and talking in corners. Nothing is getting done anymore, because of these corner visits. Sometimes they have a big group meeting in the office to talk about how everyone is doing.

I notice around a lot of deaths fewer people access the office. Certain volunteers or clients that usually come down will stay away. I think that this relieves the stress off the staff. I have a problem going to talk to a counselor that has lost five clients in a week. They are trying to tell me to keep my chin up and keep going. I want to tell them to have a good week. Go talk to the counselor next door, because you are needing some help. The office staff seem to need to reminisce about the person. I appreciate this about these people. It makes me feel better knowing that this is how they will be talking about me.

During these periods I sit around the office anticipating someone will be coming in. Then all of a sudden they are not there. I start phoning around finding out where they are, and why they did not come in. I think maybe they died too. Are you going to leave the rest of us here? You can not die! You have to stick around and finish what you started!

It really hurts. I do not know what to say, and who to say it to. We know it is going to happen, be glad they are not in pain and suffering anymore. There are also times when I just become tired of talking about it. I do not want to hear that they are dead again. I know they are dead. I know we are grieving, snappy and irritated. It keeps building up to a point where it snowballs. That is when I decide I am not coming in here for a couple of days. I am sorry, but I can not face this place.

This illness has brought a lot of death to me. It has brought a lot of friends and my partner attempting suicide. Being involved with an AIDS organization has brought a purpose to my life. It has
been part of the healing and dealing with everything. I see people's determination, and that they are not giving up. Even those who are sick inspire me, and give me hope to be like them one day. I am discovering things about myself. I am doing things that I never thought were possible. At one time in my life cooking hamburgers, and putting cocaine in my arms were the two highest priorities. I feel so good to be able to contribute. I have improved myself. I want to be able to be part of this purpose or group to help me. I feel good in knowing that I can help them succeed in something. If I can help break down some of the barriers then it makes it easier for me to access the resources I need. I always figured we are here for a reason and maybe this is it. I like to know that I have actually helped people. I like to know that there is some good that has come out of it, especially given there were people who I may have infected before I knew I was HIV positive. I feel like I owe something.

My experiences with AIDS has made me more compassionate, especially to people with terminal illnesses. It has made me more understanding of the stress, needs, and wants of those who lose someone. I have discovered that I can help someone. I can actually sit with somebody who is really emotional, and not become overwhelmed with my own feelings.

It has made me more understanding to the little things in life. I used to believe life was a big party, and you lived until you are old and then dropped over dead. I look at life now, because I know you do not live until you are old. I walk down the street and notice a tree bud in the spring. I never noticed these things before.

Sometimes, I wonder who is going to forget. Who was that guy back there that did that? What was his name? A lot of the reasons I do what I do now is because I want to be recognized for something. I did not do too much when I was first diagnosed. Now I feel I have something to offer. I want people to remember that.
Greg's Story: If I Can Learn Something, And Take A Bit From Each Person That Dies Then I Honor That Person In Their Own Way

HIV has had a big impact on my life. I found out that I was HIV positive about three and a half years ago. Before my diagnosis I was aware of HIV, but it had never personally affected me. After my diagnosis it started a process of feelings, and grieving. This process is constantly going, changing, and developing over time. HIV and AIDS grief are part of everything I do, and have changed everything to do with my life. They are unwelcome house quests, and you have to make the best of it. Once you accept it, you have to keep going, and learn to live with it.

I have always worked in human service kind of areas, and been a support type of person. I chose to work in the field of HIV when the opportunity arose. I think about it every day. It is part of my job, and it is part of my life. I am learning all the different facts, treatment and drug information. I am collecting all the things I need to know for later in life. I always say that once the cure is found I will be first in line, and I will save spots for the rest of the people behind me. I always want to be on that cutting edge of information. I can hopefully make a difference. I can travel, and have input on a national level by sitting on larger committees. These are the reasons why I am working on the front lines.

Some of my friends are quite supportive though I have not used them much. These friends are amazed that I can do that kind of work. I think I get a little more respect when I say that I work in an AIDS service organization. I talk to my partner about it. He tries to be understanding. Though, I do not want to talk about it too much. I do not want him to start worrying about that yet. We have talked about some planning for us personally, but not a lot. I do not have a legal will. We do not have a lot of big discussions. It will be easier on him if he gets exposed a bit here and there.

I think you have to be very careful who you tell. I am sure there are people at work who still do not know. People who are positive can figure out that I am positive by the way I talk. Other people do not have a clue. This is why it is not a big deal for me to disclose my diagnosis. Though, I have to be
careful for my partner. It is not just my life that is affected by this. I have taken the role that I will talk and disclose to some of my clients. Though, I am more careful with clients who know my partner. Both my partner and I are concerned that assumptions will be made that my partner is HIV positive.

The larger gay community is not an extremely supportive environment. So, I need to protect my partner and my friends in the community. I think in order to still have the same acceptance you cannot let even the gay community know. The backlashes will come, and both my partner and I are scared of that.

My family are fundamental Christian orientated. They think a certain way and I think something totally different. They respect what I do, but we will never share the same mindset about anything anymore. They are family in name only. I do not offer, ask for, or get support from my family. That is probably my own choice. It is not a support system, because of our different beliefs and values. We could never have a healthy supportive relationship.

Living in Alberta has been an increasing challenge because of the health care cuts. These cuts have impacted the palliative role of Home Care. The AIDS organization I work for is therefore needing to develop the concept of care teams, and bring on a lot more volunteers to help individuals in the last months of their life. However, the greater challenge in Alberta is the despising and non-accepting attitude toward the gay community. I think the Alberta Court of Appeal decision said it all. It says a lot when a government will spend millions of dollars to say that we are not equal, or are less of a person for being gay. I think we have gotten to the point where people do not think HIV is a gay disease anymore. However, I certainly think that the majority of people blame it on us. I can picture a redneck straight guy despising gay people, because he has to take precautions or put on a condom. The community in general is changing, but you still do not get the support.

I provide community based support for those infected and affected with HIV. I noticed how others were affected by grief when I first started with the organization. In the first year of working there some clients passed away. These were clients in the late stage of AIDS who I did not know well. After
the first year, I thought maybe this is not going to be all that bad. Now there are a lot of people I have worked with for a more extended time that have passed away. It is really hard to describe, but I am starting to see it more now in myself. It causes frustration or shortness in other areas. I have gotten angry over some people who passed away, because I did not think it was the right time. The ones that were unexpected were the hardest. I notice that I become stressed easier. My patience wears thin. I get frustrated, or have the desire to get away from it a lot quicker.

There are a couple of clients that I have worked with for quite sometime who are now in the hospital. It is the beginning of the end for one of them, and the end for the other. It is going to have a huge impact on the organization, the rest of the staff, and myself. It is difficult to guess how HIV and AIDS are going to affect people. It is the marked contrast of how differently this disease reacts that gets frustrating. You just never know. I do not want to tell people someone is really sick and help prepare them, because they may be out of hospital and be walking around next week.

Whenever a client goes into the hospital I tend to see them more. I feel a little bit guilty about that sometimes, because I am paying more attention to them when they are in the hospital than when they are not. I want to make sure that if they have anything they need done, that I will do that to the best of my ability. I try to be around and let them know they are not alone.

I notice the deterioration, and it is not pleasant to see. I try to make my visits close together so that I do not get such a big shock when I see somebody. It is how they look physically, but also it is in their eyes. I call it the stare. Their eyes are glossy. They are looking somewhere, and are not really aware of what is going on. I think the person decides, either consciously or subconsciously, when and where they are going to die. Sometimes I get frustrated, because it is just taking way too long. The person is suffering way too much, and more than others have. I am caught in between wanting the suffering to be over, and then you realize well if the sufferings over then they are dead. I do not want to wish anyone to be dead. I am caught in this emotional dilemma.
It has been an interesting process supporting a friend of mine who was around the office. It took going into hospital a few times, and the need to connect other supports with him for the change in role from a friend to a support person to happen. In other cases there are maybe one or two connections after a person dies, because they use their own support systems. However, I know his friends and partner. We joked around a lot. It is going to be hard. His death will leave a big hole.

I think when clients, family and friends have had a lot of years to prepare themselves for the death it is a lot easier. I think working with the person who is dying is the easiest in some way. The needs of the people surrounding the person who is dying become even greater. I have found that a bit strange and frustrating when you are trying to support the individual who is dying. However, I think it is important to just be there with them.

Some individuals I support need to talk about realms beyond what we know living. I certainly do not promote any specific belief system or philosophy. When they are at that point they are quite firm in their beliefs. They either know what is going to happen, or they do not and they are quite okay with that, as well. I think if you viewed a client dying as a terrible thing, then it would be a lot worse. It is a loss. Someone is not going to be around anymore. I think it helps to not think of death as all negative. I know there is something else. I do not put a label on it. I think there are higher powers, and forces of good and bad. I do not think death is the end. There has to be something else. If it is the end quite frankly does it matter? I mean you make your life what it is, and you do not count on anything else. You do not count on coming back a second time. You are responsible for how you act, and what you do. If you are not happy with how you have lived your life you better start changing some things, and be happy with it. Then, if there is anything else it is a bonus.

I do not find myself more preoccupied with my death, because I have experienced other people’s. I do not think I have connected the two personally yet. I think doing what I do, and dealing with death and grieving has changed how I look at myself. I take better care of myself, and it gives me some priorities. If you can learn something, and take a bit from each person that dies then you honor
that person in their own way. I have learned about coping with a disability. I have gotten to see one
person's dreams from a guy who probably had the worst possible life. There were times when he did
not want to continue, and times he did. So, if he could still have hopes and dreams to do things, then
both other people and myself are able to as well.

I have feelings when someone dies. I grieve their loss, and wish they were around. I still think
about them. They are still very much a part of my experiences. I think I can honor them in that way. I
do not break down and cry each time a client dies. I would probably be a mess most of the year. When
someone dies it is like another shovel load in a pile. I know the pile is getting bigger, and there is
nothing you can do to lessen that pile. You just have to learn to live with it.

I acknowledge a person has died, and it has gotten another one of us. It is not like you did not
know that it was going to happen. Things are not as happy anymore for a while. However, I struggle
for the norm. I keep on going, and keep on fighting. I do not like using the word fight. I do not think I
have done anything worthy enough to say that I am a warrior in this battle. There are little fights here
and there. One day I would like to make a big mark on it. The battle continues. We are small players.
We can make a difference on our own personal level. We can encourage people, and other
organizations who can make a little more of a difference than one person.

The only real other loss I have had in my life was my mother. So, with the grief and deaths I
experience at work it is not a devastating personal experience. It is not a number, but it is not your
mother dying. It is somewhere in between. I think we are honored to be able to ensure that people are
not numbers anymore. I think once people become just a number to you then you need some time away.
I think the number of deaths that I have been involved with is more than an individual would have in
their lifetime. However, it is nowhere near what other professionals have experienced, who have been
working in the field a lot longer.

Sometimes, I wonder if I should be more affected. Some would say that I am not really dealing
with it all, and denying some of it. I am just slowly learning, and I suffer some loss. I think eventually
one day it is going to catch up with me and then the dam is going to burst. That has not happened yet. It is hard to say whether what I am doing personally and internally right now will prevent that or not someday.

I try to set clear boundaries with the people I work with. I work with them during work hours. They are not part of my home life. They do not phone me at home. I do not provide them that opportunity. I rarely do anything on the weekend that is work related. I am not going to spend seven days a week on this. I have to have time for me. It is not going to encompass my life as much as it has already. I am not going to allow it to stress me out and be my life. It is my job.

When I am stressed and frustrated I just want to get out for a while and take a break. I have learned that it is okay to take some time if work is getting too crazy. When I find myself getting too frustrated I do not have a problem anymore using a sick day. It forces me to go to the gym and work out. I probably run faster and harder when I have had one of those kind of weeks. I need to get rid of it. I spend more time on my physical health. I try to eat better. Little things that would annoy me are not important, because what is more important is being with my partner, being held and talking. I try to make sure that other things are more balanced. So, I am able to better deal, and cope with it.

My colleagues are really supportive. There is permission and flexibility in the work schedule to take time when I need it. We know when the other is stressed out, and we try to cover for the other person. We hear each other’s frustrations. We act as a sounding board for each other. We very much empathize with each other. I do not use anyone else on staff. I think there is only a handful of people that I would talk to, and who I think really understand. It is amazing, because there is a level of understanding in people who are in support positions across the country. I mean you can say two words and there is an understanding.

Attending funerals is still important to me. I miss it when I am unable to attend a funeral, and I feel a bit of emptiness. At funerals I can see the grief going on, and I can feel with it. I know that there
are other people who are feeling the same way and probably a lot stronger. I can share that with other people.

Sometimes the support you need is not always available, because a lot is going on in the organization. I remember being quite upset and angry when this man I supported died. The unfortunate thing was the next day someone else passed away who everyone knew. Everybody forgot about this other guy. Everybody was talking about this one person, and I wanted to talk about the man I knew. I felt both some unfairness, and lack of support at that time. Fortunately, we had several volunteers involved in supporting the man I knew. We spent the afternoon after the funeral together just sharing about him, otherwise I probably would have been more frustrated.

We also have rituals in the office. When someone dies a candle is lit, a star is put up on a quilt that is displayed in the office. On a regular basis the agency has a memorial service. When a client dies that I worked with it has been important that I am the one that lights the candle in the office. I do not think the rituals play a lot of role in how I deal with things. It is often Support Services staff that are running around planning the rituals and it tends to lose a lot for me in the process. I think for me the ceremonies and the rituals at the agency are just part of the routine. It becomes part of the job, and half the time I do not want to go. I do not know if that is being hardened. I am just not surprised to see another candle burning, or a name on the whiteboard. It is just not surprising anymore.

The organization on the surface is a great place. There are a lot of really wonderful, kind, and true people who are committed to the cause. They can be very supportive, and fun. It is a more relaxed atmosphere. I think whenever you get an environment where your mixing people’s sexual orientation and everything else things have to be more relaxed. There is permission to be stressed out, and for humor to occur as a way of coping. You try to make things as light as possible because you are dealing with so much else. Sometimes the humor is pretty black.

I think especially when there are a lot of deaths close together it takes staff longer each time to get back to a normal chipper kind of environment. The atmosphere changes, personalities change, and
people get a little bit more on edge. Normal humor is thrown out the window and either people are not very happy, or really sick humor comes out. Sometimes it takes a long time for the staff to recover especially when it has been ongoing. I think we have been lucky to have had a couple of breaks between deaths. This has allowed people to respond. It takes a toll very definitely. I think this is why there is a lot of change of staff within the organization.

Maybe our agency does not do well with grieving, and does not have anything in place to help staff. However, people do not use the resources when things are in place. A mental health worker was made available, but no one used it. I think a lot is up to the individuals to make sure that their stress levels and their abilities to cope with situations are in place. Other staff complain about boundaries and barriers. If they choose to become friends with a client they have allowed themselves to be seen as that kind of support, and they whine about it when they are asked to be supportive. I believe that if staff do not want that to happen then they should not open themselves to it. I do not have the time to support other staff when I have clients to support, and myself to take care of. I do not think my job should include being a therapist for other staff. If the support workers can handle it, I do not see why other staff are not able.

I become frustrated when I see staff complaining about petty things, and I am always seeing people dying. Especially, when I turn around and see stuff that could be done to create new avenues of treatment, or lack of progress to meet the needs of different populations. This is when I tend to say things I should not. I think my grief manifests itself in a general lack of patience, and I take it out on the upper leadership of the organization. When there are deaths, and things are tense, this comes out a lot more. The deaths provide more of an immediacy, and remind me more of what needs to be done. The more losses you see the more you want to do something. Sometimes our frustration will focus energies. Hopefully that will be in a good way.

I do believe there is no reason why we could not be offering, or creating new initiatives of support to different populations. We are going to have to diversify. Every other agency has had to
respond. We just need to be willing to change. We need to learn to work with new populations. We still have the experience and knowledge base within this community to do it the best, and work in coalition with other agencies.

The people who really need the support are the street involved and lower income populations, the aboriginal community and gay youth. Other AIDS service organizations have shown they can do a lot to help these individuals. It is hard for street involved individuals to access our agency because the feel, location, and structure of the office are not welcoming. Support Services has been doing outreach to the inner city, and in prisons, but we do not have the backing from the agency. I think Support Services wants and welcomes change. I think the rest of the agency should be wanting that kind of change, and supporting us to do that. I think that they are either so over-burdened from loss, or they do not want to get to know a whole new population because that they are scared to lose them as well. I think people want the security of things remaining the same.

I think sometimes people lose track of their priorities. I question the whole existence of the society sometimes. I wonder why we are not fulfilling what we say we do. I do not understand how people can be in this business for as long as they have, and seem very resigned to the fact that this is how it will always be. They do not understand how much change and progress they have seen over ten years. Announcements about new drugs, and different medical developments do not excite them anymore.

There is one staff person who represents hopefully what I will not become someday. I have been in the business too long when I do not go to funerals anymore, or go see people in the hospital. I do not want to create that amount of avoidance to deal with the issues. I can totally understand and empathize why this person is doing that. I do not necessarily have to agree that this is the right thing or not. This person has come to this point. It is something they have had to do. So you do things to make sure that does not happen. For me, possibly that is not becoming as attached, because this person had to
become extremely attached to individuals. I may be just kidding myself. I may realize four years down
the road after trying to not become too attached that I have, and I am a nervous mess.

I do what I think is helpful for myself in the present. I know that there is a beginning and an
end. I want to accomplish and do a lot of things in the meantime. I am finding more and more hope
that help is on its way. I mean life happens and death happens. You do not put all your eggs in one
basket. I used to plan my life to be a certain length. When I was first diagnosed the goal was ten years.
It is funny because now three years later I still think ten years. The developments I have seen in the last
six months suggest it may not happen. We may have something by the time I am scheduled to start
getting sick. The calvary is coming over the hill. I try to let the individuals that I work with see that
there is hope, and there is a reason to fight. There is no reason for anyone, at whatever stage, to lie
down and give up. I am not one of those eternal optimists. I mean people are going to die from HIV
and AIDS. There have been thousands who have, and there will be thousands more. If there are going
to be more deaths then it is going to be for a purpose. So, if I can give people that kind of hope then you
know things are not going to be this bad all the time. I think it makes living easier when you have this
kind of hope. I try to prevent things from happening, from losing control, but you never know how you
are going to react in five or ten years time. I do not have those kind of answers. I do not know if
anyone does. I just do things now in hope that it will help me later in life.
4.2 ETHNOGRAPHIC ANALYSIS

The Truths That Bind: Celebrating The Strength And Courage, Honoring The Pain, And Memory Of These Individuals And Community

The second level of analysis describes the complex inter-relationships between these life stories and the community contexts that inform AIDS grief and multiple loss. This analysis involves visual images and thematic validation from the transcripts of these eight participants. Figure 2 represents the portrayal of this analysis in a circular layered image. The four layers depicted here include: The Inner Layer; Climate of Intense Emotions, and Grief and Coping Processes; Organizational Context; and Provincial Context - Alberta. I will begin with a discussion of the Inner Layer.

The Inner Layer

The inner layer represents the concept of the 'central challenge' faced by participants throughout the history of the organization. This challenge is compounded by the four roots or core themes that represent the primary present and historic participant and organizational challenges. These four roots are termed layers and cycles, fight, time, and complex and blurred roles and relationships. The visual image of Figure 2 is consistent with repeated references by participants to the theme of 'layers' and 'cycles' of multiple losses. It is also reflected in the language of participants, such as, circle, cycle, layers, wave, cumulation, and generations of loss and grief. The words layers and cycles depict a core theme in the inner layer.

Layers and Cycles

The following quotes from participants substantiate the idea of layers and cycles of loss.

When someone dies it’s just ... another shovel load in a pile and ya sorta know that’s getting bigger. **Greg**

We were losing a generation of people, I find it’s harder with each cycle, a lot more levels, a lot more layers of problems to cope with at times. **Barry**

The death was part of a circle, a wave of deaths, we’re having another wave of deaths, the collection of experiences ... the accumulation of deaths and losses, but it’s also the cumulation of the experience of these people’s lives and my connection with it. **David**
ETHNOGRAPHIC ANALYSIS OF AIDS GRIEF AND MULTIPLE LOSS FROM INDIVIDUALS WITHIN AN ALBERTA AIDS SERVICE ORGANIZATION
Interconnections of Themes of Inner Circle

There are significant interconnections between these four roots or core themes in addition to the central challenge of participants as represented in Figure 2. The 'central challenge' of participants and this community is an effort to 'balance pain and loss with hope and commitment'. The losses are deeply personal where family, lovers, friends, volunteers, colleagues and members of your own community are dying. These personal losses often motivate a response to HIV by the individuals impacted. Consequently, it was normative for these individuals, within the organization and their community, to have 'complex and blurred roles and relationships'. The 'layers' of losses and 'cycles' of connections complicate the balance of coping. Additionally, there exists the pressure of limited 'time' to cope with the losses and an urgency to 'fight' or create a response to HIV.

Central Challenge - Balance Pain and Loss with Hope and Commitment

Participants express the central challenge to 'balance pain and loss with hope and commitment' by finding meaning in the experience of loss, by recommitting oneself to the cause, or as a means to honor other individuals who have died.

I translate ... feeling particularly stressed about people's health ... or losses that are accumulating or death ... back into my own personal ... and professional commitment. David

I’m taking a bit from each person that dies. And if I can learn something ... then I think ... you can honor that person in their own way. If I can give people that kind of hope that things aren’t gonna be this bad all the time, whether or not for them, for other people I think it makes living easier. Greg

This illness has brought a lotta death to me, but it’s brought whole new life ... I want to be part of this purpose or group to help me. Perry

This type of meaningful commitment helps to transform the challenge and increase the tolerance for this work as Cadwell (1994), Egan (1993), Haviland et al. (1997) and Hooley (1997) have observed.

Complex and Blurred Roles and Relationships

Participants express efforts to set boundaries or limit their involvement and exposure to grief and multiple loss. However, given the complex interrelationships between people, it is difficult to
escape the pain associated with loss. We find in this ASO that 'complex and blurred roles and relationships' are unavoidable and normative in this organization and community. The nature of this complexity is because a response to HIV came from and in response to losses within the gay community, as Barry had stated earlier in his narrative. Staff and volunteers often maintain several roles in relation to their exposure to HIV and were often motivated from a personal response. Annette's narrative identifies the complex roles and relationships.

I went to the support group in '86 ... and at that time the group was a mixture of both those HIV positive and their family members and we kept in touch outside the group also. ... and I started to volunteer ... in '88 I couldn’t volunteer anymore and then in the 90’s was when I went to work for an ASO ... there’s been a few others (family members) that sorta keep in touch ... they come and stay with me occasionally ... I guess it’s not really completed yet ... I guess we need each other. Annette

These complex roles and relationships accentuate one’s experience of grief and loss because of the additional identification with the person who is ill, as Bennett (1995) has already noted. This identification occurs because of friendship, familial or collegial relationship, one’s HIV status, or membership in the gay community.

It’s been a real interesting kind of process, cause when he was around the office he was a friend and we joked around and then when he had to go and he was at home, things changed and it was really hard to and it took some time and I think him going in the hospital once more will help that change happen ... from a friend to a support ... that one’s gonna be hard because that’s gonna cause a lot of loss issues for (our mutual friends). Greg

There were a few people who I got to know really well and a couple of people I would count among my best friends, ...I knew some of these men very well, talked with them sometimes daily, they had a desk right across the hall, so I knew these guys very well – laughed with them and joked with them and cried with them, the whole nine yards. And I remember I felt a loss when (they) died. David.

It’s the most difficult thing – seeing the loss of faculties, of weight, I can’t help (it), it’s in the back of my mind. It always is. I just have to always look at it, that I hope I have the resources: emotionally, mentally and physically to deal with something when it attacks me. Dennis

Allison also expands this theme by acknowledging that the stress of caring for those HIV positive was due in part to the fact that she felt a need to overcompensate for her colleagues who were
not providing compassionate care due to their own homophobia. Bennett (1995) has similarly noted this in her work with stress and burnout of health professionals. Allison describes her experience below.

I'm lesbian and these were gay men and I knew what that was about. ... And so for me, I could identify with being badly treated. ... So it is my community and it's people who have shared the shit that you have to go through in being gay in good old red neck Alberta. ... so maybe I set myself up sometimes for a little more pain than I should have. But they got the best we could give. ... So there was no way I was going to let someone I knew and cared about have some red neck, right wing, gay hating nurse. Allison

At times the losses in these blurred and complex relationships are related to losses you feel in relation to your community. Dean et al. (1988) noted the chronically AIDS bereaved are more likely to be involved in AIDS activism. Barry describes the loss he experiences in relation to his community activism.

The people who were activists or involved in gay liberation ... with looking after the community ... losing a whole piece of leadership ... the people that affected me the most ... that I had come in contact with and knew these were people who were involved in the same kinds of work that I had been involved. So we were losing a generation of people. Barry

Time - Not enough or Limited Time

The idea of 'not enough or limited time' of participants is a core theme which has driven various responses by these individuals and the organization. Participants describe the sense of vulnerability of limited time as a result of their experience with being HIV positive and/or multiple deaths from AIDS.

Every time someone else dies, its like, who's next?, you’re looking around to see who’s sick and who’s next and like when it is my turn? That never leaves. You bury it. I’m not ready to go yet. But every time someone else does it’s Oh god, it’s getting closer. Bonnie

It’s not easy to watch them you feel so helpless, you know their time is limited, Sometimes ... especially when there’s multiple deaths and the fellas are so young sometimes you feel well maybe it shoulda been someone older like me ... they haven’t had a chance in life yet? Annette

Additionally, the idea of time is also important in a community where there is insufficient time to grieve before the next loss occurs.

You’ve just come back from a funeral and you don’t have time to absorb it, integrate it or figure out what you’re gonna do with it before something else is there right immediately to be dealt with. David
There was one time when I had to go outta the office ... I just had to leave ... it was hard to face at that time ... that was the summer when (several people died). Annette

Overlapping deaths or multiple losses also leave insufficient supports to cope.

The unfortunate thing was that I was quite upset and quite angry about it (a person died who he had supported for sometime), but the next day someone else passed away who everyone knew ... everybody just basically forgot about (the person I knew) and people would talk to me about this other person. Greg

Fight

The last core theme in the inner layer is the idea of 'fight'. Participants use repeated references to metaphors of war, such as, fight and battle. This language has been similarly noted by Cadwell (1991), Clever (1988), Franklin (1993), Peloquin (1990), Sherry (1993), and Sontag (1989). The language attempts to express the magnitude of devastation and response needed by the community, as Sherry (1993) has noted. Early on in the development of the organization Barry described the need to fight in reaction to, and fear of future loss of friends. His commitment to fight developed as a way to organize an urgent response to the loss and fear of greater loss and death of self and others.

We formed a small committee and started to think about what we might do, we thought perhaps we were all contaminated and that we were ... going to ... all die from it, we had to be sure the services were in place ... we needed to look after our own communities cause nobody else probably was going to do it, we’d also had about five or six people who had become ill ... I’d started to experience the loss of people ... the first people that became ill ... were activists ... there was a sense that we were under siege early on, it was also dealing with overall fear, cause who’s gonna get sick next. Barry

The language of fight also continues to motivate other participant responses as a result of their experience with multiple losses and the need for social change.

It’s that old phrase pray for the dead and fight like hell for the living. Every time, it’s amazing, but every time we go through these tough times, that always comes back into my head that some how the fight still goes on and I can’t do anything about the deaths, but I maybe can do something about those who are still living and so it’s that fight, that fight, that comes back time and time again. David

I don’t like using the word fight because I don’t think I’ve done anything that I consider worthy enough to say that I’m a warrior in this battle. There’s little fights here and there in making differences on a personal level is important. One day I would like to make a big mark on it. But the battle continues, but we’re small players and we can make differences on our own
personal level and that's really important and we can encourage people and we can encourage societies like organizations who can make a little more of a difference than one person. Greg

The language of fight is also in response to the challenges created by the Alberta and Organization Contexts. A discussion of these participant challenges follows.

**Provincial Context - Alberta**

The external or fourth layer that impacts the experience of AIDS grief and multiple loss is the social and political context in the province of Alberta. The experiences of stigmatization, marginalization and discrimination were well noted in the literature review. Figure 3 provides a visual summary of the social and political challenges identified by participants in the province of Alberta. In particular, participants note the impact of heterosexism, homophobia and lack of human rights protection for gays and lesbians as adding to additional stress in the province of Alberta.

We went to social services (in a rural area in Alberta). Peter went in and said that he was HIV positive and needed help. And she says, Well, you can’t be because (this community) has no homosexuals, therefore we haven’t got an AIDS problem. ... the only reason I’m here is my family. If I had a choice I would move to BC. ... people that are there, it’s like it’s no big deal anymore for the HIV/AIDS ... they’re more relaxed about it. Here they’re still stigmatized. Perry

In the context of the kind of stuff that we’re still having to deal with around life style, around choice and around illness, that here in Alberta ... we still continue to struggle with ... particularly in relation to some very basic human rights stuff that we still continue to struggle with in this province. David

This theme was further emphasized by participant references to the Alberta Court of Appeal decision that occurred the week of the research interviews. This decision upheld a previous ruling that “the province does not have to add discrimination for gays and lesbians to its human rights laws” (Tanner, 1996, B3). This stands in contrast to eight other Canadian provinces which “include protection from discrimination on the basis of sexual orientation in their human rights legislation” (Tanner, 1996, B3). The participants provide us insight regarding the impact of this ruling on being HIV positive, and gay in the province of Alberta.
FIGURE 3 – Provincial Context - Alberta

ETHNOGRAPHIC ANALYSIS OF AIDS GRIEF AND MULTIPLE LOSS FROM INDIVIDUALS WITHIN AN ALBERTA AIDS SERVICE ORGANIZATION

CLIMATE of Conservatism
In Health & Social Services

CLIMATE of Continuing Homophobia & Prejudice

CLIMATE of Emerging Needs of
Women Aboriginals
Gay Youth
IVDU & Street & Prison Involved

Central Challenge

Complex & Blurred Roles & Relationships

Fight

Layers & Cycles

Context

Alberta
Alberta and (this city) here we get into the politics of the whole thing and being instances throughout the years, court trials, that made it extremely difficult for an HIV positive person to have a positive healthy view of oneself in this community especially from the, what we call the right wing conservative aspect of the government here. ... I think the court case (Alberta Court of Appeal regarding the Vriend Decision) or the ruling denies gay people for what they are. So now you’re gay, now you’re HIV positive. That’s two things, two strikes against you. Dennis

I think the court decision yesterday said it all. That there’s still a huge despise and non-acceptance for the gay community and being gay you’re considered less of a person. ... I think it’s gotten to a point where they don’t think it’s a gay disease anymore, but I certainly think that the majority of people blame it on us. ... Sure it’s changing and sure there’s lots of support, but when the government will spend millions a dollars to just not to say that we’re equal, I mean (that) says a lot. Greg

I think the epidemiology of the disease has made people more accepting because there are currently in Alberta more and more of those innocent victims emerging. I don’t think there’s any more tolerance or acceptance of the disease from the point of view of it effecting injection drug users, people in prison or gay men. ... Politically we’re in a climate where that perception is not gonna be changed. Today in the paper Delwin (Vriend) lost his appeal to have sexual orientation included in any kind of charter in this province and one of the judges used morality six or seven times in his dissertation. Allison

The context in Alberta also complicates people’s grieving by creating social/moral judgment and limiting access to supports. This experience for AIDS bereaved has been extensively noted by Boykin (1991), Cadwell (1991), Cho & Cassidy (1994), Dane & Miller (1992), Doka (1987), Richmond & Ross (1994); Schoen & Schindelman (1989), Sowell et al. (1991) and Walker et al. (1996). Perry and Bonnie elaborate this point in the following narratives.

I went to school with this (guy) and found out he passed away and heard that my home town just went nuts ... half the town was like behind his family and the other half (was not) ... So when my folks told me they’d moved, I was relieved that they’d moved from there. ... And the man that passed away in my home town three others in this family are infected, one being lesbian and the other two being gay males. ... So I don’t know what their parents are doing. They must be just devastated. They’re such great people. They were sitting well at the top (of the hierarchy in this community) and very nice, respectable people. They lost a lot through this. Perry

They live in a little hick town where nobody knows anything and isn’t telling anybody and if anybody asks, it’s well my diabetes is getting worse, so that if and when I die that’s what it’s gonna be. I figure I don’t have to live there so. I know the town, I know the people, it’s safer for her not to say anything. I won’t ever have to go back there until I’m in a little box and I’m ashes. Bonnie
When asked to reflect on the state of change in attitudes in this community and province participants reported some minimal optimism. The two responses below identify this ambivalence.

There seems to be more people in the community willing to get involved or that aren’t afraid to talk with other people. I mean there’s still lots who are ... but there’s a lot more people out there in different areas that are getting involved ... And there are some changes but then you’ll turn around and something will happen and you think, Oh God! We haven’t accomplished nothin in five years. But I know we have. **Bonnie**

I think it’s quite varied, ...I think it is really coming true that HIV is showing up in every nook and cranny of this province. But I think there’s a lot of folks who really will deny it. ... but there seems to be more people who at least when it strikes home with them are more responsive. **David**

While participants express slight hopefulness in the above comments they also continue to express considerable concern about the attitudes of others. This ambivalent optimism regarding attitude change is further validated by the mixed public reaction following the 1998 Supreme Court decision which afforded gays and lesbians protection against discrimination in the province of Alberta. While some sectors in the province of Alberta celebrated that gays and lesbians were finally afforded protection from discrimination, others continued to publicly express extreme heterosexist and homophobic ideas. The following narratives highlight this concern regarding attitudes.

The community in general, I think we’ve seen a growing level of support and involvement. ... I think we’ve also seen some polarization in society around a bunch of issues and certainly have gotten polarized around the issue of sexuality, the disease of AIDS and the issues of civil rights for gays and lesbians. **Barry**

I think it’s a very mixed bag. I think there are a lot of professionals out there in the human service field who still think street works (HIV education/prevention and free needle exchange) is encouraging drug use. A lot of social workers or other human service professionals who don’t like homosexuality, who have very traditional views of family who will deal with someone around HIV only because it’s a professional responsibility, but will not address their own discomfort, their own anxiety. **David**

The concerns expressed here by David and Barry certainly led to a response by the organization to educate the community as part of its role and mission. This perception, concern, and challenge towards the attitudes of health care professionals and social workers in particular was observed early on in the epidemic by Dunkel and Hatfield (1986). It continued to be voiced in social work literature by
Chachkes et al. (1991), Shernoff (1990), Shernoff and Springer (1992), and Wiener and Siegel (1990). The Canadian Association of Social Workers (CASW) also sponsored various projects to challenge social workers in their response to HIV/AIDS (Clarke, 1995), as David described in his narrative. However, despite various efforts Eldridge and Lawrence (1996) summarize that prejudicial attitudes by health care professionals towards stigmatized groups or persons with HIV disease remain and factual information alone is not sufficient to create behavior change. This suggests a continued and expanded role the organization could serve in responding to its mission to educate and assist in a community response to HIV disease and the groups it impacts.

Participants also express continued concern regarding access to medications, health and social services. These stresses add to the losses already experienced by those HIV positive and the individuals and organizations supporting them.

There is question whether drugs anti-retrovirals will be covered here in Alberta the new drug that I’m on isn’t as yet, my coverage will only exist because of surplus in the funds at this point. **Dennis**

The ASO’s just playing with some concepts of care teams for really developing the palliative role now since Home Care’s being cut back a lot. So we’re gonna be bringing in a lot more volunteers to help individuals in the last months. **Greg**

The problems are more insurmountable today and in some ways there’s more problems to deal with than there was ten years ago. Prejudice, homophobia, people’s insensitivity, ignorance, fear those were the problems I think ten years ago. And those you could fight cause you could change the people, you could invoke agency policies to get people to change their attitudes and behavior. I think today, the whole systems are out of whack in social services and health care and it’s policy and governments – those are the big structures that are so out of whack today. **Barry**

The problems are more insurmountable, as Barry describes, because we see erosion in basic health and social services. This is occurring while individuals and organizations are faced with increasingly complex and diverse circumstances of clients (Cain, 1997), and the course of HIV disease. At the same time there is greater insecurity and increasingly competitive funding arrangements for non-profit agencies as these narratives and Cain (1995) have identified. Therefore, many challenges remain for
those HIV positive, AIDS bereaved, and the individuals and organizations attempting to create a response to HIV in the province of Alberta. A description of the Organizational Context follows.

Organizational Context

The third layer depicted in Figure 4 is the Organizational Context of this ASO. This organization is viewed as an alternative service organization in this community similar to that described by Cain (1993) and Lustiger-Thaler and Shragge (1993).

We were different ... because of the perception that we were a gay organization or the perception that we were an agency dealing with the disease that people were all afraid of that we wouldn’t operate in a typical fashion. Barry

When it came to the (ASO), it was obviously working on the edge, working on something very new, but also carried a lot of suspicion with it as well, particularly in the general community and also disdain. David

Over the course of a ten year history organizational changes developed. David describes these changes as resulting from the “professionalization of HIV”.

We now have (a) professional fund (trust fund to help those HIV positive) we have professional fundraisers we have professional educators, we got professional social workers ... we’ve become much more segmented, compartmentalized ... we bring in special people to organize the walk (fundraising event), we bring in special people with special skills to sit on the Board. David

These changes have come about as the organization has grown quickly in response to the increasing needs of those HIV positive, and to the changing financial climate for non-profit agencies.

The major thing is the growth, how we’ve expanded ... some how I don’t think the closeness is there ... it’s just seemed to have grown too big ... we didn’t have that many people in education, we didn’t have all the resources and we didn’t have all the support people that we have now and I think the function is making money too cause we know our funding has been cut. Annette

Certainly stresses that non-profits today experience, in dealing with funders and with fundraising and all of those things. I think it’s far more severe than it was five years ago, or certainly ten years ago. Barry
FIGURE 4 – Organizational Context

ETHNOGRAPHIC ANALYSIS OF AIDS GRIEF AND MULTIPLE LOSS FROM INDIVIDUALS WITHIN AN ALBERTA AIDS SERVICE ORGANIZATION

Alberta

Layers & Cycles

Context

Professionalization of HIV

Loss of communal system of support

Central Challenge

Challenge for community to cope with Unacknowledged Disaster & Trauma

Creative Org & Community Grief Rituals

Fight

Complex & Blurred Roles & Relationships

Time
These changes and challenges, at times, add to the experience of multiple losses.

A sense of loss sometimes hasn’t always been around the fact that people are dying it’s also dealing with other losses in the agency ... sometimes it’s been a loss of funding, a loss of resources ... that you’re gonna have to fight all over again with agencies that aren’t terribly supportive ... whether it’s social services or health or access to drugs ... we’re fighting battles that are tougher today than they were ten years ago. Barry

Along with these organizational challenges is the awareness that the organization has changed in mission. There is a sense that the connection and “ownership on the part of the gay community” has “been lost”. Dennis further adds to David’s concern on the loss of connection with the gay community.

Climate and culture’s changing. I think it used to be more open to gay people, to me it’s an issue that has never been fully addressed, but I mean, there are more and more diversity coming and I’m, I do worry that at times the whole thing will flip right over and that it won’t be serving such a gay clientele. I mean it’s happening in all the organizations there. ... I mean it’ll be great if the gay people aren’t needful of the services because the infection rate between gay people has just dropped right off. ... I don’t want them to drop off because they see they can’t get services there anymore. Dennis

David also perceives the “roots of the organization ... to some degree have been forgotten... or our solidarity with people with HIV was greater then than it is now”. This shift in mission is described by several participants as two camps within the organization. David defines himself as in the camp “for the people who need us, those who are infected and affected”.

I just see more and more two camps and I’m glad I’m in the camp I’m in because I know that we’re there with the people who are really hurting ... I think people have lost a sense of why they’re there or what the organization is about ... I mean they’ll go on their way with the very administrative type of office environment that doesn’t really fit the needs of a lot of people who come through the door. David

Allison and Dennis extend this concept to the board level by also describing two camps. One camp “the humanitarians” seems to understand the experience of being HIV positive, while the other camp “the accountants” are the financial representatives of the board. Allison describes her own struggle as a board member and the changing organizational mission.

You’re (referring to board members) here because there are people sick out there and that’s the only reason you’re here and you’re not addressing it as a priority ... and because the accountants and the lawyers take up the majority of the Board, in a lot of ways I feel impotent in making any change on that Board. Allison
Greg expresses frustration in the uncertain organizational mission, especially as increasing needs of diverse populations are emerging.

I question what the whole existence of the society (is) sometimes and wonder why they’re really there and why they’re not fulfilling what they say they do. ... I just think there needs to be a commitment to change just a commitment to be innovative has to happen that there has to be a philosophy to address the emerging needs ... the whole street involved populations, the aboriginal community, the lower income, ... gay youth.  

Greg

The challenges expressed here in organizational mission are similarly noted as challenges facing many ASOs by Cain (1995, 1997), Fleishman et al. (1990) and Ouellette et al. (1995).

Greg further states that his frustration with the organizational mission fuels his anger and sense of frustration with his experience with grief.

So when you see a lot of people dying and then you turn around and you see stuff that could be done or things that you’re working on in terms of new avenues of support or new avenues of treatment or lack of progress of the agency to meet the needs of different populations, that’s when I really get frustrated and that’s when I’ll tend to say things I shouldn’t.  

Greg

Dennis and Allison also extend the camp concept to the Board’s understanding of grief.

I don’t know if everyone really understands the impact that it (grief) has had upon people. ... And unless they know somebody personally that they’ve dealt with grief, I don’t think they have any concept of it. ... It’s about fifty/fifty. The financial aspect of the Board, the pragmatists, in some ways the more conservative aspect of the Board and in terms of grief I don’t think the Board really takes it that much unless like there was specific Board members on the humanitarian side that work with AIDS organizations and with AIDS clients and they are very much aware.  

Dennis

The Board has the accountants and the humanitarians ... I don’t think they (the accountants on the board) understand the grief stuff and maybe they don’t wanna ... They speak to a willingness to raise the money so that workshops can happen ... but I don’t think they wanna know what’s real. That’s something that the frontline staff can deal with and that’s what they hired the frontline staff to do.  

Allison

Barry extends this idea through his belief that Board members provide “lip service” to the issue of grief support.

Some people give lip service to it at the Board level ... And that lip service or just being aware that things are going to happen is not enough. Or that people are somehow going to be able to look after themselves properly is not enough. ... That dealing constantly with grief and loss needs to be built into the planning of the agency.  

Barry
The organizational changes and shift in mission have an impact on the organizational environment and availability of grief support within the organization. Fleishman et al. (1990) and Ouellette et al. (1995) similarly noted concerns that ASOs have lost their family like atmosphere and are criticized for being out of touch with the community they were intended to serve. Participants also reflect these thoughts. Allison states the earlier office environment was "homey ... a comfortable kind of place to hang ... kind of like a street front clinic". However, Allison describes that the office "now feels more like a business operation ... there's not a connectedness with the people (who are HIV positive)". David describes that these changes have created a sense of loss of the "communal type of system of support ... where it became less of a collective experience and now became very compartmentalized and it was a slow process to where we are now". Associated with this loss of the "communal system of support" was the loss of a space (a drop-in) within the organization where connection between others HIV positive occurred, and where grief support just happened.

There isn't a place to go anymore ... that part seems to have got lost and so there isn't the connection among the people that are infected the way there used to be ... Now I run into more people at the memorial services than I do there (ASO) anymore. ... at the other place (previous office) you always knew no matter how you were feeling, there would be someone in the Drop-in, you could go and sit and if you needed to talk, you could talk ... and (I) even was involved in trying to get the office re-organized (to recreate a drop-in)... but nothin ever happened with it. Bonnie

I don't think I ever went to the old place purposefully to deal with grief, but I would go there and it would happen (in the drop-in)... sitting on the couches in the back and start yacking with someone and pretty soon you're crying or hugging someone. Allison

However, though these organizational changes have had impact on grief supports, the individuals and the organization have always struggled with the issue of grief and loss and the unique challenges posed for individuals, and the organization. The organization has had an ambivalent response to providing grief support as David describes below.

We had fits and starts in our ability to kind of get some outside help on a regular basis and for some reason we just never were able it seemed to get it all together. So I decided very early on that I really couldn't rely on the Network a heck of a lot. I needed to find it within a network of support outside the organization ... I'm not sure that we've really organizationally tackled the issue. Kind of this little bit and that little bit. David

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This ambivalent response, Barry states, was due to being "too busy dealing with all the activities and being a small agency, ... trying to develop programs and deliver services". Individuals and the organization, Barry states, "were either naive or didn't fully understand the impact that this would have". The ambivalent organizational response was also due to the lack of knowledge and the new territory ASOs were facing in responding to grief.

We were certainly not knowledgeable ... we thought that maybe even just telling people to go get some counseling would do it ... we found out that most of the stuff wasn't out there and that we were in fact on some fresh territory. Barry

This ambivalent response and uncertainty of how to tackle the issue extends to the Board as described below.

Boards need to recognize and understand what happens in AIDS organizations and what happens to the staff and that it does affect everybody. Barry

How do we deal with it? I sit on the human resources committee and we were looking at that issue mostly with employees. It comes down to dollars if we had unlimited resources, I mean it would be great to always have grief counseling available for the staff. ... Is it part of your Employees Assistance Program? And so that’s what we’re looking at and I guess grief loss does fall under Employees Assistance Program, but at the same time I myself I think well you’re coming into an organization that deals with grief would it not make sense to have some workshops or some seminars dealing with anticipatory grief. Cause you’re gonna run into it and it’s far better to deal with it beforehand than afterwards. Something that we should be looking into. Dennis

However, despite the concerns regarding the financial costs of tackling this issue there is evidence of considerable unidentified costs on individual mental health and organizational functioning. Participants articulate this considerable impact and the lack of grief knowledge among staff within the ASO.

Sometimes we acted out our feelings or our frustrations or anger in a variety of ways that weren’t easily recognizable and maybe that people were psychologically or emotionally affected even for myself in terms of not recognizing when I was shutting down emotionally enough that it was affecting me in terms of my whole mental health ... or people feel they’re losing interest or they don’t feel good about coming in ... because they haven’t been able to deal with some of the loss and anger. Barry

Tension around that place you could cut it with a knife. First couple (of deaths) it wasn’t bad. Then it started to get familiar ones. Ones that we all worked with or talked to and people were getting edgy for no reason. ... people are sneaking off and talking in corners and then all of a
sudden they do a big group thing because everyone’s doing these corner things and nothings getting done anymore cause of these corner visits. **Perry**

I think there’s people there that deal very good with it. I think there’s a lot of people there who are terrified of it yet, that’s not a bad thing, it’s just different staff and new people, when it changes you can see someone else having to kind of learn all over again, like the rest of us do. **Bonnie**

I think some of the support staff don’t deal very well with the death issue. ... I think some deny it. ... There’s always a solemnness when somebody passes away. The closer they are the people get very somber looking. ... I think with so many deaths there becomes a shell developed. **Dennis**

This impact of grief on individual and organizational functioning also effects the perception of support available to those HIV positive.

And I notice around a lot of deaths I start to see a lot less of the people that access it (the agency) all the time. Certain volunteers or clients that will always come down (to the office), won’t come down all of a sudden – they start staying away. I think that relieves the stress off the staff ... I have a problem going to talk to a counselor that’s lost five clients in a week and is trying to tell you to keep that chin up and keep going. **Perry**

The energy is really down when somebody passes away or wouldn’t say negative energy, but like this nothingness at times. It’s difficult to find support in atmospheres like that. **Dennis**

Diverse resources have also been created to respond to the unique challenges of grief within this organization and community. David described these organizational supports as serving as a “kind of ethic of taking care of ourselves and providing and acting as a vehicle for others in the broader community to come together”. These rituals of grief support served as a way to achieve healing where disenfranchised and unacknowledged grief were the norm. They have also acted as a claim to not forget that a person had died of AIDS. These grief supports provided a way to create space to grieve and both honor and remember those who have died from AIDS. These include the development of individual memorial quilts, and large memorial quilt panels where the name and the year of the death of the person are displayed. A Book of names also records the name of the person and the date of their death. Additionally, unique Christmas tree ornaments are displayed at the organization each season as another way individuals can be memorialized. The organization also sponsors agency memorial services. As well, immediate notification of a death is written on a notice board in the kitchen, a memorial candle,
and recently a memorial lamp are also displayed in the agency at the time of the death. Additionally, impromptu gatherings, candle light walks, prayer vigils, and bereavement workshops provide sources of support through opportunities to honor, remember, and grieve. These sources of organizational support are similar to what is noted by Garfield (1995), Schoen (1992), and Sherr (1995). However, what is surprising is the lack of awareness of what other organizations in Canada are doing for supports. As Barry notes, "I haven't seen that information gathered up and documented".

Though diverse resources have been present to assist these individuals and the organization participants also describe that these resources of support are not used. Consequently, a strategic response to grief appears needed within this organization. This strategic response to grief support is necessary because as Allison describes it was not built into the organization, but was more reflective of efforts by individuals.

I haven't a sense that someone has picked up the torch (of doing bereavement support) ... the bereavement support ... wasn't built into the (ASO), it was built into two individuals, and what (they) did with the organization ... I don't get a sense of that being there ... now ... when the two left that left with (them). Allison

The eight participants recommended a variety of responses to assist with grief and loss including a need for ongoing education about grief and loss, quiet space within the organization, workshops and group supports, mental health counseling, and debriefing. Barry describes that it "needs to be build into the planning of the agency, ... part of how agencies do business". This multidimensional organizational response is needed due to the diversity of responsibilities, skills and coping styles of individuals, as David describes below.

I think the difficulty at least from an organizational level I think there definitely is a range of job responsibilities, range of motivation, a range of what people expect, a range of skills in dealing with personal issues and personal emotions. David

Support and access to resources are necessary because, as Allison says, there is denial of the impact of cumulative loss, and fatigue associated with grief and caring for others. These limit one's ability to seek out the supports necessary for healing and ongoing mental health.
I didn’t identify it as my own pain cause I was healthy and I was taking care of these people so their pain was important ... I didn’t go actively seek it (bereavement workshops), but it is sort of complacency sit back and bring it to me cause I’m too tired to go out and find it ... I have been reading now about disenfranchised grief. Intellectually it makes a lot of sense and I apply it to others. ... I don’t think I’ve every really sat down and said that’s what happened to me.  

Allison

A strategic organizational response should encompass a large spectrum of agency functioning as Barry describes below.

In the personnel policy ... a recognition that issues of grief and loss are going to affect all the staff and they’re going to effect the organization ... I think it’s part of people’s annual review and evaluations that needs to be talked about ... both informally and through a formal process that support is available and action is available to enable people to deal effectively with this ... like something like an employee assistance program ... or availability of outside intervention.  

Barry

David describes that a strategic response needs to include the communal system of support upon which the organization was founded and which provided considerable bereavement support. He recommends exploring ways to help rebuild this mechanism of support within the organizational structure.

What’s interesting though is that old office when we had to deal with concentrated stress or grief ... it didn’t seem to totally throw us totally out of whack ... the communal system of support was very apparent, it was accessible, and it was part of the survival ... we kind of almost naturally fell into the way of functioning as a group in our early years, although we put a lot of effort, I mean everybody had to go through training and it was a targeted process ... really develop this sense of communal effort and that we all bring varying degrees of expertise and experience and that we’re there to help each other through the process, that’s where I would start, build that strong base.  

David

Perreault (1995), Schoen (1992), and Santek (1992) have similarly noted the need for a strategic organizational response to grief and multiple loss.

Barry suggests that information and research is further needed about the impact of grief and multiple loss on ASOs. He also states there has been considerable discussion and awareness within organizations and between ASOs. He further believes that the unique dynamics of ASOs and impact of the experience of grief and multiple loss may be a means of advocating for further funding.
We recognized and talked about that (grief and loss) at our Alberta Community Council meetings that we need to do some work . . . . organizations need to get information and research around how that affects the agency, . . . maybe we didn’t know ten or five years ago but I think there’s enough body of information now, . . . I think we can even get acknowledgment from our funders that that’s a piece of the action. **Barry**

However, this ASO is at risk, as it did in its beginning, of being too busy in responding to the needs of the organization to address needs of grief support. This organization and others like it, however, can no longer claim the original naiveté. Barry notes that organizations now have information about the impact of grief and multiple loss on individuals and organizations. This research and these participants have further outlined the significant consequences on individual and organizational functioning where grief and multiple loss remain unaddressed strategically throughout the organization.

These participants also suggest strategic organizational solutions, as Table 1 indicates.

<table>
<thead>
<tr>
<th>Table 1 – Strategic Organizational Solutions for AIDS Grief and Multiple Loss</th>
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<tbody>
<tr>
<td>An understanding of grief would be incorporated in all organization policies, hiring practices &amp; performance evaluations</td>
</tr>
<tr>
<td>Informal and formal organization supports (supervision, counseling (EAP program), bereavement workshops and group supports, individual and community rituals)</td>
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<tr>
<td>Ongoing grief education and training</td>
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<tr>
<td>Create communal support within the organization (shared mission &amp; community of caring)</td>
</tr>
<tr>
<td>Office design would incorporate - (connection with and between those HIV + and a supportive environment for the bereaved, those HIV+, staff and volunteers)</td>
</tr>
<tr>
<td>Use research &amp; documentation about the unique climate of multiple loss in ASOs to advocate for additional funds to address these challenges</td>
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A strategic response to grief and multiple loss would involve all aspects of the organization including policies, hiring practices, performance evaluations, grief education and training, and informal and formal supports. It would also include building a sense of communal support, or a shared mission and community of caring within the organization. This communal support would also incorporate how an office space is designed to create two things: a connection with and between those HIV positive, and a supportive environment for the bereaved, those HIV positive, staff, and volunteers. Finally, as Barry has suggested, research and documentation of the uniqueness of ASOs and the multidimensional and considerable impact of grief and multiple loss may also be a means of advocating for additional funds to assist ASOs. With this larger social and organizational context in mind I will now discuss the personal challenges facing participants in coping with multiple losses.

**Climate of Intense Emotions**

The second layer as depicted in Figure 5 describes the Climate of Intense Emotions, and the Grief and Coping Processes in response to multiple loss. Participants articulate that the intensity of experience of supporting those HIV positive and exposure to death and dying, grief and multiple losses add to the level of stress experienced. Bennett (1991, 1995), Cushman et al. (1995), Horstman and McKusick (1986) and Visintini et al. (1996) have noted that this nature of HIV and AIDS work can lead to emotional exhaustion and stress. Participant narratives describe the intensity of this experience.

I can't answer succinctly in a little conversation about why it's different when I have three AIDS deaths in a week versus three cancer deaths in a week. ... I guess because of the intensity and the multiple loss and the anticipatory grief and the real pain that goes with this whole thing. ... the only people who can work in this for an extended length of time, the ones who really see value in it somehow, who really truly care about the communities it's impacting and the individuals. AIDS work isn't something that people who don't give a shit can do. Allison

Being at the (ASO) is constantly a challenge, a constant reminder of who you are as, number one as a human being and number two as a social worker. ... So it's just an opportunity to be reminded all the time, almost every day be reminded of what suffering is really all about, what loss is really about, what marginalization is really all about, and what laughter is all about, there's just so many very basic levels of human interaction that we see on a daily basis almost, and it really I think challenges me to think who I am as a human being and what kind of opportunities I have and what I need to be thankful for, and all the way down the line. David
FIGURE 5 – Climate of Intense Emotions & Grief and Coping Processes

ETHNOGRAPHIC ANALYSIS OF AIDS GRIEF AND MULTIPLE LOSS FROM INDIVIDUALS WITHIN AN ALBERTA AIDS SERVICE ORGANIZATION

Alberta & Cycles

Context

Emotions & Coping

Challenge

Fight

Time

Grief & Coping

Numbness

Heightened Anxiety & Catastrophic Thinking

Distance Oneself - Integrate/Reflect/Replenish

Memorialize & Share

Expeditious Investment of Feelings into a Recommitment

Complex & Blurred

Roles & Relationships

Layers & Cycles

Context

Anger
Sadness
Depression
Helplessness
Guilt

Tension builds
Episodic expressions of grief
Black humor

Challenge for community to cope with
Unacknowledged Disaster & Trauma

Creative Org & Community Grief Rituals
Vicarious Traumatization
Compassion
Fatigue

Burnout - organizational frustrations
Barry and David note how the experience of coping with repeated cycles of loss can create exhaustion.

It's the wear and tear over time ... it's year in and year out cycle that after a while I've allowed myself to be worn down. **Barry**

The difficulty for me, the difficulty is if I look at eight years, if I look in the context of eight years, it's really tiring. I feel very weary. I guess if I'm gonna survive, if I'm gonna stay sane. I just have to think, like the here and now and it's not that I forget all those names, all those stars on those memorial panels. I'll never forget them. **David**

**Emotions – Anger, Sadness and Depression, Helplessness and Guilt**

A variety of emotions are present in response to multiple loss. Participants particularly express anger, sadness and depression, helplessness, and guilt. Anger and sadness are the most frequently expressed response to multiple loss. Anger appearing to be the most strongly expressed emotion because of the stigmatization, marginalization and discrimination associated with disenfranchised grief, as Dennis and Allison describe below.

Sadness, there's some bitterness that comes through. The unfairness of it all. I think part of it is the way the system treats the whole affair of AIDS. I've heard many times, "Well, they're faggots they deserve to die. This is God's retribution." I get angry over the insensitivity and the disregard for human beings basically. **Dennis**

And yet I've cried about this and raged at times. With (these two fellas) when (one of their) parents parachuted in and took him away and said, you can't take care of him anymore, and literally, physically took him from (his partner). I just raged. I was at work and my desk was beside the wall of windows and I was pounding my fist and crying in the middle of the afternoon. **Allison**

Allison and Barry also describe their experience with anger and sadness.

I'd sit downstairs in the living room, in the dark with the fire place on and the stereo. And a scotch or two and sit there and that's when I would allow myself to cry, but it was always anger. I never hardly ever, I just didn't associate it with pain in me, it was really I was angry at the virus, I was angry at what had happened, I was pissed off that there were some people who were really special to me that were gone and I didn't identify it as my own pain cause I was healthy and I was taking care of these people so their pain was important but it came through as anger. **Allison**

Today I would probably be angrier about that another round of losses and I might be angrier but I think I would feel I probably would feel the pain of loss more and it's not the personal but just the overall loss I guess maybe feeling the wounds are being re-opened as opposed to wounds that aren't healed just get re-opened again. **Barry**
Other participants also express their experience with anger.

A lot of anger. Not as much. ... I don’t know whether it’s changed much as I’m getting used to it. ... A lot of the anger is around that I’m always the one left behind. Bonnie

Oh just loss and anger, more angry than anything, mad at him for dying, mad at my friends for dying. Perry

David describes sadness as a significant emotion associated with multiple loss. He seems to struggle with the extent of sadness by using the words sad or sadness repeatedly in the same sentence as a way to describe the amount of emotion he experiences. The word loss is also used to express the extent of his sadness.

And I remember feeling really, I felt really, I felt a loss, I felt a loss when John or Dana or Guy died … just sadness, just a real sadness, but a sadness. David

Participants also express that multiple loss can lead to depression.

A lot of depression, … well since Mark died and then everybody else and I probably spent more time on anti-depressants than I have in years. Bonnie

I think it’s caused some depression, definitely that has happened and I didn’t recognize that I was in a depression three years ago until I actually started coming out of it. I think it’s made me aware somehow that I could slip back into that. Barry

Feelings of guilt, particularly survivor guilt, and helplessness are also associated with the experience of multiple loss. Bonnie describes her feelings of survivor guilt.

It’s like they’re kinda going in groups and it’s like too many all at once. You don’t even have time to think about the one, it’s just like everybody else is dying and here you still are. Bonnie

Feelings of helplessness are repeatedly referenced and appear to trigger anger, sadness, and guilt.

David describes anger and sadness as feelings associated with helplessness. Perry associates helplessness with guilt and anger.

I felt totally incapable of really doing anything with, and really felt the weight of the impact of what was coming for him, the anger and just the realization of what the cumulative total of loss is really all about. David

I get really mad and really angry at the fact that I don’t know when to be of a help and I feel if I coulda been there. Perry
In summary these emotions and feelings are noted in relation to the various research and literature on multiple loss, disenfranchised grief, and social and political repression. In relation specifically to the experience of other ASOs, Plotnick and Gibson (1997) document in their study of Ontario ASOs similar emotions including: anger, despair and helplessness.

**Grief and Coping Processes**

The participants identify in their narratives a process of change in coping with multiple losses over time and awareness that multiple losses particularly challenge their coping. Greg and Allison articulate this experience.

In the first year, I don’t know if it really affected me and I sort of thought that maybe this isn’t going to be all that bad... but I mean right now there’s or since the end of last year, ... there’s been a lot of people that I’ve worked with for over a more extended time that has passed away and I don’t know, I mean there’s grieving and I mean it’s really hard to describe. ... I don’t know how it’s affected me yet ... the first while I saw it in other people but I wasn’t as affected as it by other people, but I’m starting to see it now. **Greg**

I know that my coping skills really sucked for the first little while when I was working with people, well not initially, but when I was sort of in the middle of it. When I was first seeing those multiple deaths. ... My colleagues have seen changes in me. I’ve gone through the sort of uncertain, I don’t really know what this is all about, but I think it fits and works with me through the evangelist stage and through the screaming at the window and crying and having to leave work and being really sad and ripped apart. **Allison**

Some participants appear to have found ways to negotiate wellness into their regime yet continue to give. Others, as evident from the reading of the narratives, are experiencing considerable consequences from their caring and coping with multiple losses within this ASO and community. However, as I have read and analyzed the narratives I see both coping patterns between narratives, and changing patterns within individual narratives over time. This would suggest the value of ongoing monitoring, education, and supports within an organization and community, particularly given the unrelenting demands of coping with ongoing intense emotions. Participants have shared retrospectively how they have coped with multiple losses within this environment. It would be extremely helpful to complete a longitudinal study of an ASO to more clearly understand the process of change experienced
by individuals and the organization. However, I have been able to glean some insight into the grief and coping processes present within these narratives as Figure 5 and Figure 6 illustrate.

**Grief and Coping Process Associated with Multiple Loss**

**Tension and Emotions Build**

Associated with multiple loss is **tension and emotional build up** or increased edginess and build up of emotions. This occurs until a break is needed because the bereaved become overwhelmed, as Perry describes below.

> People were getting edgy for no reason. Just trying to deal with it on their own. ... Yes, we’re all snappy, we’re all irritated. And it just kept building up and building up. ... to a point where it snowballed. **Perry**

**Episodic Expressions of Grief**

Associated with this build up of multiple losses within the organization are **episodic expressions of grief**. These expressions of grief are not unusual for the bereaved. However what is unique, according to David and Barry, are these expressions are an **over reaction** and are **out of proportion**.

> They in a sense over react, there is an over reaction to a crisis or a major loss or a death. It so upsets a sense of stability and a sense of groundedness, but what that says to me is that these are folks who don’t know how to, in the context of the ASO, deal with their emotions and so everything is fairly exaggerated ... at critical times there’s an exaggerated response. It doesn’t deny their emotions, but their emotion comes out in an exaggerated way, and so I don’t think there’s an effective healing there. It’s just like a volcano that blows and then it simmers. ... very episodic. **David**

I think typically people may get angry about other issues. ... Something will trigger, something that’s very minor or something that’s not terribly important people will use that to express their anger or fight about something when ... it seems to be all out of proportion to what appears to be the issue that people are mad about. **Barry**
Figure 6 – Grief and Coping Processes Associated with Multiple Loss

- Expeditious Reinvestment of Feelings into a Recommitment
  (This helps to honor those who have died and contribute to those who now need your support within the shortened period of time available to grieve before the next loss occurs.)

- Memorialize & Share
  (with those who understand)

- Tension and Emotions Build

- Episodic Expressions of Grief
  (Over reactions/Out of proportion expressions
  Black humor)

- Numbness
  (In response to being overwhelmed)

- Distance Oneself
  Temporary to Permanent & Develop Protective Strategies
  (Provides opportunity to Integrate, Reflect, and Replenish energy)

- Heightened Anxiety
  (Especially for those HIV +)

- Catastrophic Thinking
  (Associated with anticipation of greater loss)

- Anger
- Sadness & Depression
- Guilt
- Helplessness
These over reactions or out of proportion expressions may be the case in a context of chronic grief from multiple losses where there is insufficient time to grieve, and inadequate resources to cope. Consequently, as David states, there is not an effective healing. Associated with these periods is a shift from everyday humor to black humor, as Annette and Greg attempt to articulate.

I guess there are times when you feel why are we laughing, but it does help to get through that particular day even or moment whatever it is. Annette

Well it takes its toll very definitely. The atmosphere changes. The people, personalities change, people get on edge a little bit more. I mean it’s they’re not as happy and normal humor gets thrown out the window and either people are just not very happy or real sick humor comes out, which is a form of coping you have to have it sometimes. Greg

Numbness

As individuals become overwhelmed with multiple losses they experience numbness, as Bonnie and David describe below. At times individuals have also sought to numb out through use of alcohol or drugs as Allison and Perry have particularly described in their narratives.

It seems to be when they all, when three or four that you were close to go all at once, that it’s harder than if they kind of go staggered. They seem to go in groups or bunches. ... I think part of the three of a time, it’s like they’re kinda going in groups and it’s like too many all at once. ... it was like stop already. Bonnie

I do recall that there were a number of times when I would feel really bummed. ... I’m not sure if it is a numbness that I felt at different times. I’ve never been able to identify it. ... I hate to say it but I guess there’s a certain detachment that I felt, particularly in those periods when there’s been multiple deaths or deaths and other losses. David

Heightened Anxiety and Catastrophic Thinking

There is heightened anxiety and catastrophic thinking associated with anticipation of greater loss in a climate where multiple losses are normative. This heightened anxiety was particularly present for those HIV positive, because it created fear and anxiety associated with their own possible future. Perry and Bonnie highlight this experience below.

I sit in the smoke room and anticipate so and so to be there and all of a sudden they’re not there and ... I’m phoning their home and going, Where are you today? Why didn’t you come in? I thought maybe you died too? Are you gonna do this too? Are you gonna leave the rest of us here? You started something here. You can’t die, you’ve got to stick around and finish it. Perry
And I couldn’t go to the people that I was even close to ... and I just couldn’t do the funerals. It’s too many. And it makes it too close even the memorial services do (to) my reality. **Bonnie**

Participants further describe a **struggle back to some type of normality**.

I mean it’s that another person has died. It’s gotten another one of us, and it’s not like you didn’t know that was going to happen but it did and you have to acknowledge it and you know things aren’t as happy anymore for a while, but you struggle for the norm, you just keep on going and keep on fighting. **Greg**

**Distance Oneself**

This effort to find some normalness in an abnormal situation happens through a need to **distance oneself from or a need to get away or reduce the impact of multiple loss**. **David** describes this need to get away.

There’s been times when riding on a bus is a good opportunity to unwind, a good opportunity to really reflect and do a lot of thinking about people and experiences. There are lots of times when I’m bummed out when I’m feeling kinda overloaded I just do a lot of thinking on the bus. There’s been a lot of times when it has felt fairly overwhelming with all this stuff going on, particularly people who are entering tough stages of their illness or people who are terminal stage or people who have died. **David**

This time away or need to distance allows participants an opportunity to reflect, integrate what has happened, and replenish their energy.

**Protective Strategies to Reduce the Impact of Multiple Loss and Allow Time for Healing**

This distancing can take on various forms but they uniformly attempt to **reduce the impact of multiple loss and allow time for healing**. Participants describe a range of ways they attempt to achieve this. **Greg**’s awareness of the impact of multiple loss on others resulted in the development of significant **protective strategies** to limit the impact of multiple loss on himself.

I don’t want to have to pull in that amount of avoidance to deal with the issues and you can totally understand and empathize with what she’s doing. ... she has come to a point where she had to. So you do things to prevent that and whether that’s not becoming as attached. So you do things to make sure that doesn’t happen, and again you may just be kidding yourself and that four years down the road of doing, trying not to become so attached you realize you have been a nervous mess. **Greg**
This distancing involves a range of protective strategies to reduce or minimize the impact of multiple loss. These protective strategies include: forms of self care; boundary setting which limits activities and roles which provide exposure to multiple loss; limiting participation in grief rituals; and temporary to permanent forms of emotional and physical distancing, as Table 2 illustrates. The range of strategies identified here appear similar to what is noted by Carmack (1992), where her gay and lesbian participants described coping with multiple loss on a continuum of functional to dysfunctional engaging and detaching.

<table>
<thead>
<tr>
<th>Table 2 – Protective Strategies to Reduce Impact of Multiple Loss and Allow Time for Healing</th>
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<tbody>
<tr>
<td><strong>Self care</strong></td>
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<tr>
<td>Boundary setting – limit activities and roles that provide exposure to multiple loss</td>
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<tr>
<td>Limiting or being selective in one’s participation in grief rituals</td>
</tr>
<tr>
<td>Temporary to permanent forms of emotional and physical distancing</td>
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The protective strategies noted by these eight participants include: taking a day off, better self care, or to do other things to balance out the pain of loss and grief, as Greg describes below.

> When I’m frustrated and when I feel stress, I just wanna get out for a while and take a break. Whether that’s a day off or it really forces me to go to the gym and work out to make sure that other things are more balanced to be able to better deal with and cope with it. Greg

As the years and amount of loss increase, participants recognize the need to limit activities and roles that provide exposure to multiple loss.

> I was able for some of them ... to not be the caregiver, but try and still be the friend and allow other people to take on maybe bigger roles of caregiving ...but I probably withdrew to some degree around people’s final period of illness, and so in terms of saying goodbye to people, I probably said goodbye to people earlier rather than later. Barry

> I know that they’re going to die. I try to get there. I talk to them prior, before they even get that sick that I can’t that I have to worry about them now. Perry
At times the reduction of impact of multiple loss includes limiting or being selective in one’s participation in grief rituals, as Perry, Dennis, and Bonnie describe.

After Peter, seeing him in the coffin, it’s sorta like, That’s it. No more. I’ve never crumbled at a funeral and I was just mush. Never have I been like that, And I just won’t allow it again. Well I will not allow myself to lose that composure. So by using those (rituals) at the (ASO), the candle. ... I don’t mind seeing people after it’s over. They wanna come and talk that’s great. Come and tell me about it. I’d like to hear about it. But I just don’t want to be part of it (memorial service) and being vulnerable. Perry

I attended some services of individuals who I had a more of a kinmenship with. At the same time there were some that were too close that I didn’t attend. ... I think some I haven’t gone to was because I didn’t have the energy at the time. Dennis

(ASO) Memorial services. I sit there and blubber at every one of them because even going to them, it still Mark’s or Tyler’s or Dana’s or you know, it’s still all those people every time. But I need to go to those, cause I can’t go to the funerals, I need to go to something and that’s the thing that I can do. Bonnie

At times the effort to distance oneself from multiple loss results in a shift from a temporary to permanent form of distancing in one’s relationship to self, others, and AIDS work. Barry and Bonnie describe this distancing in relation to themselves and others.

I think that I get to the point sooner than I used to saying this is a person that you’re gonna lose. ... I find that it’s harder with each cycle to get as close to them as I did one time. ... I can understand when people get older that you don’t make the same kind of friends. ... because you’ve lost these friends, you’re a little more cautious in some ways in terms of investing emotionally in some friendships because ... you know what it feels like to lose them. Barry

I mean there’s a part of me that’s gotta wall, and not a big wall, but there’s a part of me that won’t let anybody get past a certain point. Like no one will get as close to me as Mark did. And it doesn’t mean I won’t spend time with people, it’s just I don’t like to let anyone in like that, and part of that’s self protection. Just because I’m not gonna be left again. Bonnie

This reduction of impact may also extend to include: involvement in other types of activities or volunteer work, or a need to limit or stop involvement with ASOs and related work as a way to escape and balance out the pain of loss and grief. Bonnie describes this shift and distancing from AIDS work.
That's when I have to stay away from anything that's involved with AIDS. I have to go somewhere else or do something else ... it's why I've got off a lot of the committee work at the ASO, and why I put more into the co-op ... it's getting that balance ... I get moments where I just have to get away from all of it, because it's too much. Too much loss, too many people, I'll be in there (the ASO) a lot and then all of a sudden I need to get away from it for a while. Or get involved in all these things that are all AIDS oriented and then I've gotta just take a few months and get involved in things that are totally not involved with that cause it's too much. I can't seem to hit a happy medium. It's with all or nothing ... it was kind of at a point where that was the only thing I had and without that, I had no life at all ... (I) had to try and find some other corners. **Bonnie**

**Memorialize and Share**

Connected with this distancing oneself is the need to memorialize and share the individual and collective loss. Bonnie had described earlier that in the context of multiple losses, she grieves not only the recent losses but the many cumulative losses. Also associated with grieving is establishing a connection with those who share the grief and share the experience of AIDS grief and multiple loss. Allison and Greg identify how important this shared connection and understanding is to their own healing.

I was going to the (memorial services) ... to get the hugs and to share. To share the discussion, to talk about who was gone, but also to share the hugs, to share the tears, to share the indignity, to share the anger. ... A lot of times (she went) cause I knew that other people who were sick were gonna be there and they knew what we'd all gone through. I knew you were gonna be there and that there was more (than) one of these people that you and I had sort of really been there together for. **Allison**

I think there's only a handful of people that once we've gotten to this point, you can even talk about it. I've talked to other people about it and it's amazing, it's a level of understanding that people who are in our positions across the country. I mean you can say two words and it's an understanding, ... but it's that level of empathy that you can find. **Greg**

**Expeditious Reinvestment of Feelings into a Recommitment**

Associated with the healing is a creative process of expeditious reflection, integrating, remembering, and finding a way to reinvest because of insufficient time to grieve. David and Dennis describe this below.
I don’t want to walk in the door kind of unloading on my family. So I try to clear my head, but in the process of clearing my head ... I’ll just do a lot of reminiscing, a lot of thinking ... I walk a lot partly to get some fresh air and partly just to have some quiet time, just reflect and just you know remember. I know that for some folks the struggles gonna be over and I know my energy is going to be needed for, you know, the next person coming through the door. David

When I heard the news of each one, I would just go through a recollection of them. ... I go into a, I think a sort of introspection of looking at why I feel this way and acknowledging that yes I do feel this way. Not that it’s not good, but there are ways to get out of it, you know, acknowledging loss, I think is important and that’s probably why this numbness is there a little bit because it’s hard to take. And but again, I look into myself and think well, you know, it’s time to do this, time to move on. Dennis

This creative process of coping includes an attempt to achieve some balance or resolution in their grief process by investing the emotions, particularly anger, connected with the pain of loss into a recommitment to the cause, or a sense of urgency to fight.

When there is a number of losses that have taken place or when things are really tough with people’s health or when there’s a number of deaths that occur ... I notice that in myself I become more aggressive about HIV and AIDS. I get a feeling of anger and I translate that into a feeling like we need to be more radical or socially aggressive about the issue. David

The more loss you see, the more you wanna do something, and sometimes our frustration will focus energies in hopefully a good way. Greg

Additionally, where there is insufficient time to grieve participants invest their feelings associated with grief also as a means to honor individuals who have been lost. This assists participants in coping with the multiple losses by feeling they are both honoring others who have died and helping those they now support.

I made a difference ... because of the accumulative experience of other people that’s helped me to be able to put it all together and make a difference to somebody else ... the concrete ways in which we remember individuals ... represent the memory of the person as well as somehow are an aid to other people to help them through their struggle and their journey, it’s that way of continual giving as opposed to just losing, ... but losing with at least a purpose. David

Consequently, given the repetitious cycles of grief and loss experienced by participants, it repeatedly leaves these participants without adequate time to complete their grief process. This has been noted in relation to AIDS multiple loss by Lennon et al. (1990) and Carmack (1992). This would further explain from my clinical and community experience why those who leave HIV work have a considerable period.
of recovery following the daily exposure to multiple losses. Participants provide us evidence that these repetitious cycles of loss and grief create a form of chronic trauma, vicarious traumatization, compassion fatigue, and burnout due to organizational frustrations as is noted in Figure 5 or Figure 7 and discussed below.

**Trauma**

Evidence of chronic trauma is noted in these participants by their efforts to quantify the amount of AIDS-related loss they have experienced. Participants identify a magnitude of loss that appears similar to what is known in a significant disaster.

Participants had extensive exposure to multiple loss and deaths from AIDS, as Table 3 summarizes. Four participants divided these experiences into two categories: personal deaths, and the cumulative total. Two participants referred to the total number of deaths without separating the deaths into categories. One participant did not put a number to the deaths, but referred to it as more than what one would experience in a lifetime, but less than others who have worked in the field a lot longer. Additionally, one participant said the total number of deaths were too overwhelming to count them all, but was able to estimate the personal losses. Given the above information, the total number of deaths expressed by six of the eight participants were five hundred and three deaths from AIDS. Additionally, the seven participants who referred to personal losses included a total of three hundred and fifteen deaths. Participants incurred these cumulative losses over a range of one and a half to eleven years with the average length of involvement being six years. Indeed the estimates by these participants represent a considerable number of deaths and losses from AIDS over a rather condensed period of their lives. Collectively these participants represented nearly seventy years of experience with HIV and AIDS both within and outside the ASO.
Table 3 - Summary of Participant Exposure to AIDS Multiple Loss

<table>
<thead>
<tr>
<th>Age and Background of Participants</th>
<th>Number of AIDS Deaths Experienced by Participants</th>
<th>Years of Involvement with ASO</th>
<th>Total Years of Experience with HIV within and outside ASO</th>
</tr>
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<tbody>
<tr>
<td>30-57 years of age</td>
<td></td>
<td>1½ -11 years</td>
<td></td>
</tr>
<tr>
<td>Anglo-Saxon/ European Canadian descent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 HIV+/4 HIV-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 ♂ / 3 ♀</td>
<td></td>
<td>(With average involvement being 6 years.)</td>
<td>70 years of experience for these 8 participants</td>
</tr>
<tr>
<td>5 gay/lesbian</td>
<td>(*Note approximately 6 of the 8 participants were able to quantify these numbers.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 heterosexual</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

These extensive losses are occurring while those within and outside the organization seem to struggle with or be unaware of the magnitude of impact, or disaster in their midst. Considerable disenfranchised grief is evident within this organization. Throughout my analysis the tremendous sense of loneliness and isolation of participants struck me. This loneliness and isolation was expressed in relation to multiple losses despite these participants being well connected to informal and formal support communities. In retrospect, it is not surprising that participants noted considerable therapeutic value from the research interview process given the extent of disenfranchised grief and loneliness noted. Participant narratives identify that their grief experience remains a private affair whereby individuals grieve in isolation except at events like memorial services, memorial quilt displays, or annual events like the yearly candlelight vigil or AIDS Walk for Life. I would further suggest that participant reports of isolation and “others not understanding”, except those who are familiar with the experience of
multiple loss to AIDS, add credence to the idea that these individuals and organization are coping with unacknowledged disaster. Participants in Hooley’s (1993) study also reported that “persons who were not AIDS care providers did not understand” (p. 763).

Trauma was also evident in participant attempts to articulate the amount of cumulative loss. As they attempted to do so they expressed a sense of this being overwhelming. At times, the effort to describe this triggered a flooding of emotions that required the interview to be stopped.

Participants also attempt to describe the cycles of impact of trauma related to multiple loss, as Allison notes below.

And it’s raw and it’s ugly and it’s totally unjust and then it happens again. It’s sort of, I don’t know it there’s an analogy. Carrying a child for nine months and giving it up and then getting pregnant and carrying another one for nine months and giving that one up and then all of a sudden you’re pregnant again and you carry that for nine months and lose it again. ... I can’t parallel how gut wrenching it is? It’s not something I can sit down and describe to anyone else who hasn’t been there. Allison

Bonnie also describes how these multiple losses layer upon each other complicating one’s grieving.

The enormity of the numbers all at once it’s you can’t, it kind of overwheels, you can’t separate them individually at that point. It’s just all these people and you know when there’s a bunch like that, it’s not even just about the ones you knew, it’s about all of them. You know, it’s like there’s ten people and even if you only knew four of them, you grieve for all ten of them. Because it was all at the same time. Bonnie

Barry and Bonnie add to this thought by referencing how the deaths become experienced as a global rather than a personal loss.

I probably would feel the pain of loss more and it’s not the personal loss but just the overall loss, I guess maybe feeling the wounds are being reopened ... wounds that aren’t healed just get reopened. Barry

A lot of loss, but I don’t know if it’s that’s there’s ... in one way you notice the loss more. Like every little thing, whether it’s ability to work, whether it’s friends, whether it’s, you know, just your body’s ability to do things. Everything seems to be lost for a while. Bonnie
Several participants also made reference to a particular time in organizational history where several key individuals were lost in the same period. Barry, Allison and David have also described these periods as generations or cycles of losses. Barry summarizes these thoughts and the impact on organizational functioning in the following narrative.

I mean the office sometimes can almost shut down during that period when there's two, three people who've been connected with us that died, within usually, within weeks or days. ... It's just more traumatic at times. Well certainly one of the time periods for me was when we lost about four or five people, who were involved, within a short period of time. **Barry**

**Vicarious Traumatization – Evident in response to multiple loss**

I also note evidence of *vicarious traumatization* in participant narratives. All these participants identify the impact from their peer and professional roles in supporting others. Participants experience trauma in coping with a context that creates immense challenges because of the confrontations and exposure to repeated trauma, human suffering, discrimination, marginalization, and stigmatization. These participants exhibit characteristics that are consistent with vicarious traumatization. These include “symptoms of secondary stress in the context of profound changes in sense of identity, meaning, world view, and beliefs about self and others” as Bettcher (1996) has noted, earlier (p. 23).

This research did not focus particularly on identification of vicarious traumatization, but I would like to offer beginning evidence of its presence until future research can be completed. I would like to suggest that the presence of ‘a need to fight and struggle for the cause of HIV’ may be a change in world view. This ‘need to fight’ occurs because of the repeated exposure to marginalization, discrimination, and disenfranchised grief and multiple loss from AIDS. Additionally, changes in world view and beliefs may be related to the real and perceived ‘urgency of time’. Barry had described earlier how this urgency of time had driven his response to HIV. However, it also resulted in a neglect of self and his own future planning that had significant consequences on his own wellness. Those HIV positive have also expressed their sense of pressure of time to accomplish something given the knowledge of
their potentially shortened life span. Barry and Bonnie also speak about chronic depression as a more permanent shift resulting from continued exposure to multiple loss. Dennis notes an increased focus on obituaries which may again reflect a world view change as a result of multiple loss and disenfranchised grief. The presence of a 'more permanent detachment as a protective coping strategy against multiple loss' may also be a potential belief and world view change in response to multiple loss. Finally, the increased presence of 'catastrophic thinking' may well be a shift in belief associated with multiple loss. These ideas are speculative but do suggest the need for future study in the area.

**Compassion Fatigue – Evident in response to multiple loss.**

We also see from these participant narratives that HIV work results in considerable personal sacrifice, exhaustion or energy drain. However, there is no evidence of depersonalization or an unfeeling and impersonal response to those HIV positive. I see evidence more of compassion fatigue rather than burnout. Consequently, I do see some benefit of Figley's (1995) Compassion Fatigue Self Test, as a self evaluation coping tool, though it would need to be recognized that it fails to incorporate the unavoidable and normative blurred roles and relationships within an ASO. The presence of compassion fatigue versus burnout, may be the case particularly given the personal motivation to assist those in their community. The sense of personal accomplishment, helping others, and honoring those who have died by carrying forward embodied knowledge to assist another person appears to help motivate people to maintain their commitment. The lack of evidence of depersonalization and the sense of personal accomplishment that motivates one’s commitment with HIV work appears similar to what is noted by Haviland et al. (1997) and Oktay (1992). However, I do suspect that the personal familiarity of participants with the journey of coping with HIV and AIDS grief may reduce the likelihood of depersonalization. Given the evolving nature of these concepts and their application to HIV, the particular definition and meaning assigned to the experience here remains speculative until further study is more conclusive.
Burnout – Evident in relation to organizational frustrations.

Uniformly participants articulate that their experience with organizational frustrations creates a questioning of one’s commitment to the role and work within the ASO. This has been further substantiated by follow-up observations that six of the eight participants have changed their role and involvement with the organization at a time when it is clearly undergoing uncertainty in its role and mission. Many participants have articulated their frustrations with organizational changes as a critical motivating factor in their decision to change their involvement with the ASO. This factor is seen as motivating changes far more than an overload of grief and multiple loss. This may be the case particularly if the sense of personal accomplishment, that motivates a commitment to the work, is thwarted by the organizational frustrations.

In summary, I have described the cyclical process of coping that participants refer to in their narratives. These cycles of death and loss layer upon each other over years of caring and support, creating a form of compounded and complicated grief. Biller and Rice (1990) noted similar findings in their qualitative study of gays and lesbians experiencing multiple loss from AIDS. These cycles and layers of multiple losses are further compounded by normative complex and blurred roles and relationships, and organizational and provincial contexts that create significant barriers for healthy functioning. Consequently, we can appreciate in our reading of these narratives, how unresolved grief and multiple losses can accumulate and impact individual and organizational functioning. This accumulation occurs despite participants’ best efforts to curtail the impact. Figure 7 summarizes the layers of this complex individual and organizational analysis.

Comparatively, I see minimal differences between those participants who are HIV positive and HIV negative, men and women, gay or heterosexual in this study. Disenfranchised grief and isolation were noted similarly in participants who were in paid and unpaid roles within the ASO, peer and professional, and those HIV+ and HIV-. This is understandable given the complex and normative blurred roles and relationships observed in this organizational community.
FIGURE 7

ETHNOGRAPHIC ANALYSIS OF AIDS GRIEF AND MULTIPLE LOSS FROM INDIVIDUALS WITHIN AN ALBERTA AIDS SERVICE ORGANIZATION
The helping professionals, despite reporting supportive individuals in their lives, appear to exhibit a need to protect their immediate significant other from the impact of their experience with AIDS grief and multiple loss. They prefer to seek support from their co-workers who understand the experience of AIDS grief. Clarke (1995) similarly noted this preference for collegial support in his research on social workers in the HIV/AIDS field. I wonder if there are beliefs present that limit these professionals from seeking and receiving support from those in their close personal circle? Allison noted in her narrative, a minimization of her own pain given that she was healthy and those she was working with were more needful. Possibly these professionals exhibit unacknowledged grief and survivor guilt that create discomfort and minimization of their needs for support from within their own personal circle. Possibly these professionals find it difficult and uncomfortable to articulate the impact their work has on them. In contrast, the majority of HIV positive participants exhibited greater heightened anxiety in relation to multiple loss, because of the association with fears of their own future.

All participants exhibited amazing resilience and varying degrees of impact to multiple losses overtime. Dennis describes that “the resilience of the positiveness of people’s energy” helps them survive “all the hard issues, hard times and the deaths”. Egan (1993), Fahrenbach (1992), and Gluhoski et al. (1997) noted similar resilience in professional caregivers, and in gay communities coping with multiple loss.

Participants uniformly describe four key individual coping strategies that assist them in their resilient survival, as Table 4 illustrates. The first strategy is ongoing and consistent self care. However, ongoing and consistent self care also requires incorporating the second strategy because the challenge of coping with multiple losses can be defeating.
Table 4 – Individual Coping Strategies of Resilient Survival

<table>
<thead>
<tr>
<th>Ongoing and consistent self care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connection with at least one other person who has the shared experience, shared grief and shared understanding</td>
</tr>
<tr>
<td>Memorialize the individual and collective loss through personal and community rituals</td>
</tr>
<tr>
<td>Experience personal growth and personal accomplishment from the journey with HIV and helping others – provides a sense of continual giving instead of just losing</td>
</tr>
</tbody>
</table>

The second strategy is a connection with at least one other person who has the shared experiences, the shared grief and the shared understanding. This need for social support is well documented in assisting the bereaved with multiple loss and complicated grief. This connection helps break the loneliness and isolation. It also helps to normalize one’s experience in an abnormal context, whereby at least one other person acknowledges the unacknowledged trauma and disaster.

The third strategy is the need to memorialize the individual and collective loss through personal and community rituals. The need for these activities have been well documented in AIDS grief literature.

Finally, the resilience comes from the sense of personal growth and personal accomplishment that occurs as result of their journey with HIV and AIDS. Participants describe experiencing personal growth in their understanding of themselves, of grief, of their spirituality, and of the full range of human emotions and experiences. The experience of personal growth in response to coping with AIDS was identified by staff in ASOs (Gibson & Plotnick, 1997), social workers (Clarke, 1995), psychotherapists (Cadwell, 1994), and in gay bereaved (Fahrenbach, 1992; Werner, 1992). These participants also describe a sense of honor and privilege as a result of their experiences. Participants uniformly describe that personal accomplishment comes from knowing that helping others provides them a sense of making a difference. The act of helping others honors the
individual(s) who have died by carrying forward their embodied knowledge to help someone else. In this way the participants feel they are making a continual contribution rather than just experiencing more losses. This sense of personal accomplishment provides participants a form of healing activity in a context where there is limited time to heal cumulative multiple losses. Personal accomplishment and satisfaction were noted to reduce emotional exhaustion and depersonalization in social workers (Oktay, 1992), and AIDS care providers (Haviland et al., 1997). These rewards and recognition in AIDS work act as buffers against burnout and assist with retention in the AIDS field (Bennett, Ross & Sunderland, 1996).

The participants in this study also provide potential ideas or signs of awareness when HIV work and multiple losses from AIDS, in particular, are getting to be too much and one needs to do things differently.

I’ve been in the business too long, where I don’t go to funerals anymore, where I don’t go see people in the hospital, I don’t want to have to pull in that amount of avoidance to deal with the issues ... I think we’re honored to be able to ensure that people aren’t numbers anymore. And I think once people become just a number to you then you know you need some time away. 
Greg

I think if I ever got to the point where I no longer accepted the deaths, then I would say I’d have to get out. David

I’ve seen people in the AIDS movement who have been there for a decade ... I mean, the energy doesn’t exist for them any more. I want to do things because I want to do them not because I have to do them. So, I guess it’s time to move towards more positive energy. ... Well I question my ability to deal with him losing things? This new fellow reminds me very much of (someone else I knew). ... I wouldn’t wanna see him go through what this other man went through, which was nothing but loss all the time. Dennis

I can remember being aware, intellectually of course at first, but then more sort of as a whole body awareness a real understanding that ... the chemically coping ... being aware that I couldn’t keep doing that ... I knew I had to do something differently ... but I had to take better care of me. Allison

I just have other things and maybe because I have a granddaughter now and I’m more focused on doing things with her or for her. ... I think I’ve chosen not to become as involved with the organization. ... I just feel I can only do so much and to make choices. Annette
I guess one of the things that needs to happen for me is to seek some time off to look at some of these issues. And I certainly recognize that if you don’t then you become useless to yourself and useless to the organization. ... I think people need to recognize also ... if the job is gotten to be too much. ... your ability to deal with this issue goes on long enough that in order to be healthy you need to in fact separate yourself from it. ... I think people should leave for healthy reasons as opposed to just collapsing, imploding. Barry

That’s when I have to stay away from anything that’s involved with AIDS. I have to go somewhere else or do something else ... it’s why I’ve got off a lot of the committee work at the ASO, and why I put more into the co-op ... it’s getting that balance ... I get moments where I just have to get away from all of it, because it’s too much. Too much loss, too many people, I’ll be in there (the ASO) a lot and then all of a sudden I need to get away from it for a while. Or get involved in all these things that are all AIDS oriented and then I’ve gotta just take a few months and get involved in things that are totally not involved with that cause it’s too much. I can’t seem to a hit a happy medium. It’s with all or nothing ... it was kind of at a point where that was the only thing I had and without that, I had no life at all ... (I) had to try and find some other corners. Bonnie

In summary, these eight participants have documented how the cycles of AIDS multiple losses and deaths layer upon each other over years of caring and support. These grief experiences occur in organizational and community contexts where insufficient resources and time are available to grieve. Therefore, we see an impact on individual and organizational functioning despite participants’ best efforts to reduce its impact.

Participants described the loneliness, isolation and disenfranchised grief. These participants articulated a ‘central challenge’ that was woven throughout the individual and organizational history. This central challenge was ‘balancing pain of loss with hope and commitment’. From this central challenge emerged four core themes or roots: layers and cycles; not enough or limited time; fight; and complex and blurred roles and relationships. Participants described the ‘layers and cycles’ of multiple losses they experienced, in a context where there is ‘not enough or limited time’ to grieve before the next loss occurs. This sense of time creates an urgency to ‘fight’ in a setting where there are normative ‘complex and blurred roles and relationships’ within this organization and community. A cyclical process of coping was identified in response to AIDS multiple loss in this organization and community.
This process includes: tension and emotions build; episodic expressions of grief occur (over reaction and out of proportion expressions, and black humor); numbness (due to being overwhelmed); heightened anxiety & catastrophic thinking (associated with anticipation of greater loss and especially noted in those HIV positive); efforts to distance oneself (temporary to permanent forms which provide opportunity to integrate, reflect and replenish energy) and protective strategies to reduce the impact of multiple loss; memorialize and share with the select few who understand; expeditious reinvestment of feelings into a recommitment (which helps to honor those who have died and contribute to those who now need your support).

This cyclical grief process occurs in an organizational context that has experienced a professionalization within its organization, loss of a communal system of support, and has had an ambivalent response to grief and loss. It is also experiencing an erosion of health and social services and organization funding, attempting to respond to emerging needs of diverse populations, and addressing a shift in mission and critique for being out of touch with the populations it is intended to serve. This is occurring while it attempts to address the ongoing challenges created by heterosexism, homophobia and AIDS phobia. Trauma, vicarious traumatization, compassion fatigue and burnout (in response to organizational frustrations) are also noted in these participants.

Participants recommend a strategic organizational response to grief that would encompass broad formal and informal practices within the ASO. These include: organizational hiring; performance evaluations and policies; sources of ongoing support and education; and a space (drop-in) within the ASO where connection with and between those HIV and a supportive environment for the bereaved, those HIV positive, staff, and volunteers occurs.

Participants define protective strategies they use to reduce the impact of multiple loss. These are self care; boundary setting (limit activities and roles which provide exposure to multiple loss); limiting or being selective in one’s participation in grief rituals; and temporary to permanent forms of emotional and physical distancing. Participants exhibit considerable resilience and identify four
strategies for their resilient survival. These strategies include ongoing and consistent self care; connection with at least one other person who has the shared experience, shared grief and shared understanding; memorializing the individual and collective loss through personal and community rituals; experiencing personal growth and personal accomplishment from the journey with HIV and helping others which provides a sense of continual giving instead of just losing.

The conclusion with implications for social work practice and recommendations for future research follows in Chapter 5.
CHAPTER 5

CONCLUSIONS:
IMPLICATIONS FOR SOCIAL WORK AND FUTURE CHALLENGES

This study has added to the beginning body of literature documenting the impact of AIDS grief and multiple loss on individual and organizational functioning. This research identifies the resilience of these participants within this organization and the creative attempts to manage, what has seemed like an unmanageable problem. This ASO and community, like many in the country, has a rich history of creative responses to grief and multiple loss. This research in fact documents these rich and creative traditions.

These participants and this ethnographic analysis have provided us a new and complex understanding of individuals, an organization, and community in grief. These participants have described unique grief and coping processes in response to multiple loss within this ASO. In many respects, it is not unlike other grief processes. However, the key differences are the layers and cycles of multiple losses, incomplete and complicated grieving as the norm, expeditious reinvestment, and the strong need to connect with specific people who really understand the experience of AIDS grief. I believe this research has given a language and form to what most of us have struggled to explain. Consequently, I believe it is important that ASOs and other organizations dealing with chronic grief and loss be informed about what is identified here. This knowledge can create understanding, acknowledgment of abilities, and an opportunity to identify individually and organizationally specific solutions and strategies of support and healing.

These grief processes have much to teach us about the creativity of the human spirit to find ways to survive and reinvest in a positive way in one's caring and commitment even under extreme conditions. We find in these participants creative channeling of painful emotions, and personal and
social actions that bring meaning, memorializing, and ongoing assistance for others. These individuals and organizations have been resilient. It would be useful to discover what assists individuals in sustaining resilience in this type of environment. In particular, I was surprised to discover that no research has gathered information on the rich and creative individual, organizational, and collective rituals within ASOs in Canada. How do these rich rituals help sustain individual, organizational and community resilience? In fact these participants had difficulty recalling when and how certain rituals began, yet they continued for many years following. Given the turnover in staff, this rich source of organizational history that could assist future members may become lost. The gathering of this information would no doubt be useful and meaningful to assist in future resilience.

I believe this form of ethnographic analysis may also be beneficial as an assessment and educational tool for other organizations, communities and individuals coping with sustained chronic grief. I see beneficial applications to the elderly, younger disabled, First Nations communities, and organizational programs involved in care provision. Figure 6 may provide an image to help others conceptualize the complex forces that impact an individual or organizational life.

The findings of this study also have broad implications for areas of Future Research, Social Work and Professional Education, and Social and Organizational Policy.

Future Research

Feminist, collaborative, ethnographic, and narrative approaches to research design and analysis were used to understand the layered and complex experience of AIDS grief and multiple loss within this organizational community. The intent of this study was to provide voice and empower a marginalized and disenfranchised group. It achieved this through my commitment to and belief in feminist and collaborative approaches to research and social work practise. These research approaches have been further able to capture the current and historic purpose and challenges of these individuals and ASO. This study reveals how powerful, complex and informative ethnographic and narrative approaches to research are in making the unknown of our daily life known. These particular approaches to research
design and practice are highly recommended for future qualitative research, and in particular with AIDS service organizations.

This research was designed with the community in mind. It was designed as a form of social action and a resource of knowledge for the communities most impacted by AIDS grief and multiple loss. I would recommend replication of this study to provide a comparison of this ethnographic analysis and the grief and coping processes described here. Replication of this collaborative method in other communities would also help to identify the specific barriers and resources present within a particular community. It would also assist in understanding the broader social, political and cultural forces that are impacting the individual and organizational experience with AIDS grief and multiple loss.

These participants represented Anglo-Saxon and European Canadian descent and it would be particularly useful to complete a similar study in a culturally more diverse community where racism, and economic disparities create further disfranchisement. I would recommend future participants include those who have left the ASO. This would help us understand both the reasons for this change and to identify the ongoing evidence of trauma from multiple loss. I would also recommend interviewing other participants within the ASO who are less familiar with AIDS grief and multiple loss. This may provide a comparison and further insight on the impact grief has on individual and organizational functioning.

Future research should include longitudinal and comparative studies of ASOs. This would assist us in understanding the process of change, and evolving coping strategies experienced by individuals and organizations over time in response to AIDS grief and multiple loss.

These participants have identified evidence of trauma, vicarious traumatization, and compassion fatigue in response to AIDS grief and multiple loss. I would recommend specific future studies focus on these areas in particular. Additionally, future burnout research may be beneficial in focusing on identifying organizational frustrations given participants voiced a questioning of their commitment due to these frustrations.
Participants expressed isolation with their grief even though they reported supportive personal relationships. They also reported that multiple loss impacted the nature of their relationships. I would recommend future research be completed on those within ASOs who experience multiple loss, and on their significant other. I suspect these individuals may have some insight on the impact of multiple loss on individual and relationship functioning.

Social Work and Professional Education

These participants report and a review of the literature substantiate that we still have considerable challenges in relation to 'judgmental attitudes of professionals'. This is rather discouraging considering the educational efforts made by CASW and other professional groups, ASOs, and those living with HIV and AIDS. However, as Eldridge and Lawrence (1996) noted, prejudicial attitudes by health care professionals towards stigmatized groups or persons with HIV disease remain and factual information alone is not sufficient to create behavior change. This suggests a significant role that professional bodies and educators need to play in screening attitudinal barriers of professionals and assisting with the development of non-judgmental attitudes. AIDS specific courses within curriculum provide many opportunities for learning about all aspects of the human condition as these narratives have described. They provide us opportunities to understand the interconnections of individual, familial, community, social, political and cultural forces within an individual’s daily lived experience. As professionals we could not ask for a more comprehensive challenge to our learning and ongoing professional development.

AIDS grief and multiple loss is also breaking new ground and pushing new boundaries in our individual, community, organizational, professional and theoretical understanding of grief. Peer and professional supports for those HIV positive need to maintain an evolving and open approach to alternative conceptualizations of grief that may better help us understand the AIDS multiple loss experience. This poses particular unsettling challenges, but also allows for creative new paradigms of understanding. Consequently, ongoing education and training is necessary personally, professionally,
and organizationally within ASOs and service agencies as part of one’s response to AIDS grief and multiple loss. Social Work and other professional educators also need to take up the challenge to provide ongoing and evolving education about grief and loss in their curriculum.

**Social and Organizational Policy**

The erosion of health and social services in this province, and ongoing battles with discrimination created by AIDS phobia, heterosexism and homophobia add to the experience of loss through the consequences on those HIV positive and this organization. Individual and organizational resources are redirected to survival rather than to cope with the ongoing losses and expanding challenges of HIV disease. However, while these are the current challenges for ASOs they also have a rich tradition of supporting and benefiting from the development of volunteer, group, and peer support and advocacy. These avenues provide the continued opportunity for connection to assist with the many losses created by HIV disease. They also provide for the creative solutions those HIV positive and ASOs have consistently been capable of, even under extreme situations. However, I am suggesting that ASOs take a leadership role in coordinating this effort and providing ongoing fervent political advocacy for social change and services for the many challenges facing those living with HIV disease.

These participants have also voiced the evolving attitude changes in response to HIV. Some progress has been made in changing community attitudes towards HIV. However, the marginalized groups – gay, aboriginal, street and prison involved, continue to be most impacted by the lack of attitude change, as these participants have noted. During this research process the Supreme Court has passed legislation securing human rights protection for gays and lesbians against discrimination. This occurred with considerable sacrifice and effort by Delwin Vriend and his supporters. This major human rights victory in this province, however, was responded to by considerable anti-gay backlash. The writer remains ambivalently hopeful that attitudes will change over time as gays, lesbians, bisexuals, and transgendered people live their lives with continued vibrant dignity and courage to achieve the freedoms they have now been legislatively afforded.
This research has also documented the evolving history and challenges that AIDS grief and multiple loss have on the organizational functioning and policies of AIDS service organizations. The stories of these participants validate the observations of Cain (1993, 1994, 1995, 1997) about the historic changes and current challenges in ASOs. ASOs must take up the challenge of addressing the evolving challenges of HIV disease, while clarifying the role and mission in service delivery, education, and advocacy. However, ASO policy and commitment must now extend to recognition of the significant and complex impact AIDS grief and multiple loss has on individual and organizational functioning.

This research also documents the creative resilience and response of ASOs to the challenge of coping with chronic trauma created by AIDS grief and multiple loss. ASOs must incorporate in their program planning, policies and practices how individual, organizational and community resilience can be sustained. Additionally, initiatives like the AIDS Bereavement Project of Ontario have attempted to provide resources of support to nurture the ongoing wellness and creative coping of ASOs. These participants also recommend several strategies for ASOs to consider as organizational initiatives to address grief and multiple loss.

The first recommendation is that a response to grief and multiple loss must be strategic throughout the organization including hiring and evaluation practices, policies, resources of support, education, individual, organizational and community rituals. Various attempts at these elements have been made in many ASOs. However, the leadership to implement these and make it a priority within all aspects of the organization is at times missing, and this appears to be one of the ideas strongly voiced as necessary by these participants. If ASOs continue to neglect the impact of multiple loss it will have dire unidentified consequences for individual and organizational functioning, as these participants have noted.

The second key strategy is creating a space that has two roles: it creates a connection with and between those HIV positive, and is a space where grieving can happen for clients, staff and volunteers.
These participants spoke of a lost space, a Drop-In, where this occurred. Creating a specific room or location may be one way to tangibly create a location where 'connection' happens within an ASO. However, equally as important was creating an atmosphere within an ASO which gives permission for diverse expressions of grief.

The third key strategy David called 'the sense of communal support'. He is speaking about the quality of the environment and team you work with. He is speaking about the sense of shared mission, commitment, and understanding. These qualities create 'the connection' that is necessary in developing resilience to chronic multiple losses where limited resources and time are available to grieve. It is hard to put a dollar figure to such a quality. He described it as needing to start with your hiring practises, but it was also about ongoing education and team development.

The fourth key strategy would be to use this research and other written resources to substantiate the challenges grief and multiple loss bring to the organization. Barry suggested this could be used to advocate for additional funding. This organization is experiencing trauma and disaster yet within and outside the organization there appears limited awareness and acknowledgment that this is occurring. I wonder if the alternative nature of ASOs, their disenfranchisement from other organizations and the broader community, impacts access, and community and funding recognition for essential grief supports as part of its healthy survival as a community organization? Possibly the Canadian AIDS Society (CAS) and provincial AIDS councils could play coordinated roles in advocating and supporting this research and funding recognition.

The final key strategy is to expand the needs of grief support as a form of community development, as Allison appeared to recommend. She noted how there were others who were more disenfranchised and who needed support and connection from the ASO. Additionally, these participants also expressed a lack of knowledge of grief concepts and awareness of the impact of grief on their lives. They also struggle to conceptualize the uniqueness of their grief experience given the evolving theoretical understanding of AIDS grief and multiple loss. Therefore, ongoing organizational grief
education is necessary. Additionally, outreach which provides grief and education support as a form of social and community development is a role the ASO can play in reducing isolation and contributing to an understanding and healing of the bereaved.

This research began as a form of social and political advocacy for those HIV positive and the AIDS bereaved. I have been honored to help discover and share these eight narratives and ethnographic analysis. The willingness of these participants to reveal their tremendous personal journey with AIDS grief and multiple loss has driven my own commitment to this demanding and exhausting task. It is my hope that the new knowledge revealed by this research will be carried forward as a means to honor the many I know and remember, and to contribute towards the meaning and healing of others.


Ennis, Frances., Boland, Bobbie., & Murphy, Helen. (1995). One day I was fine: A book about grief and AIDS. St. John’s, Newfoundland: Newfoundland and Labrador AIDS Committee.


Raudonis, Barbara M. (1992). Pearls, pith, and provocation: Ethical considerations in qualitative research with hospice patients. *Qualitative Health Research, 2*(2), 238-249.


INTRODUCTION: The purpose of this study is to understand your experience with AIDS grief within an AIDS Service Organization.

1) Before we discuss the specifics of your experience within the organization I'm wondering if you can tell me a little about you. I would like to know your age, and the social, ethnic, or culture communities you belong, or receive support from.

2) Looking back can you tell me the ways in which HIV/AIDS has touched your life over time. (Prompt for whether this has changed since contact with the

3) How did you come to be involved with the ASO and what is your role there?

4) What has been your experience with AIDS grief within this Organization? (Prompt for specific examples or a particularly bad time, and number of deaths/losses.)

5) How did you cope? (Prompt for how he/she makes sense of this experience with so much death, and suffering?)

6) How do you think people in the organization, and the organization itself cope with AIDS grief?

7) What sources of support are available to you within the organization? (Prompt for knowledge of written policy and procedures)

8) What sources of support would have been helpful to you?

9) Can you provide me an example of a time when you felt you needed support but felt that you couldn't receive or get the support you needed? (Prompt for why he/she thinks he/she couldn't get this support.)

10) How do you think others - family/friends, the communities you belong, and society in general views your connection with the

11) Has your life changed by this experience with AIDS grief and can you describe to me these changes?
APPENDIX E

Interview #: 1                        Date Of Interview: Feb17/96

V okay. So we're just going to get started
A And as a beginning I'm asking people
to kind of just tell them/tell me a little about
yourself. With a few things in mind- your age,
kind of maybe, your kind of cultural ethnic
background as part of that, um, and the places
where you get support or what your the
situation is within the communities that
support you in someway.
A Oh okay. Well I'm (laughs) (Full
name), um, 45 years old, ah, (pause) come
from a a german irish background. Um, that
probably says a lot, Hah, probably says a lot
about how I tradtraditionally would deal with
loss and grief, and bereavement. I don't know
that I follow the traditional cultural type of
line, ah but anyhow, I guess that will come as
we talk.
V Mm, hmm. (softly in background)
A Um, how do I, well (long pause), I
think I, I think I pretty much, ah, privatize a
lot of my um, yeah, I think I privatize a lot of
my feelings around, ya, multiple loss or grief
or bereavement. Particularly in respect to
work, anyhow, ah I don't really share that
much with other people. Um, I'm fairly
selective about what I share with whom and
when I share. Uh and I tend to it tends to be
more episodic, that I would really need to sit
down and dump or unload, you know, with
somebody else. Uh, and I can think of a
number of (clear throat)
over the past eight years that I've been there --
eight and a half -- I can think of a number of
times when it's been fairly specific kinds of
events that have triggered my need to really
um really seek support from others. On-uh-on-
you know on a more general way uh (pause).
It was interesting, I was thinking, I've been
thinking about this for the last couple of days
and I think what really comes clear for me is
uh you know when there is a number of losses
that have taken place or when things are really
rough with people's health or when there's a
number of deaths that occur, uh I tend to get
really uh I notice that n myself I become more
uh um 'aggressive' about HIV and AIDS. Um,
I become, I get a feeling of 'anger' and I
translate that into a feeling like uh - we need to
be more um um radical or um socially uh uh
aggressive about the issue uh and and it's
interesting that it just happens, you know, it
happens I can notice it happens every time that
there's, you know, that I'm feeling particularly
stressed about people's health or changes that
are going on or losses that are accumulating or
death. Yuh, I just feel myself kind a falling
back on what I perceive as a social work ethic
of being um uh (pause) you know almost like
um you know, uh, 'becoming angry' with the
system or becoming angry with some kind of
uh what I would perceive to be a uh an
inability of society or a system to do anything
about it and so I think as a social worker I feel
like it's my duty to some how, you know, uh
speak in anger for the people who are
experiencing these losses and so I sort of
almost professionalize it or, at least for me per-sonally, it's translated into what I see as a
professional commitment as well as a personal
commitment, as you know, as a caring human
being and then as a social worker. Uh so have
no control of what's going on for them. Uh I
don't get, I don't necessarily get gloomy or I
don't get um 'sad', I just translate it into back
into uh what my own personal commitment
is...to continue working at the network and
what my professional commitment is and I
guess that's how I see that I that I can make
any sense out of what's going on. It's that old
phrase you know pray for the dead and fight
like hell for the living. Every time, it's
amazing, but every time we go, you know, that
we go through these tough times, that always
comes back into my head, uh, that some how
uh, the fight still goes on and I can't do
anything about the deaths, but I maybe can do
something about those who are still living, and
so it's that fight 'that fight' that comes back
time and time and time again. So that's
(pause) But what's also interesting is that I'm
not sure that a lot of other people other people
really understand um I don't confide in a lot of
other people because I'm not sure that a lot of
other people 'really' understand what it's all
about. Uh, I mean they may uh you know, ...
I'm not sure that I really want to take the time
to educate someone, get someone else to the
point of being a support for me, because I just
don't have the energy to do it. Um and I really
don't really understand believe in a lot of other
toll is uh of chronic illness um so I just don't
bother. I don't really talk with my wife all that
much. "Hhhow" there's different times when
I'll talk with her about some stuff that's
happened, but I don't just don't put a lot of, I
don't rely on a lot of other people -- except for
maybe folks that I work with, but otherwise, I
don't have the energy. So uh uh I just kind of
go back into myself and where I'm at as a
human being and as a social worker. Uh uh
it's interesting working with S. well it's
been interesting working with everyone at
the network, particularly in the support
services anyhow, because we've all been able
to a different times you know, pound on the
wall or beat on the desk or you know kind of
collectively express our (voice wavers) our
anger uh and having
S. there now, is a good way, because she's
a very uh, uh you know she's just a very um
um expressive woman, so there's no problem
you know you can just turn the key and she
gets going (ha ha) so it's easy to kind of get in
that groove of just you know uh sounding off
when you need to uh. And I think you know,
over the past number of years, um there's
been a number of opportunities like that
because of the folks, people who have worked
in support services, based on different
personalities we've all at different times I
think have been able to um you know like 'lean
on' each other uh (breath in) the interesting
thing is I (intake breathe) I really believe uh
more and more that uh (pause, breathe) I uh ‘I
hate to sound so’ snobbish about it or so elitist
about it, but I think it’s like a club um (pause).
You turned my key Val! “So anyway” uh
(pause breathe out) uh (longer pause) Well
anyway ahem. You got to hold for a minute
(Recording stopped).
A Well anyway
V Are you thinking about taking a couple
of weeks off?
A Mmm Yeh, uh (pause) uh, I’m not
sure, I’m not sure if it’s a lot of what’s been
going on, say with people’s health. I’m sure
that may maybe has something to do with it,
but I think it’s more around what I see as an
ina an inability, I get very frustrated and really
tired and I think I’m getting tired or at least
weary of what I perceive as the inability of
other folks to really really “get it” you know?
um (sniff) I’ll be very honest uh ‘I’m very
disgusted’ with a lot of the other people at the
network right now uh just really disgusted,
because I think that uh uh I uh I think that
clients and support services have just been
going a bum rap and continuing to get a bum
rap and that’s been going on for a long time,
uhhh and I thought that I could do something
about it, but right now I don’t feel I can do
anything more about it and I think that’s
what’s really getting me down ummm and I’m
sure that people would come up with all kinds
of rationale rationalizations and excuses of...
but that’s what I’m feeling and I can’t deny what I’m feeling uh so I think that, more than anything, says to me that uh (pause) uh the reality is that the kind of work that we do um probably does in a sense make support services kind of an elite kind of a club, I mean I wouldn’t “buy” that, but I’m sure that some people think that support services thinks that we’re the top of the you know top hogs in the pen and uh MMhm (in background)

V Uh, but uh I think that uh I just see more and more two camps ahhm and I’m glad that I’m in the camp that I’m in because I know that we’re there with the people who are ss who are really hurting. I’m not sure I know where everyone else is at uh, I have a perception as to where they’re at, but um I...

V Can you tell me more about, uh about that other camp?

A Yeh uh (pause), I think there’s an in... I think people have lost a sense of why they’re there or what the organization is about...I think they I think that they’re doing something really worthwhile and worthy, you know worthwhile, but I’m not sure who they’re doing it for or whether they’re doing it for themselves or whether they’re doing it for the people who come through the door. “I know why I’m there”
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203  V  Mm Hm
204
205  A  Uh but I just get a sense that a lot of
206   other folks in that office have lost the sense of
207   why they're there
208
209  V  Mmm
210
211  A  'and therefore' the office to a degree has
212   lost a sense of what it's all about
213
214  V  right
215
216  A  Or who it's there for um um (clear
217   throat) and 'it what's becoming clearer and
218   clearer' is that support services to people who
219   are infected or affected really need to be
220   separated out from whatever else goes on in
221   that office and 'luckily' there's more people
222   who are recognizing that. It's a shame it has
223   to happen, but I guess that's the way it's going
224   to have to go. Uh... so that we can really
225   make, at least, a portion of the organization
226   responsive to people who are infected and
227   affected. The rest of the organization can do
228   whatever the hell they want.
229
230  V  Hm mm
231
232
233
234
235
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270 influence over um can I do it any better? can I
271 do it any different? You know, um, and can I
272 make the experience any more uhuh tolerable
273 for people who are going through it? “So” it
274 forces me again to fight when I need to fight
275 for whatever I think it is I need to fight for
276
277 V  Hm hm
278
279 A  Or whatever ... you know .. fight “for”
280 people or ‘help’ other people to fight for
281 themselves uh so (intake of breathe) it’s it’s
282 interesting um way back when when T.G.
283 worked for the network, uh, I remember T. had
284 a lot of problems, partly because of T.’s
285 approach and T.’s approach, for good or , you
286 know, for good or for ill, was a basic thing you
287 know, no, you know he was very transparent,
288 he always .. always said, you know “I’m here
289 for the people who ‘need’ me” and I don’t
290 want anything to get in the way of my ability to
291 be here for the people who need me. And he
292 finally left because the organization was going
293 in a direction that he didn’t agree with. Uh,
294 but he always said, you know, if we’re not here
295 for the people who need us, those who are
296 infected and affected, then we have no business
297 being here at all.
298
299 V  Hm mm
300
301
302
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A And I don’t totally agree with some of
T.’s style or some of his approach, but I
certainly have to agree with I have to agree
with you know, his philosophy. And the
philosophy that a lot of other people have, uh
so (breathe out) it’s those kinds of things that I
think that really help me make sense out of the
losses and dying and the deaths um it’s
knowing that other people are will, you know,
“knowing that I think I still have someting to
contribute, I still have something that I can”
uh some way that I can still make a difference,
uh yeh. (long pause)

V I’m wondering -- you’ve been there a
long time and (pause) if you can give
me a sense of how HIV has impacted your life
over time, like over history, including your
own personal life, like I don’t know if there’s
others who you know in your own world who
are HIV positive you really talked about that
just how HIV has impacted your life over
history, that might include the network, that
might include other parts of your life, it might
include relationships within your own family,
like how that’s changed or impacted ..... 

A MMmm (long pause) Uh (pause) This
is the first
place that I’ve worked where I’ve stayed for
eight years. Uh, that probably is fairly
significant, at least in my life anyhow, ummm
(pause) I uh I don’t know, I guess uh in a sense
Val I find that really hard to answer. Um
(pause) you know, I've always I've always had
the opportunity to work in situations where um
that were I'd say I think sort of on the edge I
guess, uh, so when it came to the network, it
was obviously you know working on the edge,
working on something very new, uh, that also
carried a lot of uh obvious, you know,
obviously carried a lot of suspicion with it as
well, particularly in the general community
and "also" disdain. Um (pause) I think more
than anything, working at the network has
allowed me to, has really been a very freeing
experience uh it's just allowed me to get
involved in some areas that uh uh where I had
a sense of safety to function and to to operate, a
sense of "safety" to live out, you know, a
particular slo ah ethic as a social worker, as
well as a human being um, not to say that if
the safety wasn't there I would not have done it
otherwise, but you know, working at the
network certainly has provided me the
opportunity to to live what I say that I am. Um

V    What would that be?
A    Well

V    Can you describe an ethic a certain way
of being that there's freedom to do that -- what
qualities would that have?

A    Uh (pause) Well I think uh I think for
me (intake of breath) you know, as a social
worker,
it's not just a, I could have worked I guess in a number of different places, or a number of different issues or organizations. Uh and not really been all that challenged, uh you know, mental health or addictions or all the way down the line, home care, I probably could have worked in a lot of other places where I would not necessarily have been challenged, where a been, where it would have been a very kind of - comfortable kind of environment, uh but uh I really would not have been challenged -- where there were "or" where there was not much of a challenge in the first place, uh but work, but being at the network has been a is constantly a challenge and um (intake of breathe) uh a constant reminder -- a contant reminder of who you are as, number one as a human being and number two as a social wor, I mean what your code of ethics and social worker and social work tells you how you need to behave. So it’s, it’s just an opportunity to be reminded all the time, almost every day be reminded of what what suffering is really all about, what loss is really about, what marginalization is really all about, what uh what human misery is really all about and what um “laughter” is all about, you know, there’s just so many very basic levels of human interaction that we see on a daily basis almost, uh and it really taps into who you know, it really I think challenges me, anyhow, to think (intake of breathe) now uh who I am as a human being and uh you know what .. what kind of opportunities I have and you know what
I need to be thankful for, you know, all the way down the line, it uh it's just a, you know it's just a really good opportunity to kind of ensure that you don't think of yourself too highly, you know, kind a keep yourself humble to some degree, but also uh ... it helps you to uh, realize that you know you are accomplishing something or that if you can leave an impact on one person's life, you've done something, you know, you've done something significant. Uh (pause) and in the context of the kind of stuff that we're still having to deal with around life style and around choice and around illness, that here in Alberta there's still, we still continue to struggle with um take all those other things I mentioned, you probably could experience anywhere else, but particularly in relation to some of the very basic human rights stuff that we still continue to struggle with in this province, the network is a neat place to be, to be challenged about, or to be ... just to be challenged about that all the time uhhhh and maybe I can't do anything about it, but I'm sure glad that I'm there to be able to be a part of the struggle anyhow. Uh, so.....

I wonder if you can kind of take me (telephone rings) .. you need to get that. Do you?

Uh Uh
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V    I wonder if you can give me a sense of how it’s been over time, like I know you started a long time ago and been in several offices, how it was that you started at the network, like how that all came about and kind of walk me through what it’s, if you can give a sense of what it’s been like over the years being there and maybe things that stand out in your own mind about changes or shifts or could you have a unique perspective about the history and uh there’s lots of pieces I don’t know about....

A    Uh Well, you know I started at the network, probably partly by accident. Uh, ‘cause I’d only recently moved into (this city) from the States and was sniffing around for a job and just happened that the position opened at the network at that time. And, of course, I had a lot of preconceptions about, I had a lot of preconceptions about not getting accepted for the position and I think I was really surprised when I was accepted, not because I felt that I uh I felt very comfortable in being able to contribute something, but I wasn’t sure that as as a straight man that I would, you know, really cut it, or that that what’s the organization was looking for at that point in time. So I was really surprised that I was accepted. Uh, (pause), you know I just found it really exciting um when we were in that original office, and we only there for a few months after I was hired before we moved into the office on 7th ave, but I guess I
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473 just found it really exciting, I found it exciting
474 working in a) working in something that was
475 struggling for resources that was sort of tucked
476 back into the corner, you know almost like a
477 store front -- well it wasn't a store front it was
478 up on the 2nd floor, but it was (breathe in) I
479 know for folks who had access to the office, it
480 was really it was not nice at all having to climb
481 up those long set of stairs, you know, I know
482 for them it had an impact, uh a negative
483 impact, for me it kind of had a positive impact,
484 because it was starting from the ground up
485 with something, uh an and and you know I
486 think for me in that sense it was really
487 exciting, uh some
488 V    That was when when was that?
489 A    That was '87,
490 V    Okay
491 A    Yeh, so it was. I started in August of '87
492 and we moved to the new office or the 7th
493 avenue office in um January of, January of '88
494 right so we were only in that other office a
495 short time, they had been there for already for
496 about eight months by the time I started. Uh
497 (pause) to be, I mean to be very honest with
498 you, uh, I think that uh, (sort of outbreathe and
499 whistle noise) well, I'm not saying that it was
500 any better eight years ago or seven years ago or
501 six years ago, it was just very different, at least
502 for me, uh I think I'm less comfortable now
503 with where we've where the organization has
504 moved to not where the issue has moved to
505 within the
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507 community of (this city), but where the
508 organization of the network has moved to. Um
509 and maybe it's just nostalgia, I don't know, but
510 I think that there was more, you know, there
511 was just a different challenge, uh there was
512 um, lots of struggle obviously in '86 and '87
513 and '88 uh, but there was also a maybe a
514 greater sense of achievement, that were you
515 know, once you had got over one hurdle, you
516 know, each hurdle that we faced there was a
517 great sense of achievement. There was also
518 more of a sense of a community ownership that
519 I think that I really certainly sensed that
520 there's a lack of community ownership or ah at
521 least from the gay community anyhow. In '87
522 and '88 there was certainly a greater sense of
523 commitment and ownership on the part of the
524 gay community and somehow that's been lost.
525 Uh, I think to some degree it's been very
526 much, ah you know, special issues, special
527 interests ah have sort of taken over ah and and
528 the roots of the organization I think to some
529 degree have really been forgotten, or at least
530 don't don't carry as much impact, and I think
531 maybe that's part of the problem with a lot of
532 the people who work at the network now who
533 are fairly new, don't have a sense of some of
534 the early "struggles" and therefore, they're
535 there for a different reason I think. Uh (pause)
536 um tha you know, so so I think for me (pause)
537 dealing with the losses and dealing with grief
538 and dying and death, uh at that point in time
539 was just very different because there was, it's
540 almost like
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we’re all in this together and we all gotta
support each other and we all being, even
people from other organizations, and at that
point in time there were only a few other
organizations like STD and the hospital and
HomeCare and CSS and that was about it, you
know?

V  Yeh Yeh

A  So we all kind of, you know, we all kind
of felt things together um and uh so there was
more more of an opportunity to really um,
there was more of an opportunity to get
support from other people or to feel
comfortable in accessing other people, because
we all got together on a fairly regular basis and
there was a group of of professionals - service
providers who got together I think monthly,
for a period of time, we got together just about
monthly, uh and then it just sort of fizzled out
uh sooo (breathe out) there was, it was an
adventure and I think, at least for me anyhow,
it was a sense of adventure, it’s a sense and
not in a childish way but in a real way, it
was really really an adventure, it was and and
it was just more of a sense of communal
support because we all had to stick stick
together uh and in someway, it’s ironic, I think
our our solidarity, maybe that’s a corny
term. I can’t think of the term I want right
now, but our solidarity with people with HIV
was greater then than then than it is now, uh -,
yeh at least that’s the kind of sense
that I have, umm I remember ah I remember
some of the early deaths and actually feeling
very feeling very, not feeling very but feeling
somewhat uncomfortable in attending the
funerals because the funerals were packed and
the gay community came out for the funerals.
Uh, uh I remember feeling (chuckling) like I
had to go number one: to prove myself and
number two: to ah start to kind of be visible
and fit it uh, I mean that was not my major
motivation, but that was part of what I was
feeling, certainly I was going because these
were people who I was who I got to know and
work with uh, but I mean over obviously over
time, uh becoming more and more
comfortable. Um I got to develop rela-
tionships with individuals, which is I think
another I don’t want to ramble off on too many
tangents here uh but uh I very much struggled
with um, I very much struggled with what
what my relationship was going to be with
people whom we were working with ah and I
never anticipated that I would be a friend to
everyone that we worked with, as well I never
anticipated that I would be a friend to
everybody who was a volunteer or who worked
at the network. Uh and that’s just unrealistic.
I think on a professional level, we all got to we
got along well because we we recognized
that we needed each other. Uh on a client or a
consumer or people ‘infected’, on that level uh
obviously people kind of sought out those
whom they were most comfortable with and
they, you know, we always supported that so,
there were a few people who I got to know
really well and a couple of people who I would
say were prob, you know, I would count among
my best friends, uh and uh and and .. and and I
would consider, you know, to have been a
privilege to have been considered their best
friend, to have been that close to them, you
know, through their dying and death. Um but
I think for a lot of the other folks that we dealt
with, that we worked with um it was um you
know sort of, they were part of this bigger
community that was experiencing something
and “I” was part of this community and so I
just saw that I had a role to play along with
others in the community, you know, in
supporting this individual and I wasn’t
anybody special I was one person playing a
role uh and uh and ah and and felt very
comfortable and good about that and I thought
that the netw, you know, that the support
services had a role to play uh one of many you
know, in supporting, you know, these
particular individuals. And some of them were
individuals who I just would never want to be a
friend to or I would never choose as a friend ah
and, you know, I , you know, I was
comfortable with that. Uh but I uh, I always
felt, that you know, that no matter what
circumstances brought them to having HIV
that they deserved the very best that we had to
offer. Ah so um, yeh I think that the
experience over the las over those first those
first five years say, for me was you know the
real growing process and the the evolved, for
the evolution of this community
into recognizing how it was going to respond
to HIV uh and you know the develop-ing
process of you know, what I consider to be the
pro-fessionalization of HIV, um and I think, to
some degree, that’s been good and to some
degree it’s been very nega-tive or bad uh but I
think to the degree that the com-munity has
lost its sense of mission, I think the pro-
professionalization of HIV has been “bad”, to the
degree that the community, others in the
community have recognized a role that they
need to play in are developing their skills
around playing that role and I think it’s been
‘good’ and only time will tell whether the
professionalization of HIV in (this city) or
Alberta, has been a positive or negative
experience in the long haul, over the long haul.
Uh today I’m not sure that I wanna be or I’m
not sure that I will be around uh in five years
uh at least with with the network anyhow. Uh,
but that’s what I’m feeling today, who knows?
Uh, but I do know that it’s, you know, I think
it’s that sense of mission, that sense of
commitment, a sense of uh you know, um
solidarity, ‘cause I don’t know that we could
going through it any other way, you know and,
you know, just our experience here in
(this city) is traumatic enough, and I’m not
sure you can get through it any other way than
just feeling constantly committed to uh uh you
know to solidarity and and to a mission, almost
like, you know, like it is a mission, um and
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and uh and that we’re all, you know, we’re all kind of struggling along together.

Ah so anyway, I uh, I don’t uh.. Uh I guess you know the point at which we’re at now, uh is uh (pause) hm I think there’s so many opportunities, but I think at the same time there’s a lot of ‘um’ there’s opportunities to accomplish something really neat stuff, but I think there’s also a lot of uh opportunities to uh fall into traps of just mediocrity or really losing our direction altogether and that period when we were down on 107th avenue, hm I think because although it wasn’t always great because of the smoking across the hall ah yeh I think that even in that office, you know we really felt like we we felt like we were a family, I believe we felt like we were family, you know, we felt a closeness um but I thi but everything was dependant on personalities, everything was dependant on who on who worked there who volunteered there who was in and out of there and that really uh that identified what the flav what the ethic and what the flavour of the organization was going to be like, so where I see that we moved, at this point in time, to you know, becoming ah very segmented and very compartmentalized, has a lot to do with personalities and a lot to do with just the evolution of the organization. Uh, so I find it much more difficult to uh rely on a communual type of ah system of support at this point in time. It’s a lot more difficult that it
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was five, six, seven years ago, because it was at that point in time, as I'd said a little while ago, it was there and it was very apparent and and um it was accessible and it was part of the survival. Now it's less a part of the survival uh so anyway I uh

So how do you, sounds like a question -- how do you survive? -- and it sounds like that which you've noticed a shift and so basically resource in some ways that was there for you, is not there and so

Yeh, interesting

And so would that be accurate?

Sure, I think so, yeh. Uh (pause) hm (pause). You know I said earlier that I really don't uh I don't tap into others too much, but thinking .. now that I'm thinking more about it, I do. Uh uh so it's more of a smaller group that I tap into and I think it's not only it's not very conscious, not on a conscious level I do it, but very on a but very much on a subconscious level. Like a facilitator for groups uh I talk with fairly regularly and I find that my discussion with them is not just business, but it's more, you know, kind of sharing something, you know, and feeling like after I've finished the phone call that, you know, I felt good about what, you know, what we were able to share, you know, around whatever was being experienced. Uh, so I find that I, "Yeh", I find that that helps a lot. And even say the sharing
that we would do within support services, I find important, ah at least sort of like as a shot in the arm or as an affirmation uh of what whatever you know I’m feeling at a particular point in time. Um so where I see that there’s not that broad based communal community type of ah you know system of support, that I get it, at least on a professional level, from other folks that that I have contact with. Uh, I yeh I think ah you know I think I probably uh (pause), you know, I think I probably seek out those folks who I feel uh I feel confident or comfortable in in (the whistle) mm how should I say it, let’s see uh I mean I could talk with a Home Care worker and talk very business or, you know, in a sense very business about someone, support for someone in home. Uh or I could talk with someone like P. and it’s just a different kind of conversation or I could talk with someone like Sharon or Donna or Don and it’s a different kind of conversation. Partly because thh, because there’s a common understanding about what we’re feeling and experiencing. Yeh, I guess that’s what it is. Uh yeh. (pause)

Are there other ways in which you’ve, you know, been there for 8 plus years there’s ways whether they’re conscious or unconscious, there’s ways you need to figure out or I don’t know, sometimes it’s not necessary to plan, but are there things that you’ve needed to do over time to survive, or what have you done, I mean that might not be clear in your own mind, but
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what what cause being on the front lines of
AIDS work for 8 years is quite a fete really, I
mean I think that that’s not often the case

A  Yeh right uh huh
V  And so.. part of what I’m trying to
figure out is what is it that we’re doing and
what is it that helps us and
A  Hm I go to church every Sunday Val.
And there’s been a lot of times when I’ve sat
there and just thought what the hell am I doing
here? what is this really, I mean why waste
my time? Uh and there there’s been other
times when I just sit there and say, well maybe
there’s something to all this. And then there’s
other times when I really believe that I gotta be
there. Uh, so out of the course of eight years,
it’s been up and down up and down up and
down, you know periods of you know long
stretches where I’m just there and that’s it just
filling filling a seat, other times when I’m
really there mental-ly and other times when
I’m really there ah ah emotion-ally and really
struggling you know ah and just feeling like I
gotta be here because it’s doing something for
me. Uh (pause) so that so that uh you know,
obviously, that at different times has been a
real help. Um

V  The the church you mean?
A  Church yeh

V  Can you tell me a little bit more about
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what what’s what’s qualitatively there, what’s
what is present about being there, what does it
give you?
A  Well, (pause) hm, uh part of it is just the
uh, part of it is the uh the opportunity to just
sort of be private uh yeh just you know
although there’s maybe noise going on around
me I can easily shut it all out and just be
private and “do some thinking” uh uh and part
of it is a belief that I have in God uh, not
always don’t always understand what it’s all
about, but part of it is just a belief I have in
God um and ah willing to slug it out week in
and week out even when I’m not really sure
what God is all about. So and I uh I’ve had
that belief for years and years and years and at
times its I’ve felt comfortable very good about
it and at other times I’ve haven’t felt very good
about it at all. Uh but uh I do know that no
matter what your system of support is, ah at
times it’s going to work for you and times it
ain’t going to work for you. Uh so my system
of support, at least from religion anyhow, is
probably no different than what anyone else be,
any system anyone else would have in place I
guess uh when it works for me it works for me
most like 80% or 90% of the time it works for
me and 10 or 20% of time it doesn’t work. But
I guess I say well it does work for me 80 or
90% of the time so I just go with it. Um at
time aaaand and at times I need answers, at
times I guess I just need uh just an opportunity
to kind of get into my own
thoughts uh and uh like a space that creates
some kind of atmosphere that allows me to get
into my own thoughts. Uh I’m not sure that
there’s a lot of times that I walk away with
answers, there are a lot of times that I walk
away and feeling a bit re-energized or
energized or confirmed in what I think I need
or you know, what I think I need to be doing or
what I think the answer is, you know. Uh, so
you know I haven’t had any revelation or
anything like that, but uh just most times I
walk out feeling like well like all right, ah I
really didn’t screw up this past week and um
ah I’m really not sure what the greater scheme
of life is, but at this point in time this is where
I need to be, this is what I need to be doing and
you know, uh and uh just sort of catching my
breathe I guess. ah So (clears throat) Second
thing would be uh second thing would be uh
mmmm talking with other people, particularly
with other social workers, uh let’s see, I find
more and more I have the need to I have the
need to talk with other social workers uh uh
about some ver, you know, around some very
basic issues, like social awareness and uh
advocacy and almost like a like a philosophical
type of type of debate or argument or
discussion, uh because of the stuff I guess that
we deal with on a day in and day out basis uh
(pause), that at times seems really horrendous.
Uh I often wonder so .... it’s not that I lose a
sense of the whole but I often wonder where
does it all “fit” and how does it all fit within a
scheme, you know, within a
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880 greater scheme of things? Uh, so there’s a
881 number of times that just having a really knock
882 down drag out debate on things like advocacy
883 or ah or ah civil disobedience, or you know,
884 whatever, you know, really is kind of
885 energizing for me because I kind of, you know,
886 I can uh at least fit the reality of the stuff we do
887 with day in and day out within within some
888 kind of context ah. Yeh. I just find I find that
889 that uh chall being challenged on that more
890 philosophical kind of level I guess is really
891 important for me. Uh yeh, at least in a way it
892 kind of brings me back into perspective I
893 guess. Or at least helps put everything that
894 we’re experiencing into some kind of
895 perspective and it certainly keeps keeps me
896 humble keeps me kind of grounded so that I
897 don’t get to uh yeh I don’t get I don’t lose lose
898 a sense of the reality for people it keeps me just
899 grounded uh inuh as a social worker uh, that
900 for me uh for me it’s very, it is very much front
901 line type of struggle and I’m not sure that I can
902 see myself uh as an administrator, of course
903 that’s a bit ironic, I’ve been partly an
904 administrator for the last eight years, but I
905 could never see myself totally as an
906 administrator, I could see never see myself out
907 of who, out of, you know out of that daily
908 struggle type of connection, so these kinds of
909 debates are really good, you know that I’ve had
910 an opportunity to do a lot of travelling because
911 of sitting on different kinds of committees ah
912 and all of those travels, whether its been been
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...to Toronto or Ottawa or Vancouver east or... west have always been with social workers and there isn’t a lot a times when that at night sitting, you know, having a beer and just talking about social work type of stuff. So, you know, it’s it’s at least, it’s I find it very energizing, find it very, you know, kind of really ‘keeps me grounded’, you know, ah and it’s ah it’s just a very good healthy intellectual exercise too. So...

V: What’s, uh just, you know, for kind of information for the research, is it about the committees you’re involved with and what why they’re important to you, what it is about that that’s important to you.

A: The big one right now is with uh Canadian Association of Social Workers. Uh, and it’s an ad hoc committee, so it’s not a standing committee within the national association, uh it’s pulled together on an as needed basis and represents people, or has representa-tion across the country from coast to coast, um so we’ve been ah working on stuff three or four different things one is uh a basic statement or a like a policy statement on HIV and AIDS that the organization or the national association has written up, uh that’s not really fancy, uh very basic straight forward basic policy statement this is who we are and this is why we think we ought to be involved. Aah a booklet which assumes almost like a primer like a lot of those pamphlets we get out, which
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really are just primer primers give a bit of information so the booklet is really a primer, particularly for people who have never, social workers who have never address-ed, had to deal with the issue. Now we're, at this point, now we're working on ah one of the modules within the comprehensive guide for care of people with HIV ah. The guide is like a set of resources ah and and each module contains ah information and resources and resource information as well as well it's just a whole book of resources or reference as well as experiences, and and this particular module is on psychosocial care. Um so in fact we're, we've they've hired a writer, but this committee is actually providing all the guts for all the material for this writer to then take and put into a format that that's workable. Um, and then there's going to be a special edition of the Social Worker. So it's all focusing on HIV and AIDS and a national perspective and addressing the needs of social workers or the role that social workers have played in a national perspective, as well as trying to speak to those non-degree social workers or other caregivers and care providers who don't have a degree, but trying to speak to their needs as well and how to better how to give them more resources and better support then. So it's a neat opportunity to contribute something uh to be involved at that level to be able to contribute something on a national level. Um the other neat one was uh well in '88 I think it was, when
the province of Alberta was putting together its
first plan of action. Uh uh it was uh I forget
what the title of it was, but anyhow, it was a a
group, a nat a provincial group of people from
across the province who were pulled together
for about a year long process, it seemed like a
year, of developing a pretty much a plan of
action that Alberta helped Prov AIDS with
kind of endure, so at least we were supposed to
give some sort of framework to how prevention
and care was going to move forward in
Alberta, a lot of the recommendations were not
acted on, but at least it provided an opportunity
for the community to have a say in what really
needed to be done around care and support and
prevention and education. Uh and then the
national association of schools of social work,
uh I sat on a national group for that one as
well, that looked at the training needs for
social workers and made recommendations as
to what needed to be happening in social work
programs, both in the colleges and universities
across the country. What the curriculum
needed to be and all that kind of stuff. Uh so
uh the uh I’m trying to think of there’s been a
couple of others but I think from a professional
perspective it’s been really neat to be able to be
to be able to number one be able to represent
(this city) and represent the (this city)
community to some degree as much as I was
able to uh in some of these national types of
things as well as provincial uh yeh and then of
course the biggy was the Caring Together
project. Uh which uh provided well as
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1016 manager at least as manager of the second half
1017 of the project, provided me the opportunity to
1018 get involved in the issue on a different
1019 level. Uh hm uh I think that uh, particularly
1020 for Care for the Caring Together project, it was
1021 not so much what we accomplished within the
1022 framework within the time frame of the project
1023 as to what we started. Uh, ‘cause I’m pretty
1024 sure that probably a lot of the stuff that we
1025 started we know we did not accomplish or
1026 didn’t come to fulfillment within the time
1027 frame and is going to take a long time before it
1028 really kind of has its its long term impact is
1029 felt. That’s fairly typical I think with any
1030 kind of project. Uh uh I I what’s interesting
1031 is um when I started eight years ago, uh I I
1032 had come from a number of years of
1033 experience as a social worker uh and when I
1034 started at the network it I saw this as the
1035 greatest challenge that I thought I was ever
1036 going to have, probably ever will have as a
1037 social worker, uh and there were times when I
1038 was just sure that I wasn’t up to it that this was
1039 way beyond my skills and ability uh and as I
1040 look back over eight years I think two things
1041 are clear to me: one is that I’ve that I had
1042 numerous opportunities to a to have an
1043 impact and I had a responsibility to take to
1044 make use of those opportunities because they
1045 were all some of them were handed to me
1046 almost on a silver platter and to some degree
1047 those commit national groups that I was on or
1048 even Caring Together, were like, it was like a
1049
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1050 blank cheque, you know ah and so you’ve got a
1051 responsibility or I thought I had a responsibility
1052 to use this opportunity to ensure that uh as a
1053 social worker I did something good and that I
1054 really represented what as I I perceive the
1055 needs of people who are infected and affected
1056 that they that always had to be forefront you
1057 know, and that ah if (this city) and me had
1058 this opportunity then I really couldn’t screw
1059 up. (end of tape). So I think in respect to in
1060 respect to.. I can’t parcelize how uh how I deal
1061 with loss in respect to ah, you know, iiii, you
1062 know, in respect to our dealing my dealing
1063 with people at the network or or death or or
1064 dying or death. I mean it’s just all part of the
1065 whole, you know, uh I eh I guess I’ve used
1066 every opportunity to come along as a way of
1067 drawing some strength and support, ah you
1068 know, whether it’s been sitting on groups
1069 nationally or provincially, ah whether it’s been
1070 uh working with other organizations uh I guess
1071 everything that I’ve been involved in I’ve seen
1072 as an opportunity to ‘to do a little healing’.
1073 Uh, I’ve seen, for myself. I’ve seen as an
1074 opportunity to uh underscore uh or reinforce
1075 the experience of of those infected and affected
1076 um so in a sense it’s been a little bit of um not
1077 grandstanding, but, you know, just advocacy.
1078 We’re using opportunities to advocate to
1079 remind people that this wou really all about,
1080 you know, even in a in along with everything
1081 else, “this is what we’re really all about”. Uh
1082 so I I guess I’ve seen all these opportunities as
healing processes as well as reaffirmations of
what I'm here for uh and reaffirmation of the
livvves of people like Dana, people like uh
um, um hmm god I can't even begin to name
them all Sherry and all the way down the line,
you know. So uh 'yeh'... So it's all part, you
know, for me it's all sounds like a neat little
package, but it isn't, but it's all, you know, all
pieces that are linked together.

V Okay. Over eight years of your career
you've experienced lots of grief and I'm just
wondering if you could talk about that
time, you know, what it's been like
really experience AIDS grief and multiple loss.
A Uh Uh tiring. Uh (pause) hm The
difficulty for me, the difficulty is if I look if i
look at eight years, if I look in the context of
eight years, it's really tiring 'I feel very
weary'. Uh so .... you know um, I, you know, I
I guess if I'm gonna survive, if I'm gonna stay
sane, I just have to think, you know, like the
here and now uh and it's not that I forget all
those names, all those stars on those memorial
panels at the network, I'll never forget them.

And it's good, at least for me, it's good that
they're up there uh and that they're hanging
all the time. Uh I can't ever forget them but
uh I just I think in order to survive, I kinda,
you know, I need to at least stay focused. The
people who are living right now need my
energy, you know, uh but it is tire, you know, I
it is "tiring" uh .... I you know when the quilt
when the national quilt was here, what was it?
last summer or the
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summer before? I found that I found that
tiring. I remember a couple of times you know
I went through I went through uh I we were all
there at the at the opening and I remember
walking through couple a times and I just felt
tired like a really big weight with all that life
experience, all that pain and all those deaths. I
really felt, I just felt very tired. Uh so I guess,
you know, I go I go back to that thing, you
know that, "I remember the dead but it’s the
living who still I still gotta fight for, fight with,
you know, sometimes, you do fight with (both
of you laugh) Fight in concert with. Uh, yeh,
there are a number of times when uh I pull
out the book with the names in it, uh so now
we’ve started the second book. So there both
those books are in my desk and there are a
number of there are sometimes like four
o’clock in the afternoon when I just need to
maybe relax, I’ll pull out one of the books, put
my feet up on the desk and start doing, kinda
paging through uh just to just as a memory as a
reminder of, you know, who we’ve known uh
but uh the cumulative toll (whooh). I don’t
know uh (long pause) I don’t know Val (ha)
you know, I really don’t know uh I I you
know, we have we have rituals, we have things
like the uh memorial
services and we have the book with the names
in it and we have memorial panels. Uh I
haven’t I don’t deny. I mean it’s not that I
haven’t thought about this cumulative total of
deaths that we’ve had here in (this city) and I
certainly have been impacted by lots and lots
and lots of those folks, but uh ‘I don’t feel
particularly raw’, but I know that when I look
at the total I do I do feel a weight, I do feel
tiredness about it. Um so I just don’t focus on
it too much I just focus on who were who who
who’s living right now, who’s struggling right
now yeh yeh.

V If you were to put a number to a
cumulative total for yourself, what would what
do you think that might be?
Mmm whew god, over a hundred,
(voice cracking) certainly over a hundred. Uh
(pause) can it be that many?(whispers question
to himself), I guess it is. yeh. (clears throat)
some of those folks I did not know. Some of
the names in that book and some of the stars
on the panel are people I did not know uh and
uh weren’t even known to the network not that
many, but a few. And then even some of the
folks who were known to the network, I really
didn’t know. You know like you had contact
with or N. or whatever uh. So I really didn’t
get a sense of them as an individual. I guess,
you know, in a sense it uh I can’t I could not
add there names to the total. Uh for me it’s at
least a hundred anyhow. It seems fairly
amazing that that many people that I’ve known
had some kind of connection with uh. But I
would say people who are really who who
I really felt the loss, with whom I really felt the
loss was uh well at least, you know, probably
well over thirty people anyhow. Uh, people I
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knew, people who you know I laughed with or
ya, you know, you know was supported in
some some sh some shape some way shape or
form. Well over thirty people surely, uh maybe
closer to fifty people who I would say, you
know, I really, you know, interacted with. It’s
gotta be more than that um yeh.

Could could you tell me about a a time
where either one of those who died who were
really important to you or really just a really
bad time when there when you were really
feeling that tiredness, that weight.

Mmhm Actually there was three
experiences uhhh that were very vivid - one
is a fella who who wound up living at
Kairos for uh for a few months. I guess he was
maybe there for a year, that was about it. Um
and just a really almost like a really sad soul, a
person who was really kind of uh isolated um
uh a man in about of about, well he was about
mid-forties to fifty years old and just had oh,
you know, had sss had a really a really difficult
life as a gay man uh living in Alberta and um
came from a small town to (this city) knowing
that he was really in a probably the last year of
his life. Uh and did okay at Kairos, but uh uh
had a lot of internal struggles around his own
sense sense of himself as a gay man and uh, so
anyhow. I remember uh working very closely
with him around a number of different issues
uh but he always had a real hesitancy about the
network

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because everything the network represented he had a kind of aborted... I mean I think to some degree he was a lot of internalized homophobia, I mean, he really, everything the network represented he hated and hated about himself uh and I felt very frustrated that there was not a lot that I was never gonna be able to do and with him it was just basically addressing some very human needs, very basic human needs around that, uh just around meeting some very basic needs. Anyhow, I remember seeing him when he was in the hospital for the last time and and no one was visiting him anyhow, except for one volunteer we had connected with him and I think a priest from some church, uh so he was in terminal stage, probably uh had no more than a few hours left and I remember sitting with him in his room and feeling very lost, just feeling like, just feeling very lost that uh totally incapable of doing anything, 'cause he was a person who, in a sense, seemed to have shut everybody else out and and yet relied on us but yet didn't want us, you know, it's that real internal struggle that he had and I was sitting in his room just feeling like, you know, what am I doing here? you know, I have no answers. This is a very uh I just it felt like a very it felt like a great conflict not that I didn't want to be there, but yeh it it was just a really weird experience. I remember walking out just feeling weird about it all uh and feeling very sad that this guy was pretty much gonna die alone. I I remember that uh i think the priest from
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whatever church he was connected with wound up being there I think around the time that he died -- “NO” he did die alone and no one was there I mean there were nmssso a couple a people in and out but he wound up dying alone and the nurse wasn’t even there, you know, they went in the room and found him dead. I remember really feeling not depressed, but just really sad over that whole experience. Uh, the second experience would be uh uh Alan and um uh ‘Alan and I clicked’, uh you know, we became really good friends uh you know, so uh it wasn’t the first obviously it was not the first time I was really touched by another individual who was living with HIV, but Alan and I really clicked and we we got and I got to know him well and he got to know me well and kind of really, you know, we just (breathed out) uh got to be very good friends. So that was really a tough one. When he died it was really tough um uhh just because I knew it was probably one of the few opportunities I would have I would have to really uh connect with another person on that level uh. There’s been there’s been a couple times when I probably have come close, but not as close as I ever was with Alan and it may never happen again. Uh but it was just a really it was a very special experience very special experience. And I think dealing with his death for me was I think made easy because of the closeness of our relationship um it was just made easy because it wasn’t so much grieving a loss as much as it was just
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1286 remembering a really good special friendship.
1287 Uh uh and I think the third experience would
1288 be uh would be with David uh and you’ll
1289 probably remember this uh. (Pause) On I I uh
1290 only because uh I think I really surprised
1291 myself the degree to which I was really hurting
1292 uh yeh I think it was the degree to which I was
1293 really hurting and and couldn’t, you know, and
1294 knowing that there was nothing I could do uh.
1295 Yeh knowing that there was nothing I could
1296 do. Uh so (pause) that range of emotions.
1297 Those three instances, those three experiences
1298 represent such a range of emotion uh that’s
1299 been I think that they kind of you know
1300 ‘capture’ a lot of you know what I’ve
1301 experienced over over the court and and they
1302 capture quite a quite a range of years as well
1303 Uh ‘Yeh’.
1304
1305 V What would be that range of emotion,
1306 what what would you mean by that?
1307
1308 A Well I think at one end it would be you
1309 know a sense of distance uh or at least being
1310 held at a distance by an individual who really
1311 wanted us but didn’t want us wanted that
1312 connection but didn’t want it, you know. To
1313 the other end where, you know, ahhh where
1314 um the I I felt totally incapable of really doing
1315 anything with and really felt the weight of the
1316 impact of what was coming for him uh the
1317 anger and the just the realization the
1318 realization of what it all you know, what the
1319 cumulative
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total of loss is really all about. Uhm so it’s that range, yeh that range of emotion, well it’s not an emotion range of yeh range of emotion I guess, from uh. I don’t know that I ever despaired, but I know other individuals have despaired you know. Um and it’s the impact of other’s despair or someone else’s struggle or really connecting with someone in a very special way uh that can’t help but, you know, have an impact on me. Um You know, I never depaired, but there were a lot of times when I felt very sad, um really um, really sad or really sad. Other times I felt very angry other times I felt you know energized you know. Um satisfied, um fulfilled, depending on the people depending on how much they let me hes let me into their life, how they’ve shared with me how they’ve relied or taken from me yeh or how much they’ve given to me. So, Uh

Can you tell me a little bit more about that, what you get you say or something...

A MMMmm Uh (long pause). Well (clears throat) I guess I would guess that uh (pause) hm. This is a tough one. I never really I “never” in my wildest dreams ever thought that um I would be this close to death. Uh or have this kind of experience uh or yeh. I guess yo youu I guess what it all come what it all comes down to is what I mentioned earlier, that uh dealing dealing with the kind of issues that we deal with connecting with people the way
that we do, uh (pause) there’s a the common
denominator the common denominator is is the
experience the experience of loss and the
experience of the experience of loss and
experience of preparing yourself for something
that is totally scary -- uh it scares the livin’
crap out of ya. Uh I never thought, well
obviously I never anticipated that I would ever
be in a situation where I would be this involved
with people going through this kind of process
uh. I think, you know, like for me, it’s
stripping in a way all of the other things, uh
you know, all the other factors involved, but it
also, as you strip away all those other factors,
you get down to a common denominator you
also see the people loose a sense of their
identity. Uh, yeh the common denominator is
that that everyone we dealt with uh is going
through a sss an experience that is terrifying,
filled with all kinds of anticipation, um but
they also loose their sense of identity in the
process uh and uh (pause) I guess that has, you
know, that’s that’s had the greatest impact on
me, um to keep, you know, it it’s it’s a
recurring theme time and time and time time
again uh and a a constant struggle to help
people hold on to some piece of their identity
as it’s slowly being peeled off of them. Uh yeh
uh and and trying to draw on some experience
from the past what you what worked with
someone else in order to apply it to a new
experience someone is going through. Uh and
applying learning from the past. Uh you know
what’s interesting is uh I’m dealing with
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1388 someone right now who's very close uh a good
1389 friend of a fella who lives out in Vancouver
1390 and she's here and he's there and there's all
1391 kinds of struggle around that distance. Uh,
1392 what's interesting is that uh is that that process
1393 that he's going through and he may be he may
1394 die in a month and he may die in a year, but he
1395 knows he's going to die he's going he's
1396 preparing himself, he's going through that
1397 process and it's a real struggle for her to try
1398 and figure out how best to be a support to him
1399 "at this distance" uh in that process and it's
1400 just the same kind of thing repeated time and
1401 time and time again that in a very large degree
1402 it's a very lonely experience it's a lonely road
1403 that those people gotta walk and um I mean
1404 that's been that's been itself out time and
1405 time again um and it's real in a sense it's uh
1406 you know in in a sense I guess it's lonely for us
1407 too, because we know we can't walk it with
1408 them, we can 'be there' with them but we
1409 really ain't experiencing the same thing that
1410 they're experiencing. Uh so we struggle
1411 through our stuff to figure out how best to help
1412 them and support them and they struggle
1413 against this tide that is ever so slowly or
1414 "rapidly" moving them along to death. Um I
1415 mean in in I think in that sense uh it's it's
1416 watch it's seeing this realization of people
1417 being stripped away of everything that they are
1418 and just just being reduced to a common
1419 denominator and that is a human being, you
1420 know, flesh uh and a soul inside, you know, uh
1421 and all the um yeh all, you
know, everything that they go through in order to. I guess I believe that before a person dies that they come to this realization that everything else is gone and that they’re they’re essence ‘is’. Maybe they haven’t really lost all of this identity maybe it just becomes part of their essence and that’s what they die with. Uh but it’s watching having to go through that process having to uh go through that struggle of losing it all to be able to realize it all at the end uh so anyway. Uh

So what you get is opportunity to see that common denominator between “all” of us as human beings.

A Yeh yeh. Yeh I think for me it’s uh I mean, you know, I’m a social worker but that’s the skills that I bring or the knowledge whatever, but I gotta be there as a human being. Uh ahhh yeh, it’s just a it’s just a human experience repeated time and time and time and time again. Um yeh and maybe that um those three kind those three experiences that I noted, I guess in a sense just sort of um ah ssss you know, they kind a represent it all, you know. Um On the one level, uh a sense of frustration in not being able to do anything and that other errr a sense of a sense of frustration that this person wouldn’t take the hand that was reac, you know as I reached out or as other people reached out to the other end sense of frustration -that there’s an individual that’s
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1456 being stripped away, you know, to go into that
1457 hospital bed and uh and the realiza-tion that,
1458 you know, mourn the loss and and that he
1459 certainly wanted support, but he was also
1460 rapidly approaching that point where he was
1461 really going down the road alone. (emotion in
1462 his voice) I need to stop a minute whew.
1463 V  Can you tell me more of what it’s like to
1464 kind of uh I mean I’ve certainly been there as
1465 well, kind of they’re there and they’re on their
1466 journey and you can go so far and I think
1467 that’s what you’re saying -- you’re there and
1468 you’re somewhat helpless ta you’re as present
1469 as you can be in the moment, but you know
1470 that there’s a point where they’re gonna have
1471 to walk on alone and what’s it like at that
1472 moment. I mean that sounds like you could
1473 get hooked into some real sadness or
1474 something about
1475
1476 A Um Most uh it’s the separation it’s the
1477 separation. Uh (pause) ohhh probably because
1478 so many of the people that we deal with we
1479 deal with on a very intense level um whether
1480 it’s the person infected or people affected -- we
1481 deal with in a really intense way uh and when
1482 it gets to that point where that individual who
1483 is infected is really on that road alone, in a
1484 sense, uh it’s a uh it’s a yeh I think we
1485 probably experience the same, to some degree
1486 we experience the loss or ah it’s like close to
1487 the ultimate loss, you know, we’ve exper,
1488 we’ve kind of experienced other losses with
1489 them
along the way, but this one, yeh uh it’s like
going into the great unknown uh and the
realization that it’s a physical end uh. So uh I
I quite impactful um but I think it’s the
realization that it’s the realization that in a
sense that’s all there is. “I believe that” this
essence doesn’t just end but I don’t know what
the hell’s beyond you know. Uh I and you
know uh and I guess it’s it’s that thing you
know that old saying where uh you know
where you fear the unknown well I guess for
me anyhow it’s a fear of the unknown it’s a
sense of experiencing the loss uh but it’s also a
ssss it’s a fear of that they are really are goin
it alone or at least as far as we human beings
are concerned, they’re goin it alone and they
and you can’t go with them that uh that you’re
at the end of the road or you’re you’re left
behind and they they go on. It’s that ... I
remember talking with a client about this uh
and it’s hard to express. She was finding it
difficult trying to express it finding an ex-
pression for it and I was as well, but it’s that
just that sense that it’s the ultimate separation
the ultimate separation from a connection with
another human being. Uh which uh it’s a
finality it’s a finality of it you know, uh that
this person you in some many times put your
heart and soul into or at least put a lot of
energy. There was so much energy used uh so
much time and resources and just energy and
and uh really investment uh um and to see a
person go on and know that know that you
know, what’s out there you know uh it’s quite
impactful and in a sense it’s really scary and
uh really really sad you know, sad because uh
uh it’s a it’s a it’s not a way I never believed
that that they’ve been wasted lives that uh um
but that they were shortened, unnecessarily, you
know shortened. Uh but it’s the climat it’s sort
of like reaching a climax and the the come
down after the climax you know, well just
energy draining you know. So, I uh I uh both
physically and emotionally draining or mental-
ly mentally draining. Yeh yep. But a lot a
times at those memorial services or funerals
you know that’s what I goes thro that’s
what I feel is just a drain, you know, um yeh I
feel a real drain uh but for some reason I
seem like able to get pumped up again or get
rejuvenated um re-energized yeh.
V I’m wondering if you can just reflect on
a time when there’s been a lotta deaths at the
same and how you you’ve mentioned three that
were really significant, but sometimes there’s
also not only those deaths that have been
important and people we really touched us in
some way whatever that might be but times
when there’s five, ten, fifteen and can you tell
me about what it felt like then, when you were
trying to support people and you’ve just gone
to a funeral, you know what it’s like trying to
carry all that stuff and any moments that
stands our for you and if you can kind of
describe that.
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A  Mmmm (pause) Nothing really No
nothing really stands out. Um (pause) Even if
I go back quite recently, like last month, uh
nothing stands out except to say that um that
there was you know an adrenalin rush uh
whew I guess what I remember anyhow is that
uh it was like anticipate or or we kind of saw it
coming and once it started we we kind a got to
the point realizing - well here we are in
another wave - uh in a sense it was an
adrenalin rush uh sort of this this build up of
energy or adrenalin, you know, to deal with
you know some pretty significant stuff that was
happening uh or you know, providing support,
critical support to people who needed it at that
point in time yeh and I I think it’s probably
very similar to um it’s very similar to what
happens uh critical it’s called critical incidence
stress where you just kind a get pumped up and
you, you know, you apply lots of energy and
lots of resources to deal with this situation uh
but it’s after that’s over that uh uh that uh
some people fall apart or some people have
really, you know, are deeply emotionally
scarred um.

V  What’s your own experience with that?

A  My own experience would be um
(pause) no my own experience would be the
same thing I think, just the uh uh just just
feeling the adrenalin rush or the yeh adrenalin
rush. Um I’m trying to kind of quickly reflect
back on a number of, you know, over the years
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1591 and uh particularly those points as your are
1592 mentioning that I think we really experienced
1593 when say the four of us were in the support
1594 services. Ah but I don't know that anything in
1595 particular stands out except that, you know, as
1596 we got phone calls or as we saw, you know,
1597 things were approaching, you know, critical
1598 point or terminal stage was approaching it
1599 was sort of just being caught up in the wave of,
1600 you know, the approaching wave -- going
1601 along in the wave with everybody else um.
1602 □ Was there something different about
1603 yourself during those times or that others
1604 Darlene or others would notice about you
1605 that's different than let say other times when
1606 it's more of a day to day experience(He is
1607 speaking over)
1608 A Mmm Yeh right. (pause) Hm (pause)
1609 "NO" um I don't know that there's anything
1610 that folks would necessarily notice. I "do"
1611 recall that uh there were a number of times
1612 when I would just feel really bumed.
1613 (telephone rang) Uh there there certainly there
1614 certainly were times when uh I would when I
1615 would come home and and say, you know,
1616 we're having another wave of deaths, you
1617 know uh, there's been another death today or
1618 whatever. Ah but I don't know that uh I
1619 really can't remember any times when I when I
1620 physically felt different or emotionally felt
1621 different um. No not really. Uh there certainly
1622 were times when individuals died within those
1623 waves uh whom I was particularly close closer
1624 to uh but as a general rule um hm uh well I
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1625 don’t know if it’s numbness Val you know it’s
1626 interesting that book that you showed me
1627 recently “Sometimes My Heart Goes Numb”
1628 I’d really love to read it. Uh for some reason
1629 that yeh uh that struck me, that title struck me.
1630 Uh and I’m not sure if it’s just a a numbness
1631 that I felt a different times. I I mean uh and
1632 that’s very and that could very well be true.
1633 I’ve never been able to identify it. Uh but
1634 maybe it’s very true that you know you just get
1635 numb to it all, you know, uh.
1636
1637 V You had mentioned earlier sometimes
1638 the days are you know you’re really present
1639 and other times that you sort of when we first
1640 started talking about that you just function, I’m
1641 not sure what word you used when reflecting
1642 on those times or what that was really about.
1643
1644 A Ah I think that’s more recently some of
1645 the stuff that I’m feeling. Ah hm
1646
1647 V It’s more about organizational
1648 frustrations
1649
1650 A Yeh yeh organizational frustrations.
1651 (pause) Ah “I” uh you know, I would have I
1652 guess I would have to say that there’s a -- I
1653 hate to say it but I guess there’s a certain
1654 detachment um you know I guess there’s a
1655 certain detachment that uh that I felt,
1656 particularly in those periods when there’s been
1657 multiple deaths “or” deaths and other losses, a
1658 certain degree of
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detachment. Geez it it almost makes me sound
1660 like a doctor ooh god. But uh yeh probably a
1661 certain degree of detachment. Uh that you just
1662 sort of well you start doing you start doing
1663 things out of habit. you know this is these are
1664 the procedure, you know, this is the way you
1665 always do things and so you just keep on doing
1666 the same old, you know, applying the same old
1667 procedures or the same procedure to you know,
1668 another set of circumstances um. So I guess
1669 there’s a certain degree of detachment uh and
1670 particularly if they if they weren’t individuals
1671 that I was really very con-nected with, uh I
1672 think there’s a certain , you know, the
1673 detachment might be a little bit, you know,
1674 more pro-nounced. Uh “most times when I
1675 leave the office” when I leave the network
1676 leave the network I really leave leave the office
1677 and I don’t you know carry stuff home with
1678 me, you know, at least in my head, but there’s
1679 been times when I know riding on a bus is a
1680 good opportunity to unwind, but it’s also a
1681 good opportunity to really reflect and do a lot
1682 of thinking about people and experiences uh
1683 yeh I got to, you know, there are lots of times
1684 when I’m on the bus and I just uh when I feel
1685 when I’m feeling bummed out uh when I’m
1686 feeling kind a overloaded uh I just do a lot of
1687 thinking on the bus. Uh there’s been a lot of
1688 times when uh it has felt fairly overwhelming,
1689 you know, with all this stuff going on. Ah
1690 particularly people who are entering tough
1691 stages of their illness or people who are
1692 terminal stage or
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people who’ve who’ve died. There’s been
times on the bus when I’ve just you know,
whew, you know, I know I don’t want to walk
in the door kind of unloading on, my family.
Um so I uh try to clear my head, but in the
process of clearing my head when I say I’m on
the bus, I’ll uh I just do a lot of reminiscing, a
lot of thinking a lot of, you know, did this go
all right? you know, what could have been
done different? uh you know doing a little bit
of self doubt, uh a lot of self questioning as
well as just remembering, just remembering.
Ah yeh ah I take walks a lot, particularly uh I
liked it better at the 107th avenue office
walking in that neighbourhood over behind us
was a lot I found a lot more pleasant uh I’d go
out at a lot at lunch. Ah Jasper Aves is okay, at
least the park is good, you know, that Grant
Notley Park I think his the name is that’s close
by. So uh I walk a lot, uh partly to get fresh
air and partly just to have some quiet time, just
reflect and just you know remember uh. Yeh
uh because I know that I you know, I I
know that for some folks the struggles gonna
be over and the en the I you know my energy is
going to be needed for you know, the next
person coming through the door. Uh so I just
try to do that self care. I guess sometimes I do
it well and sometimes I don’t do it well, uh but
I try to do that self care stuff so that I’ve got
the energy for the next person coming through
the door. Yeh

V So that means that the reflecting, the
walking, that’s what you mean by self care.

Right yeh uh the dif you know you
asked earlier, about you know, you’ve been
you’ve been at it for eight eight and a half
years like (hee) how do you do it and what’s
what’s significant about your experience over
eight and a half years and uh I don’t know uh
except what’s said already and that is um you
know, I mean I go to church and you know I
use that at least as quiet time to do some
reflecting to get a bit of energized uh I kinda
go back to some basic values in myself um tap
into other individuals that uh who I believe you
know, can be en-ergized by me or I can get
energy from. Um yeh there’s been what’s
interesting is I mean there there’s been times
when I’ve thought about leaving the network
but it’s never been because I’ve been felt
overwhelmed by the losses or the deaths. It’s
always been for other reasons. Uh (pause),
you know, I’ve come to accept the losses and
the deaths um I just accept it. I don’t under-
stand it, I don’t like it uh and I don’t pretend
not to be affected by it, but I accept it. Uh and
uh I think if I I think if I got to the point where
I didn’t accept it anymore (breathes out) it’s
not that I’m resigned to it, but I just accept that
that’s a part of this process. Uh I think if I
ever got to the point where I no longer
accepted the deaths, then I would say I’d have
to get out.

V Yeh Yeh (whispered in background)
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1761 A Uh, yeh. But as long as as long as yeh
1762 as long as I’m able to accept it and help other
1763 people somehow work through whatever
1764 whatever I’ve got I can help them, you know,
1765 if it’s going to help other people work through
1766 what they’re gonna have to go through, then
1767 uh then yeh then I mean maybe uh I guess in
1768 that sense I feel like, you know, I’ve been able
1769 to contribute something. It’s just not that I’m
1770 impacted by all this, but I’m able to somehow
1771 to use it to help somebody else
1772
1773 V Right (whispered in background)
1774
1775 A help someone else out, that I gain a little
1776 bit more insight into, you know, what’s goin
1777 on for me and what this experience is really
1778 can be a uh what the experience is all about uh
1779 to help other people kind of find their way
1780 through it, yeh. Yeh uh the the the neat
1781 well ya the neat thing is that uh there are times
1782 when ah there are times when because of
1783 where that client is at, whether that client is a
1784 friend or lover or a partner or care giver or
1785 person infected, uh when when they
1786 their need is such that you wind up pulling on
1787 all the uh wealth of experience, a wealth of
1788 expertise, a wealth of, you know, a uh
1789 experience, you’re able to just give so much ah
1790 ahhh. I guess what I’m tryin to say is hm. I
1791 think there’s enough opportunities like that to
1792 make it, in a sense, worthwhile. Uh there’s
1793 plenty a times when you just wind up kinda ah
1794 you’re doing some
very minor type of stuff with folks and that’s
all that they want you for uh or they they need
you for, but there’s plenty a other times when
you’re challenged, then you’re challenged to
really dig down deep, you know, and draw on
something that has made sense or worked uh
and you’re able to give that and help someone
else through a process. That, you I guess in a
way, it I I’ve experienced that enough, that it
makes everything else seem worthwhile uh it
just makes everything else seem worthwhile.
Yeh. Uh or uh I don’t know if it’s worthwhile,
but at least it kind a gives makes sense of it all.
At least it makes sense of it all. Uh so the
times when I can go home and feel like yeh
damn, you know, I really I really made a
difference today and uh I made a difference not
not because of my own ability alone, but
because of what uh the accumulative
experience of other people that it’s helped me
to be able to put it all together and make a
difference for somebody else. So uh

You have sort of in your body the stories
of many

Right yeh right yeh sure yeh definitely
uh
So there’s some meaning in bringing
those forward and your offering lots of things
about this other person
(speaks this over top of Val)That’s right
yeh
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A  Yeh uh well I think if we take kind of
1830  if we take something like Living Resource,
1831  which really is a collection of people's
1832  experiences and what it’s meant to do is help
1833  others uh. If we take um all the different
1834  concrete ways in which we remember
1835  individuals and and hope that number one
1836  they they represent the memory of the person
1837  as well as somehow are an aid to help other
1838  people through their struggle and through their
1839  journey. Uh yeh uh uh yeh it’s that way of
1840  continual giving as opposed to just losing and
1841  and, you know, (pause) yeh it’s it’s it’s losing
1842  well it’s it’s it’s really the giving. It’s not
1843  losing just for no good reason, but losing with
1844  at least a purpose anyhow, or at least some
1845  kind of purpose anyhow yeh yeh
1846
1847  V  You mentioned something earlier about
1848  uh accepting death and loss and dying and
1849  there’s some tears at the moment and I also
1850  wonder I guess and you know cause we kind of
1851  we sort of talked about around how you then
1852  accept pain and suffering cause we see lots of
1853  that and I just wonder how you make sense of
1854  that in the world, in the lives of people with
1855  HIV.
1856
1857  A  Yeh (pause) Oh well um (pause) well uh
1858  (pause) I mean I’ve had I uh I’ve had to I’ve
1859  had to make sense of pain and suffering in my
1860  own life uh. (pause) I uh I uh some of the, you
1861  know, what’s striking me right now is um I
1862  can
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1863 remember uh I can remember some very
1864 personal discussions I've had with individuals
1865 uh whether they've been infected or affected
1866 um. Some of them really stand out in my
1867 mind, I mean others are just kind of flashes of
1868 memory, you know, uh but these would be
1869 discussions, these would be discussions where
1870 people really kind of bear their souls, you
1871 know, have really, you know, talked about
1872 their own struggles and their own hopes and
1873 dreams and accomplishments and all that stuff.
1874 I mean where you really see a sense of the
1875 whole person uh with pain and suffering in it,
1876 you know, uh ah those the ones that really
1877 stand out for me uh you know and I guess in a
1878 sense kind of tacked in with some of my own
1879 understanding, you know, of pain and
1880 suffering or what my experience has been. I
1881 mean at least they've been a way of kind of
1882 acknowledging you know some of the stuff I've
1883 been through uh, but they've also been
1884 opportunities to I don't know um kind of really
1885 honour the whole individual you know and and
1886 give me the better sense of how that person just
1887 how they see themselves in the scheme of
1888 things I guess and how they view they really
1889 view their life and uh it doesn't make it
1890 doesn't mean that the pain or the suffering is
1891 going to be any easier, but at least I know as
1892 they go through that pain and suffering I can
1893 see that that's a whole living human being
1894 there, you know, that um has either dealt
1895 successfully dealt with pain at this time and
1896 not at this time you know and it
1897 has some ups, you know, .... A lot of times you
1898 don't get that kind of insight into the lives, or,
1899 you know, don't get that kind of insight into a
1900 lot of people that we work with. Uh these
1901 would be times when the the it was just a really
1902 neat opportunity to talk with these folks on a
1903 very human level, not as client and counsellor,
1904 you know, but just a man to man or a man to
1905 woman or woman to woman, you know, uh.
1906 Again it's getting down to a real essence uh
1907 and taking away all pretenses, you know, we're
1908 talking on a very human level ah and getting
1909 to really share some deep stuff. Uh I haven't
1910 had a lot of those, but I've had enough that
1911 have that have really touched me and really
1912 have helped me kind of uh come to ah ah come
1913 to terms to some degree with pain and
1914 suffering in my own life you know. I ya it
1915 might sound corny, but hmmm "I think that"
1916 uh that uh some of the experiences I've had
1917 from working at the Network have certainly
1918 helped me deal with some experiences in my
1919 own life. Uh at least I felt a bit more strength,
1920 you know, uh in dealing with you know my
1921 own personal experiences. Umm and at the
1922 very least maybe it did make some sense out of
1923 it all or anyhow, make some sense out pain and
1924 suffering uh times when I felt like a) it's all
1925 unfair and it doesn't make any sense etc. etc.
1926 and people with HIV quite eloquently put me
1927 in my place and ananand it's not to say they've
1928 chastised me for making, you know, for for for
1929 making judgments about their experience, but
1930 in in in a sense they've basically

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have um humbled me I guess uh and showed
me that there's more to them, you know, that
is capable of. I mean they've come this far in
their life and so there's a lot there that's
capable of taking them through the rest of the
journey. Uh it's interesting coming back to
that whole sense of really connecting with
people on a very human level uh and
struggling with them uh. Yeh yeh.

V I'm wondering um you kind of move
into a little bit just to talk about the
organization and sort of your sense of how
others how you perceive others cope there or
um, you know, wherever there are certain
views about grief and that context.

A I never felt that folks at the Network
really coped with it Val. I never felt that
people at the Network really really dealt with
it. Uh um I think we always talked around it
uh I don't know that we really ever addressed
it really head on and I don't know that people
were really honest with their own emotions or
their own feelings um. I always felt that we in
support services were honest enough with each
other uh to to to really address the issue or
address, you know, what we're feeling. Um
but not 11 I don't wanna generalize it but I
think there's there's always been other folks,
other staff paid staff or volunteers who really
who really haven't addressed, you know,
haven't come to any kind of resolution around
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1965 around what they what they are feeling. Uh
1966 maybe maybe the opportunity just the right
1967 opportunity was never presented or maybe and
1968 certainly there are a lot of times when they did
1969 not take opportunities. And that as as recent
1970 as this past week, opportunities that were not
1971 taken. Um I don’t know why that is, uh I
1972 think that for uh , I I I you know, I I think
1973 that for some people it’s a job and it’s a place
1974 they go where they get a pay cheque uh but
1975 they don’t allow themselves to feel. Uh yeh or
1976 they don’t really they don’t realize the impact.
1977 I mean they see names on a whiteboard or stars
1978 on a memorial panel, but I’m not sure that
1979 they’re really I’m not sure they’re there on a
1980 very deep human level I think they’re there
1981 just to fill a job.
1982
1983 V Right
1984
1985 A An I’m not sure it’s ever gonna change.
1986 Um I don’t think it’ll ever change.
1987
1988 V Do you think there’s ways in which
1989 some people are have permission to
1990 grieve?(end of tape)I was just asking whether
1991 you felt that you felt that there were some
1992 people who had the right to grieve and others
1993 who didn’t have the right to grieve or if there’s
1994 really differences you see kind of around that?
1995
1996 A Hm. Ah hm I think I think that I think
1997 people have always had the right to grieve. I
1998
think the "way" the people express their frustration or their anger or their grief is inappropriate. That may be judgmental but I just think that I don't think that I don't think people use the opportunities that are available to them uh. So I think it comes out in very inappropriate ways. I think that their their sense of futility or their anger or their grief comes out in inappropriate ways.

V About how they carry out their work you mean?

A Yeh about how they carry out their work or how they respond to situations that come up. Um hhhaaaahhhhh obviously there have been, you know, sometimes we've done it well and sometimes we haven't done it well in creating an environment where people can feel comfortable in expressing whatever they need to express. Um but um I think the times when we have done it well uh that we still get people responding in just inappropriate ways. I and what I mean by that is uh that uh they react to situations as if it was the first time that it ever happened that it's the first time that they they in a sense over react there's an over reaction to a crisis or a major loss or a death um that uh it so upsets a sense of stability and a sense of of groundedness uh but what that says to me is that these are folks who don't know how to 'in the context of the AIDS Network' deal with their emotions yh and so everything is fairly
exaggerated uh at uh you know within uh
quote unquote crisis, you know, at at critical
times and there’s an exaggerated response. It
doesn’t deny their emotions, but but it it uh ,
you know, their emotion comes out in an
exaggerated way and so I don’t think there’s
an effective healing there. It’s just like a
volcano that blows and then it simmers, you
know? Uh and uh and I I don’t know what I
mean I’m not sure what can be done about
that. Uh I don’t know what can be done about
that. But I do I do I think it’s very obvious
that uh I think it’s very obvious that’s for a lot
of folks who have come through the Network
that for many of them it is like a volcano that
“blows” and then without any kind of healing,
without any kind of processing, it’s just a
“blow” and then simmer blow and then
simmer, you know,

Okay (in background)
very episodic
right
Uh, but the the kind of opportunities
that are available aren’t used, you know?
Things like funerals, things like memorial
services, uh things like taking the opportunity
to talk with a, you know, a counsellor, “not
even within the Network” but outside, you
know, not a lot of self care. Um that’s I mean
that’s that’s a problem that I see uh
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V Have you ever felt for yourself there was a time where resources weren’t available for you in the ways you like them or around the
grief stuff.

A Uuuuumm no. Uh no. I think that I’ve always felt hmmm I think I’ve alw ‘number one’ I always felt a responsibility to myself to deal with the stuff to deal with it ever , you know, what whatever was going on for me. Uh that I couldn’t (ha ha) “a) I couldn’t uh

function with my peers” and I couldn’t deal

with clients if I didn’t deal with my own stuff

so I uh I always so I made it a point of , you

know, of addressing it. Uh UUUUuhhhhh I think that uh um hm I never really relied a lot on internal resources um I never had an

expectation that I needed internal resources.

Uh and what’s interesting is years ago when I first started uh we had certainly uh , you know,
generally do find my support now outside the
organization. Uh there are times, I mean to
be really honest with you uhh when heh I don’t
really do a lot of nostalgia type of stuff, but to
be honest with you, I think the “best” time was
when the four of us were together in support
services, because I think that we were really
well just a really good functioning unit. Um
when we knew how we could bounce off each
other, I mean, we we uh we worked I think we
worked well together. Uh and for me it was a
good source of support uh and uh since then I
think that I’ve just looked outside the
organization cause I never felt I guess to
some degree I always felt like nothing was ever
going to reach that kind of uh level of
expectation or level of

V of what we had been
A of performance that we had then yeh.
V So those external resources would be the
conversations you mentioned with those
volunteer facilitators.

Yeah, sure conversations that I have
with volunteers. I mean there are and there
are times when I pick up the phone just to call
just for the sake of you
know, shoot the breeze, you know, uh or or,
you know, there’s not a lot of folks but there’s
some folks I know that if I need I can pick up
the phone and just, you know, do some talking.

Uh

V I sense as I hear you saying here that
these are people who were part of the collective
who just know
N , maybe P, , B, maybe. Would
that be kind of that core group of people that
were around for a long long time?--
A Yeh right Yep. Or some of our very
skilled volun-teers yeh. Uh and to some
degree some folks with HIV. Uh yeh. So, you
know, organizationally, I don't know, uh I
suppose that there are other organizations that
do it better, certainly better. I suppose there
probably are other organizations who do it not
as good as even we do. Are we somewhere in
the middle? I guess we are. Uh but um
(pause) I think the difficulty, at lease from an
organizational level, is um everyone who
works there, I mean there's such a range
of job responsibilities uh and I think that
there's a range of there there's a range of
motivation that people have for working there.
There part I'm sure there's a common
denominator and that is, you know, wanting to
somehow make a contribu-tion. But I think
there's definitely is a range of motiva-tion and
therefore, a range of what people expect, both
to contribute as well as to get back uh, you
know, a ah range of skills in just dealing with
personal issues and personal emotions uh and
there's always been folks who really didn't
want to open up. Uh uh
and maybe at this point in time we just have a greater collection of folks who really I think are there for not the right reasons. Uh but I think it’s difficult for uhhh I I think it’s difficult with the organization. Uh particularly as we become more and more receive, you know, on some level, more and more just like any other organization out there like the MS Society or the Cancer Society or the this society or that society. I think to some degree, we are becoming, you know, very much like the other help focused organizations out there. Um so that maybe that takes away some of the uniqueness uh, you know, becoming more of a habitual kind of process you just do day in and day out and you don’t really attend to self care stuff because this is where you work and this is where you live, you know and you know. “This” doesn’t have any impact on that, you know. I’m trying to make sense out of something that doesn’t really seem to make a heck of a lot of sense right now.

V Yeh. In an ideal world around if you imagine the network in a place that that was putting self care in place, what what do you think would what would be there? What what qualities that are obviously causing you frustration what would be different about how that would be structured? , you know, leaving just your whole imagination open.

A Uh people in the organization would take
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2203 more ownership for uhhh how would I put it?
2204 There would be a greater sense of connection
2205 with people who were infected and affected.
2206 you know, I gotta I gotta reflect back on where
2207 we were six, seven, eight years ago and uh the
2208 people who answered phones the secretaries
2209 also had a connection with the people who
2210 came into the office. Uh people who wrote the
2211 cheques had a connection with people who
2212 came in the office, you know? Um and uh
2213 different kinds of events, I mean people felt a
2214 part of the whole. Uh mmmm at least there
2215 was a sense of there was a collectiveness
2216 collective experience when someone was when
2217 some major losses were occurring or someone
2218 was ill. I mean, god at one point in time, we
2219 had staff meetings and we talked about clients
2220 at staff meetings, you know, we talked about
2221 what was an experience for this person, I mean
2222 they were individuals named indivi-duals, they
2223 just weren’t a number on a now we’re dealing
2224 with, you know, 120 people a month. I mean
2225 at that point in time we were dealing with
2226 David and we were dealing with Alan and you
2227 know and we talked names uh you know, so
2228 there was a sense of solidarity I mean there
2229 was a sense of shared we were sharing our
2230 experience, you know. ‘Well I had a job to do
2231 and the secretary had a job to do and this
2232 person in education had a job to do’ There
2233 was still a sense of, you know, connectedness
2234 to the people who were infected and affected.
2235 Um
2236
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2237  V Why do you think that change has come
2238  about? Numbers?
2239
2240  A  I uh Well to some degree numbers.
2241  Uh to some
degree ummm I just I go back and I hate to use
2243  I hate to say it but it’s professionalization of
2244  HIV, you know, we’ve moved into a big office.
2245  Um we all have uh, you know, we now have
2246  professional fund we have pro-fessional
2247  fundraisers we have professional educators,
2248  you know, we got professional social workers,
2249  you know, uh and and uh , you know, we
2250  pigeon hole we’ve become much more
2251  segmented, compartmentalized uh. We get we
2252  bring in special people to organize the walk,
2253  we bring in special people with special skills to
2254  sit on the Board, you know. So there’s less of
2255  th there’s less of a sense of there’s less of a
2256  sense of the experience of the people who are
2257  infected and affected because you’re there for a
2258  very specific job uh and and, you know, there’s
2259  not a sense of the experience of people infected
2260  and affected, you know. That’s my take on it.
2261  Um, you know, for for good or for bad I guess
2262  we have what we’re, you know, we’re havin to
2263  deal with less public funding and more
2264  reliance on you know fundraising so we gotta
2265  get a Board who is really focused on
2266  fundraising, but a Board that has not a dog not
2267  a sense of what the hell’s goin on in the lives
2268  of people. Uh it’s interesting uh in early
2269  November, uh Kathy and I did a the Board had
2270  it’s first full meeting. Uh
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or it was like a Board development day and I
think everybody was there. A lot of new
people on the Board and uh I spent, we spent
like a good hunck of the day just in bringing
them up to date on what's goin on in support
services and what some of the issues are. We
had a panel of people who came in. For a lot
of those people it was the first they really even
knew what was the experience of people with
HIV. Um and then Kathy did her bit on
education. You know? So I guess as we need
to as we need to maintain a certain level of
income in order to function, we gotta give up
something and that is a sense of connectedness
with people who are who we're here for in the
first place. And and more of a focus on this is
your job, this is your job, this is your job and
those folks deal with their maybe they don't
feel grief at all, maybe they feel grief to some
degree, but, you know, they keep everything at
an arm's distance at an arm's length, you
know. And and there-fore, they can go home
at night and they're not bothered by it or
they're not touched by it. Um Yeh So uh
that's it that's my take on it.

V Yeh okay. I'm interested in how maybe
your family your friends, also the community
just in general would view your work, your
connection with HIV positive people. What do
you think is the sense that you perceive people
perceive you and also the work you might do
and both in your in your family circle and your
friendship circle, but also, you know, just in
general?
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A well in my fam in my (breathe) in my
own family, which is all down in the States
uhhh a couple of bro a couple of my brothers
talkin on some regularity, uh you know,
are interested, you know, uh we haven't had
an opportunity to really talk in great detail
about some of the stresses and experiences, but
you know the funny you know I feel very very
free and comfortable in talking about what I do
with them. Uh and there's a couple of other
family members who I have more of a sort of
cursory more of a a very shallow very shallow
relationship, simply because that's just the way
it is. So we we don't really talk about my
work or my this whole experience with them
because that's just not where I'm at with them.
With my wife's family it's kind of interesting I
have one ah I guess my sister-in-law's husband
who ah I go out with every once in a while uh
maybe because I'm a masacist, I don't know,
but ah he's a bit of a hard head uh but he
doesn't take offence when I come right back at
him with, you know, he's he's homo-phobic
and thinks that uh people who have HIV, you
know, uh deserve it and all that kind of stuff.
Uh but I come right back at him and we'll sit
over a couple of beers and just kind of a big
argument, you know, walk away friends, but
and it's kinda neat because I pull no punches I
tell him you know I talk about different you
know different experiences. On one level he is
very sensitive around what uh you know what
some of these personal struggles, I mean, you
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2339 know some of the emotional impact, uh but on
2340 another level he certainly has own opinion
2341 about you know homosexuality or about drug
2342 use or, or you know, I mean he’s opinionated
2343 about every-thing under the sun, anyhow. So
2344 uh we fight we argue uh and we walk away you
2345 know (ha) feeling a bit energized by our
2346 argument uh and and I I uh for some strange
2347 reason (laughs) every once and a while I pick
2348 up the phone and I say. Hey you wanna go out
2349 for a beer? Oh yeah and we know that we’re
2350 gonna get into hot and heavy about you know
2351 about what I do, but uh for some reason it just
2352 feels like I just need to do it. Um and maybe
2353 because he doesn’t take offence when I come
2354 right back at him you know. Uh and there are
2355 others in the family who nyah well I think
2356 most of here family probably uh hm they don’t
2357 really take a lot of interest in it. Uh they never
2358 really have uh. So I don’t really talk with
2359 anyone on her in Darlene’s family about some
2360 of the stuff I go through this is the only guy I
2361 really get into some heavy’s with, you know,
2362 and he’s god you know, he’s I mean he goes to
2363 his Ukranian Catholic church or something
2364 and you know I mean he’s ah into the neo-
2365 conservatism like you wouldn’t believe, but
2366 (laughs) we slug it out you know verbally and
2367 uh there’s no one else really that I can really
2368 uh. There have been a few times when um it
2369 looked like there was an opportunity to do that
2370 but ah not really not really. I uh, you know, I
2371 get my uh I get my uh the outlets I have, I get
2372 the strength I need etc.
pretty much through colleagues or through
work related.

V How does the Darlene and the kids kind
of perceive your just how

A Oh

V how do they make sense of you be
working there or how do they perceive

A Oh well actually we’re very open with
the kids and we talk very openly about death
about sickness about lifestyle, everything under
the sun. So the kids are very comfortable with
it you know and are at times are very interested
uh, of course, what peaks their interest more is
you know when I ride on the needle exchange
van. I mean we’re very open about, you
know, what I do on that van. Very open about
uh uh uh homosexuality and they’ve been to I
think they’ve been to one wedding with us
homosexual, you know, one lesbian wedding.
Um you know so for them it’s no big deal you
know and I don’t know what they say at school
(Ha Ha) because I don’t worry about that. And
Dar and Darlene is very comfort-able with it
all so. Uh but Darlene spent a year down in
the States and that’s where we met and this
was in New Jersey um in a really rough area of
of New Jersey um and, you know, we both
worked in a family shelter and, you know, so
she’s kinda seen it all. It’s interesting I mean
she grew up in (this city) with very, in a sense,
sheltered in that sense from some of the
realities and no one in her family probably
even set foot in the real hard core (this city),
 uh let alone going to, you know, the East-ern
United States, you know, hard core uh Newark,
New Jersey and uh some of that area so I think
she came back with certainly a different sense
of what life is all about which is interesting
because a lot of her family have been out of
(this city), but they really don't know what
goes on, you know, in in in , you know, they
just don't have that's not where they're at and
don't have a sense of what that life what
what life is like for a lot of folks here in the
city. Um so they really wouldn't they wouldn't
understand what I'm talking about, I mean it
just be outta their world. Uh I talked lots with
Darlene, particularly recently about some of
my feelings and frustrations and she some you
know she has some insights some ah pretty
practical pretty or pretty inss, you know,
sightful comments back uh but uh so even
within my family it's very comfortable.

V Okay. What do you think , you know,
I'm sure we chatted a bit before about Alberta,
how do you think the general Albertan or both
in relation to your work and also an HIV
positive person is perceived and in the
Network, you know, you've been around here,
or in this kind of HIV community for a while
so there you have a sense and you've been in
the same place and the same province, but
what's
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2441 your sense of what the average person still
2442 would perceive -- you and work and HIV and
2443 the Network?
2444 A   Interesting Val. I think it’s quite
2445 varied, you know, um a couple of people I a
2446 couple of people I’ve gotten to meet through
2447 church, uh one one individual in particu-lar,
2448 thinks that uh anyone who contracts an illness
2449 due to their behaviour should therefore be
2450 totally responsible for the medical expen
2451 medical expenses to deal with that illness
2452 whether it’s cancer or whether it’s HIV or
2453 what-ever it is. Ah so he this person’s attitude
2454 is “Hey you’ve made your bed you sleep in it
2455 it’s your problem don’t bother me” Uh there
2456 are other people I know who uh uh other
2457 people I know I know who who know what
2458 illness is about what illness is about, who know
2459 what struggle and pain is about uh ministers,
2460 priests who uh I’ve heard talk very freely and
2461 openly about uh uh uh acceptance and
2462 inclusion and uh, you know, ah responsiveness
2463 to people, you know, that from the altar, you
2464 know, at church. Ah so and and in a sense it
2465 gives me some hope that there is some hope
2466 left for organized religion. But uh I think, you
2467 know, I think it really depends on whether a
2468 person has any connection to others who are in
2469 pain, others who are struggling. Uh I’ve met a
2470 heck of a lotta people in the business
2471 community who ah pretty much think that the
2472 world revolves around them and that who
2473 never have really had to deal with a lot of
2474 suffering
loss or pain. Who’ve never had to deal with any kind of social issue or health issue that has taken them to an organization like ours, therefore, as far as they’re concerned, well they don’t like the fact that we get money but you know, they don’t really, they don’t really care one way or the other. It doesn’t affect them, it doesn’t impact them. They don’t know, they never have they’re never gonna have to deal with the Cancer Society or the MS Society or the HIV Society or any other kind of Society because their life is perfect. Uh and so I think there’s a heck of a lot of those folks around. Uh I think there’s a lotta folks who uh probably have a sensitivity, if if not to uh if if not to the population that we deal with, at least to the issue because they’re in the same space where they’re where they’re having to, you know, maybe they’re getting uh they’re entering they’re uh they’re elderly and having to access uh health care or having to access some kind of organization that is there to ser, just to you know, to serve around a particular health issue and so they have a particular sensitivity at least to what pain and suffering and loss is all about and therefore, uh have a degree of tolerance for HIV because they’re in the same spot as having to go somewhere for support. I just think it’s very mixed, I think it’s a real mixed bag. I think there’s a lot of professionals out there professionals profession-als in the human service field, who uh still think that uh street works (needle works) is now called street
works) is uh a supporting drug use and encouraging drug use. A lot of social workers or other human service profession-als who uh uh don’t like homosexuality, who uh have very traditional views of family uh who will deal with someone around HIV only because it’s a professional res-ponsibility, but will not address their own discomfort, their own anxiety, their own, will not feel challenged at all. Ah hm I think I uh I think there’s probably just a lot of folks who as long as it’s interesting, as long as it doesn’t touch them, they could care less, but what’s also interesting is we’re hearing from more and more of these folks who are now talking about a client that they have or a friend that they have or the son of a neighbour who is now HIV positive and uh starting to feel impacted by it. Um so the old the traditional attid feeling that we had that everyone at some point in time is gonna know somebody uh that more people will be affected I think is really coming true and it’s starting to show up in every nook and crann nook and cranny of this province. But I think there’s a lot of folks who really will deny it. And uh if they knew how much money goes into HIV and AIDS in this province, probably would scream and shout uh and luck-ily that most of the idiot back benchers in this province ya know (ha)don’t know or don’t know enough to ask and therefore we’re better off because because of their ignorance. I, you know, I there have been times when I’ve just been felt very heartened by uh a response of
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some eighty year old old codger who I thought
was like, you know, don't talk to him because
he'll probably you know preach the Bible to
me, but had been extremely responsive and
sensitive uh and some twenty year olds who I
thought were, you know, uh were were just
just left just right of Hitler you know. It
doesn't make any sense in the world to me uh I
think it's a really mixed bag, just a really
mixed bag. Uh and I think it always, I just
think it always will be. Um but there seems to
be aaaa ahh I mean there seems to be more
people who are at least one of or it strikes
home with them or more res-ponsive. What's
interesting is I always had this thing about how
fathers were so distant and so un-present and
mothers, the nurturers, the mother women
mothers were really front and centre and
fathers were always just nowhere to be seen.
Uh and generally I think that's been pretty
much played out with some exceptions and
recently had an experience with a couple
whose son died in BC um. And, obviously ya
know same old thing, the mother it was the
mother who was my primary contact and she
was the one, her husband always passed the
phone over to her when I called, you know,
the whole nine yards. But, when the son died
the husband said make sure you call Dave at
the AIDS Network. Ah so it's that kind of
stuff that helps me realize, that yeh you know,
although maybe on the surface they maintain
this facade, you know, that down deep
something's you know somehow there,
something’s clicked so. Ah and for all of those
fathers who and I think generally women who
are most supportive uh and and men who feel
extremely threatened uh but I think a lot of
them on the surface probably are very
uncomfortable but deep down inside struggle
with the fact that they can’t talk about their
son who was gay and homosexual or the family
member who’s an IV drug user and now HIV
positive or someone who’s just HIV positive
period without even talking about lifestyle.
Can’t talk about it with their friends, you
know, and struggle internally so much, uh but
who um I think um secretly anyhow, support
everything that we’re about and everything
that we do. Ah yeh.

How, I’m just wondering how being part
of the Network for eight and a half years has
changed your life here in dealing with AIDS
grief, in particular how that’s how that’s
changed your life in some ways or been
something. When you think back about when
you first started and where you’re at now, you
know, is there something that’s happened in
those eight and a half years in all the losses
that you’ve dealt with that have somehow
changed you or affected you or

Umm Uum wow! Uh “I walk proud”.
Not that I didn’t eight and a half years ago - uh
but I guess eight and a half years ago I was out
I was just a different I mean I was a different
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person and I've grown over eight and a half
years. I just walk proud, I still walk proud um.
Uh um I guess I still feel fire, you know, feel a
bit of the fire, I still got the fire in my belly. I
still feel the fire in my soul. Yeh, you know, I
wouldn't say I've changed as much as I've
grown. I've grown in my understanding of
myself and my understanding of uh my
understanding of other people. My my uh
"god", my admiration for uh for what people
can what people can tolerate for what
people can go through uh. It's just been more
of a growth than a change. But I think more
than anything it's uh (pause) yeh I think more
than anything uh it's that I uh (pause), you
know that I uh hh I just walk proud, you
know, I just feel proud to work where I work,
be connected with whom I I'm connected with.
Uh and and I never felt um I never felt like I
have to hide what I do uh but maybe now more
than ever I feel like uh I don't care who knows
and and I will use opportunities to educate
people. Uh and probably it's it's the collection
of experiences it's this this certainly uh it's
the accumulation of deaths and losses, but it's
also the culmination of the experience of these
people's lives and my connection with it that
has helped me uh, you know, helped me feel a)
that's it's still worth the fight, b) that I'm still
connecting with people as a human being and
as a social worker second um that I still need
to be doing it, you know, I mean uh and that
uh I don't, you know, I no longer anticipate
what
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2645 someone else is gonna think. I don’t care
2646 anymore, you know? I don’t care anymore.
2647 Uh and I’ll still fight with my sister-in-law’s
2648 husband and he knows I will and we’ll still
2649 argue our heads off and he ain’t gonna change
2650 and I ain’t gonna change. Uh yeh
2651
2652 V I want to uh just go back, ahh there’s
2653 something you’d said about the rituals around
2654 the Network and the memorial panels and the
2655 book and uh there’s the Christmas tree
2656 ornament and there’s a whole bunch of them
2657 and I don’t really know the history of how they
2658 started. Can you tell me a bit about how that
2659 all how those once, you know, there’s quite a
2660 few got started. What, cause they’ve been
2661 around for a long long time.
2662
2663 A Actually the first memorial panel was
2664 started by a group of volunteers. Uh and as
2665 much as I can recall, uh George who worked in
2666 support services. I think that eh that it was
2667 close to the time that the quilt was started in
2668 Canada, but that we realized that there were
2669 folks who would never have a panel in their
2670 name added to the national quilt. Uh so and
2671 uh or maybe the quilt hadn’t started yet in
2672 Canada yet, it certainly had started down in the
2673 States. Anyhow it was a group of folks and
2674 volunteers uh and George who said, you know,
2675 that we need to, in some way, remember, and
2676 in a very visible way, the people who are dying
2677 here. Uh so uh they got about half a dozen
2678 people got
together, figured out exactly what would work
or what they wanted and took off with it. Uh
the memorial services were um also just kind
of a response of the original volunteers
coordinator - Bridgette - well you were were at
the Network No okay. Bridgette, when she
was volunteer coordinator, and I had talked
about uh a way for uh for folks to come
together in a more comfort-able kind of
environment than church or a funeral home.
So we just got we just started with the
memorial ser-vices and in fact, more folks
were coming to the mem the memorial services
uh than going uh to some funerals or or at
churches or funeral homes. Uh but it was
around that time when there was still a sense
of kind of isolation about the issue uh and uh
the Network needed to do some-thing that
provided kind of a vehicle for folks in the
community to come together, as well as for us
in the Network to come together.

V Yeh is that because the family services
were really still not naming things.
A Yeh family services really whitewash
right. Uh so it really was that whole sense of
this community of people coming together uh
to uh make a panel or create a panel to, you
know, together, you know, uh remember the
individuals who have died. I mean it it's kind
of taking care of ourselves, that kind of ethic of
taking care of ourselves and providing and
acting as a vehicle for others in the broader
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2713 community to come together. Uh the book
2714 with the names was the same thing, you
2715 know, and that started around the time that the
2716 memorial services did. Uh uh, in fact, I think
2717 Bridgette bought the book. She was out one
2718 day and she picked up the book and we just
2719 kind of put in the names in it. Um so uh
2720
2721 V When did, around when did all that
2722 start this
2723
2724 A Uh when we were at the new office,
2725 which would have been '88, '89. Yeh. Sure
2726 those last couple years of the '80's right. Uh
2727 hm and uh even at that point in time we were
2728 already starting to starting to deal with a
2729 number of deaths, so uh and there was already
2730 the need for that memorial panel. That may
2731 have been, I thought it was like '89 or '90 that
2732 that panel was started up. The book and
2733 memorial services were already, you know, a
2734 part of our ritual. Um probably late '88, early
2735 '89. Yeh uh the uh candle. Wow! I don't
2736 remember when we started that. I mean that's
2737 been a fixture for a long time. Lighting the
2738 candle probably goes, that goes way back, you
2739 know, lighting the candle goes way back. Yeh.
2740 I just don't don't remember. Uh (pause)
2741
2742 V , you know, uh I was the one who kind
2743 of got this other um stained glass lamp up
2744 there. Do you think that's affected people's
2745 notion or any way around whether it's a candle
2746 or a lamp?
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2747 It just I'd wondered about that. How much
2748 was that changed or just transformed into other
2749 ways to... Have you perceived that differently
2750 or are there any....
2751
2752 A What is interesting is. We have the
2753 lamp lit and then we also have a candle and we
2754 can't we can't get away from the candle.
2755 People seem to need the candle. But we like
2756 the, you know, the lamp gets lit. They also
2757 need the candle. Uh I uh and I don't know
2758 that we'll I guess we'll never really phase out
2759 the candle. The candle, I guess, has its
2760 significance. Uh (pause) but I I uh I think
2761 that, well I don't know, it seems powerful, you
2762 know? That it's like double light, you know?
2763 I mean the candle the candle alone says
2764 something and the candle and the lamp say
2765 something together. You just you look over in
2766 that corner and what you see is brightness, you
2767 know, you see a statement. Uh so I think in
2768 that sense it's great you know? You can't walk
2769 by. You cannot...... But, you know, it kind of
2770 reflects back on where everybody is at you
2771 know. I don't know Val, you know I mean
2772 here we are corner that is dedicated, you know,
2773 and in a sense to people who have died and
2774 we've put names on the whiteboard. We have
2775 those memorial panels hanging up, but what is
2776 it doing for people I don't know. You know?
2777 Uh exe except with significant death like
2778 Sherry's uh um, but even then, there weren't
2779 that many people who said anything.
2780
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2781 V Mmm hm and we had that gathering
2782
2783 A Yeh right. There weren’t that many
2784 people that said anything. Uh so I don’t know,
2785 yeh it’s kind of a it’s an enigma, you know?
2786 Uh
2787
2788 V But there’s other ways that I was just
2789 thinking, you know, organizationally there’s
2790 sort of been impromptu gatherings. I
2791 remember when Dana died we did that group,
2792 you know, deal and stuff. We did that
2793 impromptu gathering. Are there other ones
2794 that I’m missing that? Ways we kind of, I
2795 mean, it would be sort of some preparation or
2796 discussion at staff meeting but that was kind of
2797 that ‘a mentioning’. I’m just wondering if
2798 there’s other things that you’re thinking of at
2799 all that and the names on the whiteboard....
2800
2801 A Right, No the um the candle light walk
2802 of course, I think is very significant. Uh
2803 though it wasn’t our invention, but um it’s
2804 been significant every year since uh, shoot,
2805 since probably ‘89. Uh the uh the prayer vigil
2806 uh which I’ve attended I think maybe once uh
2807 is again not our creation, but has been going
2808 on continuously for five years anyhow maybe
2809 more. Uh
2810
2811 V You see those as a memorial in some
2812 ways?
2813 A Yeh yeh. I particularly, I mean I
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particularly like the candle light walk.
Because I think that huuhh I don’t know I just find it a very healing event um You know I just find it a very healing event uh. So and uh I think it’s been quite a I mean I I I think for a lot of folks it’s been quite effective over the years uh as a as a healing kind of process.
(Will you stop a minute? took a break in the recording as his family returned)
V I’m wondering whether um another I was just thinking there’ve been other kind of things that we’ve done, we’ve had, I got that um bereavement workshop started. What’s your sense of whether they’ve been useful for people or, you know, I understood there was one gonna happen but then it got delayed or.... What’s your sense of that as a source of support for the staff and the organization?
A Uhhh I’m not, well I’m just not sure about I’m not sure about the staff and the organization Val. Uh what’s interesting is um the broader community and particularly those folks who are you know really intimately connected with those care those care givers professionals from other organizations uh have uh I mean, we’ve, you know, there’s been a number of, not a number, but there’s been a few uh uh things that we’ve done over the years to kind of uh provide an opportunity for service providers to, you know, to come together. And I see the bereavement workshop as an
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extension, it's just another vehicle, as an
extension of sort of what we've been trying to
do over the course of eight years anyhow. Um
but for the folks in the organization ehhh I
don't know, uh things have just been very
different and I I think that change probably
happened sometime when we were at seventh
avenue uh where they became, people became
more disconnected and probably felt less of a
less of a need, I mean, the fact that we had no
one from the Network registered for this last
bereavement workshop says something and it
was announced and we I talked about it with a
few people, you know? Announced it a
number of times, we had "notices" up, you
know, we even made up little invitations and I
gave them to some people. But nobody nobody
and I think this says a lot about where people
are at, you know, or how disconnected people I
like think feel. Um and at some point in time
when we were at seventh avenue ss or maybe it
was when we moved here, I don't know, but at
some point in time this transition occurred.
Uh so on an organizational level 'it's lost'. I
remember when we were at seventh avenue
and this was possibly before you came on
board, but uh, Larry Jewel uh used to meet
with us uh once a week and we kind of uh we
just kind of had a it was a free for all, kind of
an opportunity to talk about different stuff that
was happening. Particularly around support
and around treatments and that kind of thing.
We really didn't talk much on the uh on a
personal
on a the self care level. I mean we talked a lot about Larry kind of clarifying some stuff that was happening and at that point in time things were really new and and in some ways there was, it it was a period of fast change uh and it was a neat opportunity to just to come together just to kind of talk about well this is what we’re hearing, this is what we’re experiencing, so whatta ya, you know, what does, you know, what’s the scoop on this? You know? But what it did, you know, everybody came together. Uh from Ann at the front desk to right on down. Everybody came together. Uh so we were all kind of in it together, you know? Uh it was ah ah, at some point in time we stopped that practice. People started becoming too busy and didn’t have the time to take out an hour or two to sit down. Ahh so we just itttssss fizzled out. It came down to support services and that was it and some people with HIV and then it just fizzled out all together. But we turned this corner where it became less of a collective experience and now became very compartmentalized and it was a slow process to where we are now. Uh at this point in time, if we had an afternoon, if we had an hour, hour and a half session, we wouldn’t get everybody there to talk about some new development we wouldn’t get everybody there, it just wouldn’t happen and we could well we have, you know, we’ve provided two days for people and they’re not there. So. Uh yeh I don’t know.
I'm gonna just raise go back to something that you had said and we were talking kind of about the multiple loss and that cumulative effect and nothing stood out in your mind, but I was just thinking of my memory when I was it just recently started and Dana, Guy and and, you know, I'm trying to think of there was about five of them over a very short period and I remember the sense of, you know, not really understanding what was taking place, cause I was still new, but remembering that sense of catastrophe, catastrophic kind of ‘the place was just kind of reeling’ and I just, you know, you said that there was nothing that stood out in your mind. I just have a memory of my observation of that time and just wondering what you remember of that in your own experience around that.

I remember some of the deaths were very tragic. At least one or two of them because one was a drowning and one was a suicide I think. Uh it happened I think over the course of like a summer, if I remember correctly, if it’s the same, I think it’s the same experience, experiential period. Uh but they just came boom boom boom boom boom and partly because some of them a couple of them were unexpected and it was quite impactful. Yeh uh your right and and uh I guess I had forgotten that uh. It probably was at a point in time when um while we were at the old office and uh you couldn’t walk away from it so yeh, in a sense
there was this feeling of overwhelming
memory is not so vivid as yours. Um but um I
remember that there was there was other
things I mean there were other circumstances
around the deaths. It wasn’t just deaths, but
there were other circumstances that were that
were really, you know, uh I mean the one man
dying uh drowning, I mean, it was the
circumstances around that death plus the death
and plus the that death was linked, you know,
was part of a circle, you know a wave of
deaths. Um so

V Do you remember what you felt like
then? I mean was that ... it felt like those days
those weeks?

A I felt a lot I felt a lot of sadness,
particularly because of some of the individuals
involved. I mean I knew I knew god I knew
some of these men very well you know-- talked
with them sometimes “daily” sometimes three
or four times daily, you know, they would they
had a they had a desk right across the hall, so I
knew these guys very well - laughed with them
and joked with them and cried with them - the
whole nine yards. And I remember feeling
really I felt really I felt a loss I felt a loss when
John or Dana or Guy died uh yeh uh
mummmm (pause) uh I’m just seeing if I can
if there’s anything else that really strikes me,
extcept that it was just loss, you know, just
sadness, just a real sadness, but uh yeh a
sadness and and kind
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of anticipating, well you know, it ain’t going to
be the same, you know? You won’t see them
walking down the hallway anymore or you
won’t be able to sit down and talk with them
and, you know, you won’t be sittin there with
(laughs) listenin to John and his crazy stories
or Guy, you know, and his exag exaggerating
about everything under the sun you know. So I
remember a sense of a sense of loss around not
having these guys around anymore, um. Aand
you know and the same sense of loss that I
felt with other individuals as well. Uh and that
I will feel when when others that we know will
die. Uh um a lot of floods of memories, you
know, remembering, you know, different
experiences they’ve had or they’ve talked
about, you know? or different experiences that
I had with them or that we had together in that
in that building, you know, um. Yeh mixed
mixture of sadness and uh aaaaand loss, but also
just fond memories, warm memories yeh uh
yeh. Uh but I but again, around that particular
series of deaths, I think it was the deaths plus
some of the circumstances around it and then
the uni the critical the unique individuals
involved. Yeh uh but I guess it goes back to
what I mentioned earlier around, you know,
some obviously some some individuals just
touched touched me more than others. Uh I
guess in my heart of hearts, I have to say Dana
was very was high up on the list and John, of
people who I really love, you know? Uh Yeh.
Uh Uh what’s it’s interesting though is um
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3018 (pause) what’s interesting though is that old
3019 office um when when we had to deal with
3020 concentrated stress or grief um or particular
3021 experiences, maybe I’m wrong and maybe you
3022 would feel differently about it, but it didn’t
3023 seem to kind of it didn’t seem to totally throw
3024 us out of whack. Uh, I mean there was a sense
3025 of feeling overwhelmed, but it didn’t throw us
3026 out of whack like experiences seem to do now
3027 at this where we are now and I I don’t know
3028 why that is, you know? Except I I think it
3029 has everything to do with the personalities who
3030 now occupy this space and what their own
3031 issues are and what their own needs are uh
3032 yeh. Uh and the kind of environment
3033 that has been created at this new place. Uh
3034 V And what would that environment be?
3036 A More of a distance, more of a hands off.
3037 Well I just don’t understand the (can’t
3038 understand the last two words). I think some
3039 people just don’t wanna get their hands dirty.
3040 I think some people just wanna go there (end
3042 of side of tape).
3043 V People don’t wanna get their hands
3045 dirty.
3046 A Yeh, you know, I think that some folks
3048 just don’t wanna get their hands dirty. Um ah
3049 (pause) hm It’s interesting when you note that
3050 around that particular experience uh that time
3051 period when there were a lot of deaths and
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we’ve had a number of those, but there was a
real sense of a real sense of loss a real feeling,
I mean it was like a like something hanging
over our heads, you know, when we were
walking through there. Uh (pause) aaand so
much of it had to do with, you know, the kind
of environment that was created around the
work, you know, uh people who worked there
uh and the connections, and again it’s that
connectedness with people who are infected,
you know, this place, it’s interesting, this
place is still an open en open environment, you
know, like we had at seventh avenue, it’s still
an open environment, but dis disconnected, I
think it’s very easy to be disconnected, so
therefore, response to ss critical incidents is
very different and it’s just I think very very
different and and and in a sense more um, I
don’t know, as I’d said earlier, you know, just
that inappropriate inappropriate way of
responding. Uh and but you know it’s I mean
we’ve noticed that and you can go for a full
day and not see someone down at the other
corner of the office. I mean, it’s just a reality,
you know?

More isolation in this big other space?
more isolation right
In this other space we were fall falling
over each other, but there was certainly a what
you’re saying, a more closeness physically and
uh things like emotionally and community
wise.
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3086 A  Yeh and yeh I think you know we just
3087 dealing we had many more people there. We
3088 have three organizations. At times there’s
3089 probably uh 25 30 people, you know, in that in
3090 that office. Uh less of a sense of
3091 connection...god I remember at one point when
3092 we moved into seventh avenue, there was that
3093 back end of the office and I remember
3094 Bridgette and I saying maybe they oughta rent
3095 this out cause we aren’t usin that space, well
3096 you know two years later we were folding
3097 at the seams and we but uh there’s very there’s
3098 that real sense of closeness uh that we don’t
3099 have now I don’t think. Uh nah and I don’t
3100 know and I wonder for the people who come in
3101 whether they, course they had no comparison
3102 they can’t compare to three or four years ago
3103 or actually, you know, three years, so they
3104 can’t compare to four or five years ago. So
3105 maybe for them, it’s as it needs to be. Uh and
3106 a lot of the staff can’t compare can’t go back
3107 five, six years, so for them it’s where it’s eh it
3108 works good for me so what’s the problem?
3109 You know?
3110
3111 V  (long pause)I’m interested in one of the
3112 things you said and actually what I thought
3113 you said right at the very beginning about,
3114 your own, ethnic background and how that
3115 influences or hopefully I think is what you’re
3116 saying, doesn’t influence the way in which you
3117 cope with grief now but I’m just wondering do
3118 you have a I’m just wondering what that
3119 meant, what your meaning by that?
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3120
A Uh um well stiff upper at least from
3121 my own family experience, uh sort of lip, uh
3122 someone dies, you know you bury them and,
3123 you know, kind a get on with things. Or or
3124 you at least don’t express, you know, you kind
3125 of stuff it down inside. You don’t express
3126 what’s goin on, you know, in a sense you don’t
3127 deal with it. Uh I guess I was making more of
3128 a taking more of a shot at Irish or German
3129 culture than than really taking more of a shot
3130 at my own family experience. Uh, you know,
3131 uh but you know, I come from a family of
3132 seven and I think all of mmmmm you know,
3133 we all kind of deal with things differently, but
3134 et there’s some clear divisions. I mean there’s
3135 um you know, I have an older brother who is
3136 very um he’s a lawyer -you know he sees
3137 everything very much in, you know, as a
3138 lawyer sees things, you know, Uh and and an
3139 older sister who is just very emotionally
3140 expressive. Uh uh and an older brother who
3141 uh uh is very sensitive doesn’t really so much
3142 appear so, but you know the more you get to
3143 know him sort of the more you see that he’s
3144 just a really sensitive guy. Kind of on the
3145 outside he has a bit of a crusty type of uh not
3146 uncaring, but kind of can come across as a bit,
3147 eh crusty, but deep down just a really you know
3148 sensitive kind of guy. As a matter of fact, he’s
3149 the one who said -- What was his comment last
3150 summer? Ooohhh um we were talking maybe
3151 about my work and anyhow he said Hey I got
3152 no problem with
homosexuality you know I he said it doesn’t bother me at all. I don’t feel threatened by being around men who are homosexually, he says, hey you know, it’s fine you know. I’m very comfortable with it. But there was something else that he said he couldn’t he couldn’t take come hell or high water and I forget I mean it was just such a such a dichotomy, like and to this day I still don’t understand it, but it was such a dichotomy. I don’t remember what the other issue was, whether it was a lifestyle issue or what, but it was something that he just said he has no time for. Uh but on this issue he’s he’s fine. He has no problem talking about it, doesn’t get antsy, doesn’t, you know.... Uh and and it a couple of other sisters, another brother who is probably cold uh or at least certainly comes across as cold son of a bitch. Um and a couple of sisters, younger sisters, who some, you know, I’m not sure where they’re at. And it’s just quite a mixture, you know, it’s I mean seven people, you don’t just, seven very different kinds of ways of dealing with issues dealing with stress and dealing with anxiety, dealing with loss or grief. Um so. Uh

There’s one thing that that I kinda wanted to ask you around what’s your experience, you know, in support services you’re kinda sit in a funny place on one level. I mean there’s a set up where on some level people seek us out for support are a part of the
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staff. So there’s that that I think adds another

dimension to things or another way wave of

carrying other grief around. And the other

that that always really a bit complicated I

found was um, you know, you might be, you

know we just had a funeral that day or you just

got a call to say that um somebody had died

and you have to take an information call,

somebody asking about HIV testing that kinda

having to switch and stuff stuff away for a

moment and pretend like everything was all

okay. And I’m just wondering how how you

get through those moments or when you other

thoughts that come to mind where you know,

you’d worked with a partner for a long time

and you were at the funeral with them and so

the partner is now HIV positive as well and

comes in and is talking about the funeral and

how he was, so kind of you have your own

feelings and yet there’s these people who come

to you for support or you know, other

responsibilities in your work that at the

moment with you’re dealing with stuff also.

I’m just wondering how you deal with that

diversity? That I’m not sure how to describe

that. Those are just some thoughts that come

to mind.

A Right. You know what stands out is um

a very very deliberate mental process of saying

okay this is what I gotta deal with at this point

in time, this is what I’m facing. Um let’s put

this one over here for now and I gotta deal

with that later because right now there’s an

info call
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or there's some other issue that's current that I
gotta deal with. Uh generally I'll get back to,
not generally. I will always get back to that
because that that is more has potential for
some long term stuff. There are times when I
walk out when I'm walked out of the office at
the end of the day with my head spinning
thinking Good god, you know, whhhhh
someone slow things down here. Uh (pause)
uh I've never had a problem doing that switch.
I never I don't think I ever liked it, I never got
used to it, but I never had a problem doin it. I
just did it, but I always most times hated it,
particularly when you get a phone call or
you've just been come back from a funeral or
when there's some and and you don't even
have time to kind of whh absorb it, integrate it
or, you know, figure out what you're gonna do
with it before something else is there right
right immediately to be dealt with. I always
felt a bit pissed off about that ah but knew well
I gotta do it, you know? But at the end of the
day felt whew or or in fact, try to before the
end of the day, at least get sit down with
someone else and do some either pick up the
phone and call someone or sit down with
someone else in the office just to kind of talk
some things out. Uh, but if that was not a
possibility then knowing that I have to at least,
on the ride home on the bus, you know, doing
some sorting things out in my own head. Um
uh I don't, you know, I don't wanna sound too
snobbish or anything, but I think that those of
us in support services know how to do that I
mean we you know we can handle that. Uh
that’s partly why we’re there uh. I’m not sure
about the rest of the folks in the office, but
maybe that’s maybe that’s more of a systemic
issue, you know? I guess that what’s we
consider to be good social work I mean good
social work practice, to be able to be able to to
handle handle that you know professionally
and then decide how we’re going to deal with
our own this stuff. Yeh um I remember thin I
remember thinking about that and very thing a
number of times and thinking well that’s just
what we’re there for, I mean that’s what we’re
trained for so that’s what we do. Uh what was
always interesting was whether folks in the
office, well if you need to talk go to support
services (laughs) I mean what what makes you
think that we’re gonna be able to help you deal
with your stuff. Uh I always felt that kind of
felt that kind of strange that somehow it ‘fell to
us to’ to take care help other people deal with
other people in the office deal with their stuff.
Um almost I mean I always thought that
maybe that’s a little too close to home. Uh but
uh hmmm I guess it’s just another one of those
pieces where organizationally, I’m not sure
that we’ve really organizationally I’m not sure
that really have tackled the issue. Kind of this
little bit and that little bit and that little bit and
some things that have even happened in spite
of the organization have turned out to be really
effective. But I think organizationally we
really haven’t tackled the issue.
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V What things are you talking about that have been helpful despite the...

A Well the memorial services or uh the uh panels or the walk and those kinds of rituals.

V Some of them started there though right? And some were started elsewhere.

A Yeh right yeh. Uh I mean I have to say that uh I don’t wanna I don’t wanna I don’t wanna I don’t wanna put a damper on but a) I think you picked a very important issue. You just picked a damn tough organization to a to look at uh and I’m just being very honest. It’s a very tough organization to look at. It’d be interesting to see what comes out of it all.

V Yeh.

A Uhh (pause) (long) I think the only other insight would be the role of the support services needs to play uh within, ya know, within the organization uh. At least in respect, to how others deal with multiple loss or grief. And I think at some point at some times that that leadership role of support services has been very much valued and other times I think it’s been not valued at all. Uh and again I think it has everything to do with the kind of personalities in the office. I I can remember some times that it was almost like a chore to
encourage people to uh. Or people saw it as a
chore to attend even to take a half an hour out
to talk about what’s goin on for them around
particular death. Oh god you guys at it again?
That kind of attitude. Uh or um when we in
support services would really kind of push a
particular issue to be addressed having to do
with mental health or whatever and staff and
people would ‘Oh god support services is at it
again’ you know. So I I’ve always well don’t
bother me, you know, stay away, don’t upset
my apple cart. So I think for us it’s been just a
very difficult process. Uh at times there’s been
good reception and other times not very good
reception at all. I think it’s been very difficult
uh, partly because we’ve always felt that, we
always felt the need both to attend to the
clients as well as to attend to the emotional
health of everyone else who works there. Uh
so I think it’s been accepted to very, you know,
as I said. It’s been a very difficult process. I
find it very frustrating. Uh (pause)
V There’s some qualities that you are that
you you identified earlier about when the four
of us were there. It sounds like that was really
helpful for you at that time. That different
than maybe the three of you now and I’m
wondering what’s different about it? I
mean other than obviously just the different
personalities but what’s different about that or,
cause it sounds like that support that you had
isn’t there in the same way anymore

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A Well I think we I think number one, the
four of us gelled. Uh you know what was
really significant was, we got together every
Monday morning and I guess I never realized
how important that was to get together once a
week and really dedicate that time to talking
about whatever is goin on. Um and it really
helped helped us to kind of really gel and
really connect uh ..... it was just you know, it
wassss partly because of the personalities of the
four of us, but, we just clicked. Uh we, you
know, we just clicked. I mean, E. with
his zanyvous, uh uh I don't know, we just
clicked. I just felt like there was that we wer
that we just worked very well together. Um
what's different now is um uh I I think the
other thing was we balanced off each other. I
think that's always important. Uh that
each of us kind of played a role and it just
sort of fell, you know, we naturally
followed our own our personalities drew us led
us to play particular kind of roles as part of a
team. Uh which to some degree doesn't exist
now. Uh but I think it just, you know, it really
supported it supported us, you know, it it
allowed me to feel very um you know, it
allowed me to feel just very supported very
connected. I can't think of what words, but it
was a very good experience just a very very
good experience. Um hmmm

V So just coming back to I guess when I
thought you ... one I asked earlier, but if you
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really a targeted uh process and you know, for
some for a lot of folks it was a really emotional
process, but you know, it was it really zeroed
in on what you were about and if you’re not
here for what, you know, what you’re here for
and and what’s stuff goin on for you that
might impact on your ability to function in any
way in this organization. Uh so anyway, I
mean, I would say until you you really develop
this sense of of communal effort and uh that
we all bring varying degrees of expertise and
experience and that we’re we’re there to help
each other through the process, that’s where I
would start, build that kind of strong base
before you start before you start saying well!
you’re gonna do this and you’re gonna do this
and you’re gonna do this and also recognition,
that even though you’re doin this this role has
a function within this organization and that
function is to support this particular goal and
objective. Uh so you’re a part of a whole. Um
and and no matter where the money’s coming
from to pay for for the resources are coming to
support what you do, you are part of the whole.
Uh uh and I think number two would be uh
look at very practical or very concrete kinds of
ways of dealing with um stress, dealing with
loss, dealing with death. Uh think about the
rituals that you might put in place. Um think
of the policies that you’re gonna put in place
uh that are uh that support that that kick in
when events occur. And the other thing I
think is um very clearly spelled out norms --
that this is
W t O H O * O M - J O \ U i J > W W H O * 0 » ' J O \ U i ^ U N ) M O \ 0 » v l O \ l J i J > W N H O

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don't I'll take it. Not I think I

Just you and any other interests of

go about this. I guess I just wanna make

what things else I need

all pretty much by formula so

there. (pauses) You know, everything else can

say about the humanity of the people who worked

community. You know, when is that going to

what message is this going to give to the

like and identity can a very human level

will

identifying on a very human level. What other

are

all fairly standard. You know, but it's

procedures that you're gonna put in place are

and put in place. The policies and

know the kind of setting that you're gonna use

their entire environment. I mean, you

developed supports or ways of dealing with

to tell you. And who have their own

capacity to do. A capacity to do. The capacity

called people who have a capacity to be a

have a capacity to feel (pauses) directly

gather them. You and the people who

one on the list. Next week come professional

that would be. I mean that would be number

kind of compartmental each other. In so what then

of each other and mean in a sense be able to

as I mean, you know, work together and

individuals going to connect and work. As I

private to get a sense of individuals and how

experiences, uh, and maybe even looking at un

APPENDIX E

DATE OF INTERVIEW: Feb 17/96
Interview #1

I'm not at this point no. Maybe at the

I guess is there anymore you want to

happening right now. It's without spokes

as to how your kind of solve into what's

when I'm saying is getting some more through

you know you've got to decide. So I guess

experience is important and that's sometimes

of the experience of the emotional piece of the

want to get from the experience. When you

session, why is the first do with which you

has to do with. I mean, this is not a therapy

of the book. But a lot has to do with a lot

side of me one side of me says that you let me

A: Hmm, like (pause) I want you know, one

information so if you have any thoughts.

I've found where done some interviews that

been suit cause sometimes people.

your sense of the interview any thoughts you

think just leaving the laps on and just review.

Lm I wanted, before we end, a couple of

have nothing else strikes me right now.