

LOSING A PARTNER TO AIDS:
BEREAVEMENT IN GAY MEN

By

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ABSTRACT

The Human Immunodeficiency Virus (HIV), that which causes AIDS, is most prevalent within the homosexual community, and in particular among gay men. Given that the final outcome of AIDS is death, it can be assumed that grieving an AIDS-related loss is not uncommon among gay men. It is surprising then, that AIDS-related bereavement has received such scant attention in the existing body of literature, with an even greater dearth in research specifically concerned with partner bereavement in gay men. This study provides a qualitative exploration into the bereavement experiences of gay men who lost their partners to AIDS thirteen months to two years ago. Three gay men residing in the Vancouver area participated in this study. Using a retrospective time line of grief, the men were asked to plot out the bereavement experiences that had occurred since the death of their partner. Participants were then interviewed, and questions were asked about the issues placed on their time line. Participants reported a variety of bereavement reactions. Common themes across three participants were emotional reactions and connection with the deceased partner. Two participants mentioned letting go/closure. Also, unique themes emerged including caregiver, network support, anniversaries, anger/regret, and passing through stages. This pattern supported some previous theory, but indicates the need for modification and theory generation. The ramifications of AIDS-related partner bereavement are great, yet much remains to be done.

TABLE OF CONTENTS

ABSTRACT.....	II
TABLE OF CONTENTS	III
ACKNOWLEDGMENT	V
CHAPTER ONE	
INTRODUCTION.....	1
DEFINITION OF TERMS.....	2
CHAPTER TWO	
AIDS: AN OVERVIEW	3
<i>AIDS: The Coming of Age</i>	3
<i>AIDS in Canada</i>	5
CHAPTER THREE	
REVIEW OF BEREAVEMENT LITERATURE	6
<i>The Death of a Spouse</i>	6
Conceptual Foundations: The Meaning of Loss.....	6
Empirical: Short-term Reactions to the Loss of a Spouse.....	10
Forgotten Grievors.....	12
<i>AIDS Bereavement</i>	14
Conceptual: AIDS-Related Bereavement.....	14
Empirical: AIDS-Related Loss.....	18
Empirical: The Loss of a Partner.....	21
SUMMARY	23
CHAPTER FOUR	
METHODOLOGY	26
<i>Background</i>	26
<i>Research Expectations</i>	29
Stages/Phases of Grief.....	29
Multiple Loss.....	30
Caregiver-Bereavement Interaction	30
Survival Guilt	32
HIV Serostatus.....	32
Anniversaries/Holidays	33
<i>The Current Study</i>	34
Sample Overview	34
Procedures	35
Measures.....	36
CHAPTER FIVE	
RESULTS.....	40
<i>Interpretation of Data</i>	40
CASE STUDIES.....	40
<i>David</i>	40

Demographic, Personal, and Interpersonal Information	41
Elaboration of the Grief Time Line	43
General Accounts of Grief.....	48
<i>Ken</i>	49
Demographic, Personal, and Interpersonal Information	49
Elaboration of the Grief Time Line	50
General Accounts of Grief.....	56
<i>Michael</i>	56
Demographic, Personal, and Interpersonal Information	57
Elaboration of the Grief Time Line	59
General Accounts of Grief.....	69
EMERGENT THEMES	70
<i>David</i>	71
Living the Experience.....	71
Connection/Legacy	73
Passing Through Stages.....	75
Closure.....	75
<i>Ken</i>	76
Moving On/Letting Go	76
Regrets/Anger.....	77
Loneliness.....	78
Pritchard's Presence/Connection.....	79
<i>Michael</i>	80
Caregiver	80
Emotional Reactions.....	81
Network Support	84
Memories of Joel	85
Anniversaries	88
CHAPTER 6	
DISCUSSION	90
<i>Comparisons Among Participants</i>	90
<i>Applications to Current Grief Theories</i>	93
<i>Further Comparisons</i>	95
<i>Interviewer's Reflections</i>	96
<i>Summary and Limitations</i>	97
<i>Strengths and Implications</i>	99
REFERENCES	101
APPENDIX A	
PROGRAM CONTACT LETTER, PARTICIPANT INFORMATION LETTER, AND CONSENT FORM	107
APPENDIX B	
GRIEF TIME LINE AND INTERVIEW SCHEDULE	111
APPENDIX C	
EMERGENT THEMES	115

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CHAPTER 1

Introduction

The effects of the acquired immunodeficiency syndrome, or AIDS have been the most widespread and are most easily witnessed within the homosexual male population. As of June 30, 1996 over 9,000 gay men were infected with AIDS in Canada, and virtually all of those infected will die. Inherent in these many deaths are complex issues of grief and bereavement for gay men that need to be addressed to fully understand the ramifications of the AIDS crisis. Of special interest were the bereavement experiences of the partners of the men who have died, as research in this area has been scant.

The majority of the current *bereavement* research focuses on the experience of widowhood in later life. A review of the research of spousal loss in later life indicates that widowhood has typically been examined by the psychological and physical health consequences of bereavement (e.g., Breckinridge, Gallagher, Thompson, & Peterson, 1986; Bruce, Kim, Leaf, & Jacobs, 1990; Caserta & Lund, 1992; Caserta, Lund, & Dimond, 1990; Caserta, Lund, & Dimond, 1989). Psychological health consequences of bereavement in later life include depression, psychological distress and impaired psychological well-being, stress and coping, and grief. Empirical research examining the physical consequences of the loss of a spouse in later life has reported compromised physical health, an increased number of medical conditions and visits to physicians, individual's perceived health, and mortality.

In contrast, little is known about the bereavement experiences and reactions of those individuals affected by the loss of a loved one - or loved ones - to AIDS. There is an even greater dearth in literature concerning the bereavement reactions of gay men who have lost their partners to this disease. The effects of AIDS bereavement were examined on three dimensions: psychological distress (e.g., depression, suicidal ideations), substance abuse (e.g., alcohol

consumption), and professional help seeking (e.g., increased visits to doctor). Conceptual literature suggests a multifaceted nature of AIDS-related bereavement which may contribute to the difficulty in examining “gay grief” (e.g., Schwartzberg, 1992).

The chapters that follow provide an historical overview of AIDS and a review of the bereavement literature particularly highlighting the death of a spouse and AIDS-related bereavement. Drawing from these literatures, this study explored the personal accounting of three men who had lost their partners to AIDS. This study employed open-ended interviews based on a visual representation of the individuals’ grief over time.

Definition of Terms

To avoid confusion, the terms associated with bereavement theory and research need to be defined. Bereavement and loss are used interchangeably, and are defined as “the objective situation of having lost someone significant” (Stroebe et al., 1993, p. 5). Bereaved/bereft is used to describe an individual who has experienced the death of another person. Stroebe et al. (1993) define grief as “the emotional response to one’s loss,” and mourning “denotes the actions and manner of expressing grief” (p. 5). Adjustment to or recovery from bereavement is said to have occurred when individuals are able to function at levels similar to those before their bereavement experience (Weiss, 1993).

A partner is defined as a man in a committed primary relationship (Folkman, Chesney, & Christopher-Richards, 1994) with another man. Additionally, for this study, partners are seen as two men cohabiting, either until the partner’s death or until the partner entered hospice/hospital care before death. It is important to mention that the term “gay men” is used throughout this study to refer to those self-identified as such. This in no way implies homogeneity of group membership. Milestones are those experiences, issues, and/or feelings that bereaved individuals perceive as affecting their grief process.

CHAPTER TWO

AIDS: An Overview

AIDS: The Coming of Age

At its first occurrence, AIDS seemed to be a relatively distant threat to the few people that had heard of it; AIDS was perceived as a disease that affected those individuals that fit into groups best described as social outcasts (e.g., gay men); it was easily ignored. It is thought that the death of the well-known Rock Hudson brought AIDS “out of the closet” and initiated the realization that the disease was indeed a real threat to all individuals, not merely the stigmatized and the non-normative populations (Shilts, 1987). Unfortunately, as Shilts (1987) has stated:

[t]he timing of this awareness, however, reflected the unalterable tragedy at the heart of the AIDS epidemic: By the time America paid attention to the disease, it was too late to do anything about it. The virus was already pandemic in the nation, having spread to every corner of the North American continent. The tide of death that would later sweep America could, perhaps, be slowed, but it could not be stopped. (p. xxi)

Although it was also noticed that the virus was prevalent among intravenous (IV) drug users who did not identify themselves as homosexual, many medical doctors and other professionals believed that they were merely covering up their homosexuality. The narrow scope that this new virus was a form of cancer that afflicted only those within the gay community, and IV drug users, was a hastily made stereotype that resulted in the tragic ignorance surrounding the disease that cost many people their lives. Non-stigmatized communities (e.g. heterosexuals) considered themselves to be, in effect, living in a ‘safe haven;’ they were removed and perceived themselves to be immune to any and all aspects of the disease. Initially, when individuals

outside of the population believed to be at risk began showing symptoms similar to those that affected people with AIDS, it was typically explained as an unknown illness.

The medical field began to question the exclusive nature of this disease as more non-gay, non-drug users began to surface receiving the same prognoses. Hemophiliacs, children, and others that were supposedly not at risk, were coming down with similar illnesses at an increasing and alarming rate. Suddenly, the medical field was questioning the nature and ramifications of “gay cancer”. In July of 1982, as the numbers of those infected grew within, as well as outside the gay community, “gay cancer” was renamed AIDS; “[this] gave the epidemic a snappy acronym...and was sexually neutral” (Shilts, 1987, p. 171).

The early years of the epidemic can be demarcated as years of continuous denial and avoidance; “the federal government [saw] AIDS as a budget problem, local public health officials saw it as a political problem, gay leaders considered AIDS a public relations problem, and the news media regarded it as a homosexual problem that wouldn’t interest anybody else” (Shilts, 1987, p. xxiii). AIDS was an issue that was not treated as the medical crisis that it became and continues to be; it was a prominent medical issue long before it was recognized and dealt with as such.

This new finding that AIDS was a non-exclusive disease confronted individuals with many previously denied issues. First and foremost, it had to be realized that the virus could infect anyone; this virus could be transmitted through “[c]ontact of infected blood, semen, or vaginal and cervical secretions with mucous membranes...[i]njection of infected blood or blood products...[and p]erinatal transmission (that is, from infected mother to fetus)” (Harding Douglas & Pinsky, 1992, p. 7). Second, AIDS awareness also resulted in a confrontation between the homosexual and the heterosexual populations. The very public banding together of the gay

communities in the fight against AIDS created a homosexual presence that could neither be denied nor avoided.

AIDS in Canada

In Canada as of June 30, 1996, there were 13,810 cases of AIDS reported. 13,666 of these cases were adults, 144 were pediatric (<15 years old). Adult males accounted for 12,834 of the total cases reported; 832 adult females also reported being infected. Of the total number of cases 9,969 deaths were reported, indicating that 72.2% of the reported cases have resulted in death. Of the individuals reporting having AIDS, 45% (n=5,748) of the men and 36% (n=323) of the women fall into the 30-39 age category. The majority of the women that report having AIDS are heterosexual (64%), while the majority of males that report having AIDS are men who have sex with men (84%), indicating that the infection of men is still by and large more common among homosexual males.

Since 1986, when data was beginning to be collected on the incidence of AIDS cases, the number of infected people in Canada has steadily grown and increased until recently. In 1992, the number of new cases reported reached the highest that it has ever been; 1,675 new cases were reported in that year alone. Since 1992, the number of new cases has drastically decreased to the 167 new cases that have been reported by June 1996. British Columbia has the third highest incidence of AIDS in Canada, falling after Quebec and Ontario. In 1996, B.C. reported 39 new cases of people with AIDS.

CHAPTER 3

Review of Bereavement Literature

Although anyone can contract AIDS, the majority of those infected are homosexual men. The toll exacted by this disease has been large and told in terms of the number of deaths and associated grief and bereavement in gay men. Bereavement research is a relatively new area of study and has stemmed from an increased interest in the reactions of elderly widows (Stroebe et al., 1993). Little of the recent research has been conducted on AIDS bereavement, and even less has focused on partner bereavement.

A review of the literature concerned with the short-term reactions to the loss of a spouse in later life is presented below. A summary of the conceptual accounts on the meaning of loss is presented including a historical overview of the study of bereavement. The empirical findings of short-term reactions to the loss of a spouse are then presented forming a prototype of the field, as early research equated bereavement and widowhood. Movement into AIDS-related bereavement highlights what little research has been conducted in the area of partner bereavement in gay men. Conceptual literature which addresses the inappropriateness of current bereavement models and theories in the area of AIDS bereavement is presented, emphasizing the uniqueness of "gay grief," bolstered by a comparison of traditional caregivers and AIDS caregivers. Finally, empirical findings concerned with the loss of a partner to AIDS are presented.

The Death of a Spouse

Conceptual Foundations: The Meaning of Loss

The roots of bereavement research lie in the classical psychoanalytical model (Freud, 1917/1957), and the attachment model (Bowlby, 1969, 1991). Based on Freudian theory, the early psychoanalytical model of bereavement identified normal grief as the natural reaction to the loss of a loved one, which manifests itself in "narcissistic" hurt similar to that experienced with a

painful wound. To overcome the death, one must sever the psychological attachments with the deceased. Furthermore, Freud maintains that the survivor is responsible for his/her own grief work and must withdraw from others to successfully accomplish detachment from the deceased. Successful completion of the grieving process is said to occur when the survivor is "freed from the loved object and is able to invest emotional energy in new relationships" (Nordan, 1993, p. 9).

Bowlby's (1969, 1991) attachment model of bereavement focuses on relationships of attachment and the consequences of their dissolution. Bowlby (1991) contends that attachment behaviors are developed to "maintain certain degrees of proximity to or communication with the discriminated attachment figure(s)" (p. 40). These attachment behaviors exist throughout infancy, childhood, and adolescence, leading to the formation of adult attachment bonds. The death of an attachment figure severs this pre-established bond (Bowlby, 1991). Grieving is brought on by the powerful attachment feelings and behaviors experienced by the individual as he/she tries to retrieve the lost person. Furthermore, Bowlby asserts that the grieving individual struggles for the impossible reunion with the deceased and that depression, anxiety, and anger are intrinsic and necessary aspects of the grieving process.

Bowlby (1991) presents four phases of mourning: (1) numbness; (2) yearning and protest; (3) disorganization and despair; and (4) reorganization. Characteristic of the numbness phase is the initial shock and inability to accept the loss of a loved one, which may be manifested in the social withdrawal of the survivor. The second phase, yearning and protest, is one of intense emotional and psychological distress. Disruption of other relationships may occur as the survivor experiences and displays anger and a preoccupation with re-establishing the lost bond. Disorganization and despair occurs when the individual begins to accept that the loss is permanent, and may be characterized by depression and apathy. As the individuals struggle to

redefine themselves and their new social reality, they may seek and accept support from others. Reorganization is said to occur when individuals detach themselves from the deceased and is able to invest in new goals, relationships, and objects of gratification.

Parkes' (1972) cognitive perspective on loss posits that grief is a psychological process in which the survivor reviews and restructures the psychosocial assumptions about his/her world. Extending from Bowlby's phases, Parkes (1972) identifies four stages of grieving as: (1) numbness; (2) pining; (3) disorganization and despair; and (4) recovery. Parkes proposes that reactions to loss may vary in the form and duration of each stage, and that recovery is completed when the survivor accepts the loss and has reorganized his/her assumptions. Different from the perspectives of Freud and Bowlby, Parkes (1972) suggests that losses may never be fully resolved and that coping with loss may best describe recovery.

The most recent well articulated perspective on bereavement is Weiss' (1993) perspective, which emerges from Bowlby's (1969, 1991) attachment model of parents and children and Parkes' (1972, 1986) extension of Bowlby's model into adulthood. Weiss (1993) identifies two classifications of relationships: relationships of attachment and relationships of community. Relationships of attachment are characterized by the notion that the loss of the particular relationship will trigger grief. Weiss (1993) has identified four types of bonds that can be characterized as those existing in relationships of attachment: a pair bond (that existing between married persons or long term partners), parent-child relationships, transference relationships (those existing between patient and therapist), and parent-adult child relationships in which childhood attachments continue into adulthood. The loss of an individual who is in an attachment relationship is not replaceable, nor can the sense of loss be rectified by a substitution.

Relationships of community are characterized by the absence of grief for the loss of any single community relationship. This category of relationships includes friends, co-workers, and

extended family relationships (i.e., those living in a different household). The loss of an individual from a relationship of community is replaceable and can be substituted; an individual is able to find new friends and/or work colleagues as individuals are interchangeable. Thus, the difference in reactions to the loss of particular relationships can be stated as follows: “[s]evere and persisting distress follows loss of any single relationship of [attachment] but not the loss of any single relationship of [community]” (Weiss, 1993, p. 271). However, the loss of a total community (e.g. the loss of all work relationships through retirement) may result in a grief reaction similar to that experienced with the loss of a relationship of attachment.

Weiss (1993) highlights three processes that are involved in the adaptation to the loss of relationships of attachment: cognitive acceptance, emotional acceptance, and identity change. The adaptation or recovery from loss of an attachment relationship to a normal level of functioning is a somewhat misleading concept, as there are “no universally accepted criteria for ordinary levels of effective functioning” (Weiss, 1993, p. 277). Recovery after a loss is said to have occurred when the bereaved individuals are able to return to their previous levels of functioning, which is indicated by the ability to: give energy to everyday life; demonstrate freedom from pain and distress; experience gratification; feel hopeful and plan for the future; and function in appropriate social roles (Weiss, 1993).

The loss of an attachment relationship that is most studied is that of the death of a spouse. This type of loss is considered to be the most stressful normative later life event that occurs; one that requires maximal readjustment in life (McCrae & Costa, 1988). “Experiencing the death of a spouse in later life requires a wide range of adjustments to meet the demands of a radically different social environment and lifestyle” (Lund, Caserta, & Dimond, 1993, p. 252). Wortman, Silver, and Kessler (1993) state that “the impact of a major loss is...likely to depend on the meaning of the loss to the individual...a given loss can mean different things to different people”

(p. 350). Although some recent research has begun to focus on the significance of understanding the meaning of the lost spousal relationship (e.g., Wortman & Silver, 1989), the bulk of the literature concerned with later life loss is based on the empirical findings associated with the loss of a spouse.

Empirical: Short-term Reactions to the Loss of a Spouse

Early bereavement research was primarily concerned with the study of widowhood, and tended to be atheoretical (Stroebe, Stroebe, & Hansson, 1988) resulting in a field of study focused on single issues rather than on a coherent range of bereavement consequences (e.g., Lindemann, 1944). Little research was concerned with bereavement in older adults (Lund, Caserta, & Dimond, 1993), focusing instead on young and middle-aged widows. Furthermore, this early research tended to exclude comparison groups of the non-bereaved, thus clouding the interpretation of the changes that occurred following bereavement (e.g., Caserta, Lund, & Dimond, 1989). As a result of these limitations, early bereavement literature was both restricted in its generalizability to bereaved populations and in its comprehensiveness.

More recent bereavement research has moved away from the focus on single issues towards a more multidimensional perspective on bereavement reactions (Stroebe et al., 1988). The research has shifted to widowhood in later life (e.g., Lund, 1989), and a movement has been made toward the development and cultivation of theoretical frameworks of bereavement (e.g., Caserta et al., 1989; Stroebe, Stroebe, & Hansson, 1993). The research literature benefiting from these advancements will be presented below within two areas of focus: short-term psychological and physical health consequences.

Research examining the psychological health consequences of spousal bereavement in later life have focused on depression in the bereaved in the months that immediately follow the death and throughout the first two years following bereavement (Breckenridge, Gallagher,

Thompson, & Peterson, 1986; Bruce, Kim, Leaf, & Jacobs, 1990; Carey, 1977; Caserta & Lund, 1992; Caserta et al., 1989; Gallagher, Breckenridge, Thompson, & Peterson, 1983; Lund, Caserta, & Dimond, 1986; Reich, Zautra, & Guarnaccia, 1989; Vezina, Bourque, & Belanger, 1988; Zisook, Schuchter, Sledge, Paulus, & Judd, 1994). Studies comparing widowed individuals with those in control groups or matched samples of married and non-bereaved older adults consistently find evidence to the negative health consequences that follow loss. For example, Zisook et al. (1994) examined depression over time (i.e., 2 months, 13 months, 25 months) in 350 bereaved individuals. When compared to 126 individuals in a married comparison group it was found that the bereaved individuals showed consistently higher levels of depression than the non-bereaved comparison group.

Reich et al. (1989) examined psychological distress and psychological well-being between one and ten months following the loss of a spouse in later life. The sample consisted of bereaved individuals that were matched for age, gender, and income levels, to a non-bereaved comparison group. The bereaved individuals scored significantly higher on measures of depression and feelings of hopelessness/helplessness, as well as reported lower levels of psychological well-being (i.e., lower levels of positive affect) than the comparison group. However, no differences were reported between the groups on measures of anxiety or suicidal ideation in the same time period.

Research in the area of later life spouse loss has also been concerned with levels of stress experienced by the bereaved (Caserta & Lund, 1992; Reich et al., 1989) as well as the ability to cope with the loss of one's spouse (Caserta & Lund, 1992; Lund et al., 1986). Caserta and Lund (1992) found that high levels of stress in bereaved individuals continued throughout the two years following the loss of a spouse. Conversely, Reich et al. (1989) reported that although the bereaved individuals exhibited higher levels of psychological distress than the non-bereaved

comparisons, these levels of distress significantly decreased over one year of bereavement, becoming more similar to those non-bereaved individuals. Lund et al. (1986) found that bereaved adults experienced significant perceived inability to cope up to two years after the death of their spouse.

Research concerned with the short-term physical health consequences following the loss of a spouse in later life has received comparatively less attention. Caserta et al. (1990) found perceived health to be strongly associated with physical health and medical conditions. In Thompson, Breckenridge, Gallagher, & Peterson's (1984) study of individuals who had been bereaved for two months, when compared to non-bereaved individuals, it was found that the bereaved were significantly more likely to report new/worsening illness, new/increased medication usage, and lower perceived health.

Mortality has also been an area of focus in the study of the health consequences of bereavement. In their review of cross-sectional research examining the relationship between bereavement and mortality, Stroebe and Stroebe (1993) indicate that a consistent pattern emerges: first, the lowest death rates occur in the married, followed by the single, then widowed, and finally the highest death rates occurring in the divorced. Furthermore, men who had lost a spouse also had higher death rates than did women who had lost a spouse. Stroebe and Stroebe (1993) also report that longitudinal studies have yielded similar results, with "excessive mortality rates among bereaved persons, compared with non-bereaved controls" (p. 178).

Forgotten Grievors

Conceptual research investigating the meaning of loss is limited. Instead, research has tended to focus more on empirical reactions to bereavement in later life. The loss of a spouse is a normative later life loss; one that can be expected to occur in nearly half of the elderly population. Much of the current bereavement research focuses on this normative experience as if

it is a template of bereavement. Only recent research has begun to examine other types of loss (e.g., Deck & Folta, 1989; Moss & Moss, 1989; Ponzetti & Johnson, 1991; Rando, 1986; Sklar & Hartley, 1990). However, even with the increased interest in other non-normative losses, there are groups of "forgotten grievers" that are overlooked because of their stigmatized grief. This is particularly true of those who have suffered some AIDS-related bereavement.

In many ways, homosexual partnerships are similar to the traditional marital dyad. It is possible that the perceived differences between the two relationships result from linguistic distinctions. That is, the term 'spouse' may be interchangeable with the term 'partner' in many of the relationship characteristics. For example, in both instances the individuals in the relationship share a commitment to one another. Furthermore, by choosing an individual with whom they wish to share a commitment, both types of relationships create a family of choice. Bereft partners may also be similar to bereft spouses. Death results in the loss of a life partner for both heterosexual and homosexual individuals. An individual as well as a relationship that had existed over time is lost with the death of one's partner/spouse. The grieving individual will experience a plethora of reactions to their loss and must adjust to their new role without their significant other.

Although recognizing the similarities between the partner relationship and the marital dyad is important, it is of equal importance to appreciate that differences also exist. For example, the partner relationship is less socially structured than that of a spouse. Whereas a spouse receives social recognition and acceptance (e.g., medical benefits, legal rights, societal reinforcement/support), this may not be true of a partner. Also different from the spousal relationship, the partner relationship, as well as the partner's illness may be stigmatized by society (e.g., Worden, 1991). Differences also exist in the bereavement experiences of partners and spouses. Although many of the bereavement issues are similar, partner bereavement tends to

occur at a younger age than does spousal bereavement (Turner, Catania, & Gagnon, 1994), resulting in an off-time death within the relationship. Partners are forced to deal with the death of their significant other in mid life rather than in later life, which is typical of married individuals. Bereft partners do not receive the same social recognition and support that is given to those grieving the loss of their spouse. Furthermore, whereas this is not typical of spouses, partners are at risk of contracting the same disease as their partner resulting in a similar death.

AIDS Bereavement

Conceptual: AIDS-Related Bereavement

AIDS-related bereavement has received minimal attention in the literature. Schwartzberg (1992) suggests that this dearth in the research may be due in part to the fact that "traditional models and theories of grief cannot adequately address the enormity and complexity of the [bereavement] situation" (p. 423). AIDS bereavement should be recognized as a multifaceted phenomenon. Schwartzberg (1992) identifies four unique issues of grief in gay men: 1) the unique demands of dealing with continual multiple losses; 2) the importance and uniqueness of the gay male subculture and gay grief; 3) the inadequacy of current stage model approaches to grief; and 4) the need to find meaning in ongoing adversity.

In general, society considers death and dying taboo subjects. In the gay communities however, AIDS has forced gay men to confront the reality of death. Continual, multiple loss is more common in gay communities, thus affecting the grieving processes of the bereaved (e.g., Biller & Rice, 1990; Carmack, 1992; Neugebauer, Rabkin, Williams, Remien, Goetz, & Gorman, 1992; Schwartzberg, 1992). For many gay men, grief may be "an overwhelming experience...simultaneously mourning a recent loss, remembering several past losses, and anticipating still others to come" (Schwartzberg, 1992, p. 423). This notion is comparable with Moss and Moss' (1989) concept of the "personal pool of grief" for older grievers, which posits

that the experience of loss may persist over time and intensify with added losses. Gay men may experience feelings of hopelessness or despair when trying to understand their losses; as one bereft partner stated, "a few more friends have passed since Bart's death. I often find myself wondering what I'm learning from losing people I love so much" (Newman, 1995, p. 208).

Schwartzberg (1992) proposes that gay communities have formed subcultures that have emerged over the years with unique rules regarding interpersonal, social, sexual, and emotional functioning. Schwartzberg continues that "the grief of gay men in the AIDS crisis may be experienced in a manner that differs from the grief of the larger culture" (p. 424). Factors that contribute to the unique experience of grief in gay communities include the stigmatization of AIDS and homosexuality; nontraditional, nonfamily support systems of gay men; gay culture and the loss of lifestyle that AIDS has brought forward; and the fact that AIDS is a sexually transmitted disease.

"In the context of AIDS, stage models are particularly ill-equipped to explain grief reactions, nor do other traditional theories of grief fare any better" (Schwartzberg, 1992, p. 426). Stage theories, such as that presented by Kubler-Ross (1969) are unable to accommodate the continual, multiple loss that is experienced by gay men. Similarly, other traditional theories of grief as reviewed above (e.g., Bowlby, 1969; Freud, 1917/1957) place emphasis on individual bereavement rather than on the experiences of ongoing multiple loss. Furthermore, stage models assert that grief is a finite construct; that successful grief results in a final stage of recovery, or resolution of the grief process. The notion of recovery in gay communities may be insufficient due to the continuous additive nature of AIDS-related loss.

A primary challenge in AIDS-related grief is for the grieving to find some meaning or make some sense of AIDS. People grieving an AIDS-related loss may find meaning in various beliefs, memories, community involvement, and the provision of care (Schwartzberg, 1992).

Newman's (1995) edited book is a compilation of letters and stories received from individuals grieving a loss to AIDS. Some individuals find meaning in memories of times shared with the deceased, such as, "I have brought his shoes back...[d]own at the heels, one missing an instep, they are nonetheless his shoes" (p. 132); and "I have hundreds of photos from the trips we took...I remember the first time he showed me around the island. This is his country, not mine" (p. 101). Although individuals search for meaning, they may have mixed feelings in their reasoning for the death and their own course of bereavement; as one grieving gay male wrote, "[g]rief. Nine months since you died, grief tends to grab me less often but more by surprise...how is it I can feel two so completely different feelings all at once?... my sorrow cries out - come back to me...and my joy reminds me how lucky I was to have you as a close companion on my journey" (Newman, 1995, p. 172). Finally, a gay man dealing with the loss of his partner stated that "[f]riends ask me how I bear such loss...I have learned that in the course of any person's life, one of the most powerful things they can ever do in life is to tell their story" (Newman, 1995, p. 254). The search for meaning in AIDS-related loss is an individualized process; individuals will find meaning, and solace, by conceptualizing their loss in their own ways.

Provision of care for a partner with AIDS is commonplace for gay men, may be a way for them to find meaning in the face of the epidemic, and may perhaps prepare them for the death. Folkman, Chesney, Cooke, Boccari, and Collette (1994) indicate that men providing care for a partner with AIDS are unique from traditional caregivers in five important ways. First, research has indicated that the majority of carers for gay men with AIDS are men. In a sample of 265 AIDS caregivers, McKann and Wadsworth (1992) found that 77% were male. Traditional caregivers are usually women (i.e., wives or adult daughters). Second, those infected with AIDS as well as those who provide care tend to be young or middle-aged. Turner, Catania, and Gagnon

(1994) found that 64.9% of male caregivers for men with AIDS were under the age of forty.

This differs from the traditional caregiver-care receiver dyad; typically care giving and receiving tends to occur in later life and both parties tend to be older. Third, whereas traditional caregivers usually do not have, nor are they at risk of contracting the same disease as the care recipient, caregivers for men with AIDS may also have AIDS or may be at risk of being infected with HIV. Fourth, society tends to view the relationships of gay partners as informal and often stigmatizes them, which differs from the traditional role of caregiver in that the relationship between spousal and/or adult children caregivers and their care recipients is socially acknowledged and supported. Fifth, “whereas the diseases of traditional care recipients are generally not stigmatized, AIDS is stigmatized and caregiving activities are often hidden from members of the general community...and even family members” (Folkman et al., p. 747). These differences in the characteristics of the caregivers might reasonably present themselves as differences in the grief trajectory associated with AIDS-related bereavement.

Literature concerned with the conceptual perspective of AIDS-related bereavement is scant. Schwartzberg (1992) proposes that this may be due to the inapplicability of the current grief theories to the unique experiences of “gay grief” (e.g., stigma associated with the disease/lifestyle; caregivers; gay culture). The meager body of research on AIDS-related bereavement, reviewed below, has not highlighted the nature of the lost relationship (e.g., friend or partner) instead painting a picture with broader strokes. There is clearly a great need to increase the understanding of the multifaceted phenomenon of *partner* bereavement and the initial efforts in this regard (e.g., the work of Martin & Dean, 1993a, 1993b) are summarized in the conclusion of this section.

Empirical: AIDS-Related Loss

Gay men have the greatest risk of contracting HIV/AIDS by virtue of the number and types and forms of sexual expression; if their partner died of AIDS, this puts them at an even higher risk (Murphy & Perry, 1988). Murphy and Perry (1988) found that newly bereaved gay men were frequently preoccupied with their health: “[t]he slightest bruise is quickly assumed to be a Kaposi’s sarcoma lesion and the merest sniffle to be *Pneumocystis* [sic] *carinii* pneumonia... [p]hysical symptoms of stress seen in all bereaved persons...are quickly interpreted as symptoms of AIDS” (pp. 457-458).

Folkman et al. (1994) state that HIV positive men are “psychologically vulnerable to the extent to which they see their partners’ disease progression as a forecast of their own future” (p. 46), indicating that the effects on HIV positive gay men who witness the destructive course of AIDS in their partners may result in feelings of apprehension and/or fear about their own illness progression and their own future.

AIDS-related survival guilt may be further complicated by the nature of AIDS (Boykin, 1990). Some men may experience feelings of guilt surrounding the belief that they are responsible for infecting their partner, even if the infection was unintentional and/or uncertain (Boykin, 1990). Furthermore, the resocialization process of the AIDS survivors may be a source of guilt (Boykin, 1990; Murphy & Perry, 1988); a bereft partner may “often feel guilty about being disloyal when he begins to feel attracted to others after the death” (Boykin, 1990, p. 251). In his study examining the prevalence of survival guilt in gay men experiencing AIDS-related losses, Boykin (1990) found that AIDS-related survival guilt existed in gay males in general, although HIV positive men as well as men with AIDS exhibited the highest levels of survivor guilt.

Lovejoy (1990) suggests that "bereavement is so common in homosexual communities that it is known as the second AIDS epidemic" (p. 308). As a result of the AIDS epidemic, the gay male community has been forced to deal with multiple loss, which can entail the destruction of entire networks (e.g., Biller & Rice, 1990; Carmack, 1992; Neugebauer et al., 1992; Schwartzberg, 1992). Multiple AIDS-related loss results in the intensification of grief experienced as a result of repetitive loss over a brief time period. Members of the gay community have reported experiencing the loss of many persons in their networks (see Biller & Rice, 1990; Carmack, 1992; Schwartzberg, 1990). As a result of continual multiple loss, grieving individuals may experience feelings of "overwhelming grief precipitated by the occurrence of multiple losses with little allowance for separate grieving time" (Carmack, 1992, p. 9).

In an exploratory case study in which seven bereaved individuals were interviewed, Biller and Rice (1990) examined the phenomenon of multiple loss within the gay community. The researchers examined the effects of multiple loss on the movement through the stages of grief posited by Rando (i.e., avoidance, confrontation, re-establishment). Biller and Rice (1990) found that the individuals experiencing multiple bereavement "jumped from one stage to another without establishing a pattern toward meaningful acceptance of one loss before experiencing another" (p.286). Furthermore, participants were found to focus on one major loss. New losses were minimized while participants further grieved the loss that they had identified as most significant.

In her sample of 19 homosexuals, Carmack (1992) identified the processes used by members of the gay community to deal with AIDS-related multiple loss. Open-ended interviews with the participants served to investigate their experience with AIDS-related losses and how they were responding to these losses. Carmack (1992) found that balancing engagement and

detachment was the basic social process that explained how the participants were able to cope with multiple AIDS-related losses. Participants were found to cope with multiple losses in four ways: functional engagement (e.g., participants saw themselves as able to set their own personal boundaries in choosing to have an effect on the lives of others), dysfunctional engagement (e.g., participants felt overwhelmed by other people's needs), functional detachment (e.g., participants reported acceptable feelings of self-protection from emotional pain although still caring), and dysfunctional detachment (e.g., participants experienced unsatisfactory feelings of uninvolved and a sense that they made no difference to others) (Carmack, 1992). Carmack (1992) concluded that a significant factor within the experience of multiple loss is "the inability to finish grieving for one's loss before another occurs...[b]ecause the losses are continual, the sheer number makes it impossible to ever get through the grief" (p. 12).

Neugebauer et al. (1992) examined the effect of AIDS-related multiple losses in 207 homosexual men. Participants were examined along two dimensions of psychological response to bereavement: 1) depressive reactions, and 2) preoccupation with/searching for the deceased. Neugebauer et al. (1992) found that men who reported greater numbers of losses reported greater experiences characteristic of preoccupation and searching for the deceased. However, levels of depressive symptoms were not found to increase with greater numbers of losses experienced (Neugebauer et al., 1992). Contrary to the research findings discussed above (i.e., Biller & Rice, 1990; Carmack, 1992), Neugebauer et al. (1992) posit that their preliminary results indicate that the gay community has developed effective coping mechanisms to deal with multiple loss.

Many of the men that succumb to an AIDS-related illness are relatively young, the majority between the ages of 30 and 39 (Health Canada, 1996). There is a natural time line inherent in most individuals which dictates the belief that the young do not die (Rando, 1986); death comes to those who have had a full life and have reached their later years. This normative

life line is violated as the majority of the men dying from AIDS-related illnesses have not yet reached later life. Considering the young age at which many of these men die, it is not uncommon that their deaths elicit the same reactions that any untimely death can provoke (e.g., the death of a child) (Worden, 1991). AIDS confronts gay men with their "conception of the world as a place where young men don't regularly die in the prime of their life" (Schwartzberg, 1992, p. 427).

Empirical: The Loss of a Partner

AIDS bereavement is a relatively new area of study. "Although deaths from AIDS began to increase rapidly in 1989," notes Martin and Dean (1993a), "little is known about the type and intensity of bereavement reactions associated with AIDS...[e]ven less is known about bereavement reactions in the most heavily affected population... homosexual, gay, and bisexual men" (p. 317). Only one empirical study exists that focuses on the bereavement experiences of gay men (i.e., Martin & Dean, 1993a, 1993b), highlighting the dearth in current research, and indicating the need for more research in the area of partner bereavement.

Martin and Dean's (1993a, 1993b) longitudinal study has contributed interesting findings in the area of AIDS-related bereavement. It was found that two characteristics of AIDS are central to the understanding of grief reactions following death due to AIDS: (1) the extended period of anticipation of death, and (2) the harsh and unpredictable course of the disease. The known outcome of a terminal illness such as AIDS (i.e., death) may enable individuals to prepare for the emotional and practical consequences of the loss that they will experience, and this aspect of anticipation is thought to protect the grieving individual from the development of pathological grief reactions. Because of its terminal outcome, it may be assumed that the anticipatory nature of terminal diseases is also a facet of AIDS. However, "[d]eath due to AIDS is rarely a quiet or peaceful process...[people with AIDS] engage in active and intensive fights for life in an ongoing

battle frequently described as an emotional roller coaster [which often includes] unrelenting nausea, fever, incontinence, and wasting” (Martin & Dean, 1993a, p. 321). It is a possibility then, that during the later stages of AIDS the buffering effects of anticipatory preparation may be lost due to the traumatic nature of the disease.

Martin and Dean (1993a) compared a sample of men that were non-bereaved to those that were AIDS-bereaved on three dimensions: psychological distress, substance use, and professional help seeking. Psychological distress included measurements of depression, suicidal ideations, traumatic stress, and subjective threat. Categorizations of substance use included alcohol consumption, sedative consumption, marijuana consumption, other drug consumption, and cigarette smoking. Help seeking from professionals was measured by visits to a doctor ten times a year or more, weekly psychiatric visits, an increase of ten or more yearly visits to a spiritual counselor, and increased doctor visits and psychiatric visits, compared to pre-bereavement.

Results indicated that AIDS-related bereavement was associated with increased levels of symptoms indicative of severe psychological distress. Bereaved men experienced increases in symptoms of depression, (e.g., feelings of hopelessness and helplessness), suicidal ideation (e.g., thoughts, plans, and/or attempts to take one’s own life), traumatic stress response (e.g., panic attacks, alterations between intrusive and avoidant thoughts and emotions about AIDS, and the inability to be comforted by others). Additionally, respondents reported subjective threat, a preoccupation with looking for signs of AIDS infection in their body, and consciously worried and afraid about the probability of developing AIDS in the future (Martin & Dean, 1993a).

The association between substance use and bereavement is more ambiguous. Martin & Dean (1993a) found little evidence of an increase in alcohol consumption, sedative use, marijuana use, or cigarette smoking associated with AIDS-related bereavement. However, they

found that the use of "other drugs" (that is, recreational drugs such as barbiturates, cocaine, hallucinogens, and amphetamines) increased among those that were bereaved.

Martin and Dean (1993a) found that the bereaved men had a greater tendency, and frequency, to seek professional help than did the non-bereaved. Bereaved men were more likely to increase their visits to a doctor as well as increase their contact with a spiritual helper. However, no difference was found between the bereaved and non-bereaved men attending weekly psychotherapy sessions. It was found that bereaved men demonstrated increased physician visits due to concerns about developing AIDS (Martin & Dean, 1993a).

Summary

The evolution of the understanding and the ramifications of AIDS was a slow and deadly process. Although it is now realized that it can infect anyone, AIDS is still most prevalent in homosexual men. The majority of these reported AIDS cases will end with the death of the infected individual. Little research has been conducted on the experience of AIDS-related bereavement and partner bereavement in particular. Given the predominant forum on widowhood as the paradigm of grief and the central role partners take in managing the care of their dying partner, this absence of research is particularly surprising and critical.

AIDS bereavement can be seen as an experience unlike other bereavement experiences. Biller and Rice (1990) have stated that AIDS-related bereavement is "qualitatively different from the grieving experience among other populations" (p. 285). As identified by Schwartzberg (1992), issues of multiple loss, the uniqueness of the gay subculture, the lack of applicability of current models of grief contribute to the uniqueness of the bereavement experience for gay men, and the search for meaning in their loss. Multiple loss, or the continual network disintegration within gay communities is a common experience and can be directly related to the AIDS epidemic. The uniqueness of the gay subculture (e.g., lifestyle/disease stigma) results in a gay

grief experience that is different from that experienced in the larger culture. Furthermore, the lack of suitable and applicable guidelines in grief and bereavement research (e.g., stage models) results in the inability to form foundations for AIDS bereavement research. Finally, searching for meaning in the loss of a loved one to AIDS is an individualized process including strategies such as memories, community involvement/support, and the belief systems of the surviving partner.

Providing care for a partner with AIDS is not uncommon in gay communities. Important differences exist between AIDS caregivers and traditional caregivers. Traditional caregivers are females, tend to be in later life and providing care to older persons, do not have and are not typically at risk of contracting the same disease as the care recipient, are socially recognized and supported, and provide care in a non-stigmatized situation. Conversely, the majority of AIDS caregivers are men, tend to be under the age of forty, may have or are at risk of contracting the same disease as their care recipient, are not socially recognized or supported, and are providing care in a stigmatized environment.

Important to the understanding of grief reactions following an AIDS-related death is the effect of the anticipation of death and the unpredictability of the course of AIDS. Emotional preparation for the death of a loved one may take place before the death itself occurs. However, the unpredictable nature of the course of AIDS may counteract this anticipatory preparation; an individual may emotionally prepare for the imminent death of their partner when he is extremely ill, only to have the partner rally and survive the illness that was expected to result in death.

Martin and Dean (1993a) found that those that had experienced an AIDS-related loss showed an increase in psychological distress, such as feelings of depression, sadness, hopelessness, suicidal ideation, and a preoccupation with the possibility that they might contract AIDS. Little increase was indicated in the consumption of alcohol, the use of sedatives, cigarette

smoking, and marijuana use. Partners that were bereaved were also found to seek more frequent professional help from their doctors or from other spiritual advisors. The ramifications of AIDS-related bereavement in gay men are great, yet the current research is lacking such an understanding; there is an immense need for research in this area. Only by conducting research in the area of AIDS bereavement can a better understanding of the experiences that these grieving men have be gained.

CHAPTER 4

Methodology

Background

Much of the bereavement literature has focused on the collection of data using quantitative methodologies. Data has been collected cross-sectionally, although some efforts at collecting longitudinal data have been made (e.g., Gallagher-Thompson et al., 1993; Lund, 1989; Martin & Dean, 1993). The current research tends to take a snapshot approach to capturing the bereavement experience at a single point in time (i.e., cross-sectionally) or exploring the mean differences between two or more points in time (i.e., longitudinally), rather than providing a fuller moving picture of the bereavement experience over time. That is, quantitative data collection methods (e.g., questionnaires/ scales) used in both cross-sectional and longitudinal research lack a certain temporal connectedness and personal relevance that might be more effectively examined using other, more qualitative methods such as in-depth interviews.

Qualitative research methodology examines material that is not restricted by predetermined categories of analysis, thus contributing to its depth, openness, and detail. As Patton (1990) notes, qualitative methodology “permit[s] the evaluator to study selected issues in depth and detail” (p. 13). Quantitative research methods, on the other hand, use measures that group the experiences and perspectives of people into empirically tested and often predetermined response categories. Quantitative research design makes it possible to examine many people at one time, thus yielding a largely generalizable set of findings that can be concisely presented. Conversely, qualitative research typically “produce[s] a wealth of detailed information about a much smaller number of people and cases [which then] increases understanding of the cases and situations studied but reduces generalizability” (Patton, 1990, p. 14).

The researcher is an active participant in qualitative research. Therefore, validity is different in qualitative research because the absolute truth is not desired, but rather the everyday life experience of a person is sought out through conversation. In contrast, the validity of quantitative research is dependent on the careful construction of instruments that can adequately measure the “truth”, or exactly what they are intended to measure (Patton, 1990).

Patton (1990) notes that qualitative research methodology includes three types of data collection: in-depth/open-ended interviews, direct observation, and written documents/field notes. Open-ended questions enable the researcher to examine the world from the respondents’ point of view. Direct quotations may be used as a main source of raw data collection, thus “revealing respondents’ depth of emotion, the ways they have organized their world, their thoughts about what is happening, their experiences, and their basic perceptions” (Patton, 1990, p. 24). Therefore, the role of the researcher is to provide the subjects with an environment in which they feel comfortable to respond in a way that “represents...thoroughly their points of view about the world, or that part of the world about which they are talking” (Patton, 1990, p. 24).

Although what people say is a major component of qualitative research, there are limitations to the extent of what can be learned merely from what is being said. Instead, researchers should also take into account what they observe. According to Patton (1990), “[t]o understand fully the complexities of many situations, direct participation in and observation of the phenomenon of interest may be the best research method” (p. 25). Qualitative methods enable the researcher to see the body language (e.g., facial expressions, posture) of a respondent while he/she can also assess the respondents verbal communications (e.g., tone of voice).

Building upon the aforementioned, Lofland and Lofland (1984) identify four people-oriented mandates in qualitative data collection. First, the qualitative researcher must be able to personally understand the details of what goes on in the population(s) under study. In order to

accomplish this task, the researcher must create and maintain close contact with the people and situation under study. Second, the qualitative methodologist must attempt to obtain the perceived meanings by capturing what takes place and what is said in the environment. Third, the qualitative data must include considerable amounts of pure description of the people, activities, interactions, and settings in which the research occurs. Finally, presentation of the qualitative data must include direct quotations from the participants, including either written and verbal quotations. Conducting qualitative research, then, requires much of the researcher, including the ability to convey the research and its participants sufficiently and succinctly. Furthermore, adequate qualitative research includes providing detailed descriptions of the research surroundings as well as direct quotations from those involved. Adhering to Lofland and Lofland's (1984) criteria will aid in the collection and presentation of data that are rich in detailed information about the population being studied.

Inherent in understanding the population is knowing what has gone on and what is currently going on in the lives of the participants. These personal perceptions or interpretations of experiences are primary factors in both behavioral and emotional reactions to life events. Along such lines, Thomae (1970) provides two fundamental postulates of human behavior: that "perception of change rather than objective change is related to behavioral change," and that "any change in the situation of the individual is perceived and evaluated in terms of the dominant concerns and expectations of the individual" (p. 4). It can be argued that understanding individuals' interpretations of experiences may be more useful than obtaining objective reports of these experiences (de Vries, Birren, & Deutchman, 1990).

A retrospective accounting of events in which participants identify their own experiences of grief may yield novel results that are otherwise frequently overlooked on more prototypic grief measures and/or conventional questionnaires as well as the standard cross-sectional and

longitudinal approaches. Such retrospection allows the research participants to develop their own dimensions, thus producing data that are relevant to the experiences of the participant. Also, retrospection provides the researcher with a mode of identifying events, episodes, or experiences in their temporal and participant defined context. These events can then be examined as connectives across time, giving the researcher a more thorough and comprehensive knowledge of individual experiences. The notion of a time line provides researchers with a tool to aid in retrospective data collection (e.g., de Vries & Watt, 1996; Rappaport, Enrich, & Wilson, 1985). Providing participants with a time line helps orient them to the dimension or flow of time as well as delineating the passage of time.

Research Expectations

AIDS-related partner bereavement has not been the focus of much of the current AIDS research. This study was exploratory in nature and was meant to address any unique issues that might exist in AIDS-related bereavement. The current literature reviewed and discussed above formed the basis of these research expectations.

Stages/Phases of Grief

According to Bowlby (1991), grieving the loss of an attachment figure includes four phases of mourning: numbness, yearning and protest, disorganization and despair, and reorganization. Similar to Bowlby's phases, Parkes (1972) identifies four stages of mourning, including numbness, pining, disorganization and despair, and recovery. Further expanding on Bowlby and Parkes, Weiss (1993) posits that recovery from the loss of an attachment relationship is achieved when the grieving individual is able to function at a levels similar to that of pre-bereavement.

Implicit in all of these is a notion of movement over time and a variety of emotions. Following the notions of Bowlby (1969, 1991), Parkes (1972), and Weiss (1993) it was therefore

expected that we would find that bereft partners would report experiencing physical sensations (e.g., feeling stunned, shock, restlessness, and insomnia), as well as various emotional reactions (e.g., pining, disappointment, sadness, and despair) since the death of their partner. Furthermore, it was expected that bereft partners would report feeling anger directed at different sources upon the death of their partner. It was also expected that bereft partners would report searching for meaning to their loss, experiencing difficulty when attempting to redefine themselves and their situation, and that attempts had been made to establish a satisfactory new way of life without their partners as well as being able to enter into new relationships.

Multiple Loss

Following the findings of Biller and Rice (1990), Carmack (1992), and Schwartzberg (1992) who reported on the relationship between the recurrence of loss and the intensification of grief, it was expected that the experience of AIDS-related loss over time would negatively affect the participants' ability to grieve the loss of their partner. Furthermore, it was expected that the death of the partner would be seen as an off-time event and unnatural in nature.

Caregiver-Bereavement Interaction

Little is known about the response to the loss of a care recipient, or about the effect that the experience of caregiving has on bereavement adaptation. Mullan (1992) states that the "bereavement adaptation is seen as part of an ongoing adaptation process that begins well in advance of the death and extends for an indefinite period afterwards" (p. 673). This suggests that providing care for a loved one may have an affect on the caregivers bereavement experiences and subsequent adaptation to the death.

In his study on the changes in the well-being of the bereaved caregiver following the death of a care recipient with Alzheimer's disease, Mullan (1992) focused on four factors which were thought to affect the adaptation of a bereaved caregiver: prior caregiver role stressors (i.e.,

the demands placed on the caregiver and the extent to which they interfere with their activities of daily living), overall adaptation (i.e., depression, mastery), relationship complications (i.e., past conflict, guilt), and the potential for psychological preparation (Mullan, 1992).

Mullan (1992) found that the cessation of major stressors associated with caring for a loved one with dementia provided the caregiver with immediate relief. Subjects experienced a noticeable drop in their feelings of overload, as well as an increased feeling of mastery in their lives. However, feelings of guilt and depression quickly followed the initial sense of relief that the caregivers experienced. In his investigation of the potential for psychological preparation, Mullan (1992) found that, "prior to the death, many of [the] caregivers reported that they had already experienced the loss of the person for whom they were caring" (p. 681). It was found that caregivers might be able to engage in some form psychological preparation for the death of their loved one (Mullan, 1992). However, this may not be the case for the AIDS caregiver. As noted by Martin and Dean (1993a, 1993b), anticipatory preparation for the death of a person with AIDS may become lost in the traumatic nature of the disease. The length of time between the AIDS diagnosis and the death of the person varies across individuals as the duration of the illness is related to the opportunistic infections that the person contracts (Folkman et al., 1994; Schwartzberg, 1992).

The need for the provision of care can be expected to occur at some point in the duration and course of AIDS, and the primary caregivers for men with AIDS are most likely to be their partners (Folkman et al., 1994). As previously stated, AIDS caregivers differ from the traditional caregivers in five important ways: gender (i.e., male vs. female), age (i.e., younger caregivers vs. older caregivers), risk of similar illness (i.e., high risk vs. low risk), social recognition for the caregiver (i.e., non-supported/stigmatized vs. socially supported/acknowledged), and stigmatization of the care recipients (Folkman et al., 1994).

Based on the findings concerned with bereavement following caregiving and the uniqueness of AIDS caregivers, it was expected that bereft partners that were caregivers would report a juxtaposition of feelings of relief and increased feelings of mastery immediately following the death of their partner. Furthermore, it was predicted that although the AIDS trajectory is predictable in that the men were aware that their partners were going to die, they would report that they were not psychologically prepared for the death.

Survival Guilt

Survivor guilt has been defined as “ambivalence or repressed aggression toward the deceased that prevents completion of the grief process” (Boykin, 1990, p. 249). Survival guilt can also include feelings that the individual is in some way responsible for the death(s) that have occurred (Boykin, 1990). Furthermore, an individual experiencing survival guilt may experience conflicting feelings between mourning their loss and simultaneously feeling relief that they have survived (Boykin, 1990).

Following the findings of Boykin (1990) and Murphy and Perry (1988), it was expected that participants would experience feelings of guilt as they re-involved themselves in the gay community as well as when entering into a new partner relationship after the death of their partner.

HIV Serostatus

Recall that Murphy and Perry (1988) reported preoccupation with health amongst their recently bereaved gay men similar to the feeling of apprehension or fear identified by the HIV positive bereaved men in the Folkman et al. (1994) study. Additionally, Martin and Dean (1993b) found that HIV positive men (bereaved and non-bereaved) scored significantly higher on all four measures of distress than did those men who were HIV negative (bereaved and non-bereaved).

Following these findings associated with the effect of the bereaved individuals' HIV serostatus, it was expected that the grieving men would comment and/or identify aspects of their own health status. Furthermore, it was expected that HIV positive bereft partners would comment and reveal anxiety around their own illness progression and would exhibit feelings of guilt if they felt they were responsible for infecting their partner with AIDS.

Anniversaries/Holidays

Although not frequently discussed, some of the most difficult periods for those grieving the loss of a loved one revolve around special days or holidays. As Wood (1987) states, "holidays have...special meaning in the relationship, and one's loss changes the way one approaches these important dates" (p. 237). Based on the assumption that it would be beneficial to provide individuals grieving the loss of a loved one with an educational experience focusing on the disruption in their lives as a result of the loss, Wood (1987) developed a workshop with three purposes: 1) to develop fellowship (e.g., caring, support) for those grieving the loss of a loved one; 2) to provide adequate information about grief and bereavement to grieving individuals; and 3) to rebuild a sense of trust in those who had lost it as a result of their bereavement. Although Wood (1987) focuses on the Christmas season in particular, he notes that other holidays (e.g., Easter, Thanksgiving) as well as other special times (e.g., family reunions, vacations) might also impact a person's bereavement experience.

Based on Wood's (1987) presentation of the importance of holidays and/or special times in the individuals' grief process, it was posited that individuals' grief experiences would change at points in time (i.e., anniversary events) that were seen as special between the bereaved individuals and their deceased partner.

The Current Study

It is important to recognize that several different forms of qualitative analysis exist (e.g., analytic induction, ethnomethodology, grounded theory, content analysis). The methodology that guided this research is that of modified analytic induction. Gilgun (1995) states that analytic induction “combines the discovery aspects associated with grounded theory while anchoring research processes to prior research and theory” (p. 277-78). In modified analytic induction, the researcher may develop rough hypotheses or general research expectations prior to entering the field under study or prior to data analysis (Gilgun, 1995). Furthermore, modified analytic induction places emphasis on the “development of descriptive hypotheses that identify patterns of behaviors, interactions, and perceptions” (Gilgun, 1995, p. 269). These hypotheses, or research expectations can be based on current literature and research findings. In the current study, both the general bereavement literature and the literature concerning AIDS-related bereavement helped to form the research expectations (presented above) as well as guided the formation of the interview template and questions (discussed below).

Sample Overview

This study consisted of three male participants. These three men came to the study as a consequence of an exhaustive search that included letters to all relevant lower mainland agencies, internet postings, and flyers posted at a variety of information sights sought out by those affected by AIDS. Furthermore, dozens of phone calls were made to these same agencies as well as contacts in hospitals, hospices, and other existing network resources.

One participant was recruited through a letter sent to a local bereavement support group. This letter, sent to the group facilitator, outlined the study and requested that any interested individuals contact the researcher by telephone for more information and/or to set up a convenient meeting time (see Appendix A). The two remaining participants heard about the

study through word of mouth and showed interest in participating. These participants were contacted by the researcher and convenient interview times were set up. Each participant was provided with a letter of introduction to the study, similar to that sent to the leader of the bereavement support group (see Appendix A).

Participants included in this study had to meet specific criteria: they had to be gay men who had lost their partner to AIDS thirteen months to two years prior to this study and had cohabited until the time of death or prior to final hospitalization. Reasoning behind the time period since bereavement was twofold. First, the time period since the loss provided the bereaved with some psychological and temporal distance from the occurrence of the actual event and enabled the individual to look back on their own grief trajectory without encountering emotions that might occur if bereavement was examined soon after the death; the bereaved's grief experiences were no longer 'open wounds' nor were they so far past that they had become a distant memory. Second, having the bereavement occur a minimum of thirteen months prior allowed the examination of the presence and/or absence of anniversary effects associated with bereavement.

Procedures

After initial contact was made, individuals interested in participating in the proposed study were briefly interviewed by telephone to ensure that they met the selection criteria. They were asked to provide a convenient time and location to conduct an introductory interview and general introduction to the study. At this time, participants were provided with the phone number of the researcher and encouraged to phone if any questions and/or concerns arose. At the first meeting, participants were provided with a letter informing them of their rights, and were asked to sign a consent form (see Appendix A) indicating their willingness to participate. Furthermore, participants were informed of the study's goals and procedures in both verbal and

written reports (see Appendix A). Prior to the conclusion of this first personal interview, the “Grief Time Line” measure (see Appendix B) was explained and the participants were provided with a copy of the time line to take with them. A date and time was established (approximately one to two weeks) for the interviewer to collect the completed time line from the participant and conduct the primary interview. At the conclusion of this interview, the researcher informed the participant that he would receive a case analysis and interview transcript (approximately four to six weeks later; by mail) that was drawn from both the grief time line and the interview.

For each participant a case analysis was constructed offering an overview of the personal grief trajectory for each individual. Using the transcripts, each individuals’ story of grief was drafted. Following the structure of the interview, the story provided a coherent account of each individual’s bereavement experience. No analysis was included at this point and to ensure its authenticity, each participant was provided with a copy of the transcript and their story. They were then asked to review both and add any information and/or delete anything that they did not want included. In preparation for the analyses of these accounts, a second reader that was familiar with both the literature and the current study reviewed the transcripts and stories generated from them. Discussions of these led to a framework for analysis, which included the derivation of the major reported themes.

Measures

The measurement instruments that were used in the study were: (1) a temporal representation of grief (i.e., the Grief Time Line), and (2) a personal tape-recorded interview.

The Grief Time Line. The inclusion of the Grief Time Line was intended to build upon previous research (e.g., de Vries & Watt, 1996; Rappaport et al., 1985) exploring the distribution of events over time and its relationship to the self concept. On the Grief Time Line, individuals were asked to plot the milestones of their grief since the death of their partner; these experiences

could include any feelings, events, and/or occasions that were deemed significant by the participant. The context within which these milestones were elicited derives from encouraging the participant to “[l]ook back over the time since the death of your partner. Consider the things that have happened to you, the things you have done, and the things you have felt that represent your reactions to the death. Indicate these things on this representation of time on the page before you.” The death of the partner was located at one end of the time line, and the present time was indicated at the other. Also, the time line was extended both before the death of the partner and after the present day to allow for participants to account for significant milestones that either occurred prior to their loss, or those that are anticipated in the future.

The primary interview. Once the participants had completed the Grief Time Line, the primary interview was carried out. This interview session was tape-recorded and then transcribed to facilitate analysis. Interviews with two of the men took place at their homes and the third was conducted at the participant’s place of employment. Two of the interviews lasted approximately one hour, and one lasted almost four. During this interview, only the participant and the interviewer were present, and although each participant was asked if he would prefer to be identified by a pseudonym, all declined. However, all other persons mentions have been assigned pseudonyms.

The interview was divided into three parts (see Appendix B). The first part of the interview requested demographic, personal, and interpersonal information about the participant and his deceased partner. This included information such as the participants’ age, the age of their partner at the time of death, the duration of the relationship with their partner, the length of their partners’ illness, and where their partner died (i.e., at home, in hospice/health care setting). Other demographic information (e.g., education, income, socio-economic status) was not requested at this point. Although these are both interesting and informative variables, the

primary concern for the researcher in the current study was focusing on, and the examination of, the specific bereavement experiences that the participants had. Participants were also encouraged to reflect on the dynamics of their relationship and their manifestation in the grief experience, previous experiences with loss, personality and/or social characteristics that may affect the substance and course of grief, and any other personal and historical factors that the participants feel are relevant to their grieving experience. The second part of the interview required the participants to elaborate on the milestones they had indicated on their Grief Time Line. First, participants were asked *"What were your first reactions or feelings upon the death of your partner?"* with the expectation that this would elucidate the initial feelings experienced by the bereaved individual. Following this, participants were asked to expand on each milestone that they had placed on their time line; for each milestone indicated, the interviewer asked: *"How was <milestone> for you?"* If further prompting was needed, the researcher probed by asking *"What does this reveal about your grief?"* or *"Are there any other thoughts, feelings, and/or reactions surrounding this event?"* A general, more thematic question concluded this section in which the researcher asked *"Reflecting on your time line as a whole, what do you see as the central issues of your grief experience?"* The third part of the interview included questions targeting the participants' general accounts of their grief experience, and included questions such as *"Have you been able to make sense of this loss?"* and *"Do you think that you as a person have changed as a result of your loss? In what ways?"*.

The interview schedule was designed with the purpose of gaining an in-depth look at the bereavement experiences of the three men in the sample. Furthermore, the interview sought to examine the relative fit of Schwartzberg's (1995) notion of "gay grief" and the application of Weiss' (1993) framework of bereavement. Therefore, some interview questions were informed by both Schwartzberg's (1995) notion of "gay grief" and Weiss' (1993) framework. Questions

were included that targeted issues raised by the four propositions that Schwartzberg (1995) states contribute to the uniqueness of "gay grief." Questions targeting the unique demands of dealing with continual multiple loss, as well as the inadequacy of current stage model approaches to grief included *"Have you had other experiences with loss?"*, *"Have you lost anyone else to AIDS?"*, and *"Do you think that these previous experiences have affected how you grieve or are grieving the loss of your partner?"* A question targeting the importance and the uniqueness of the gay male subculture was *"What has been your experiences with friends and/or family since your partner died?"* Questions targeting the need to find meaning in the ongoing adversity of the disease included *"Have you been able to make sense of this loss? How have you done this?"*, *"What do you anticipate your future to be?"*, *"Do you think that you as a person have changed as a result of your loss? If so, in what ways have you changed?"*, *"What have you learned about yourself through your grief experience?"*, and *"How do you think the type of person you are has affected your grief?"* Finally, given that Weiss (1993) posits that the endpoint of grief or bereavement is recovery, the men in this sample were asked, *"Is it possible to recover from such a loss? If so have you achieved this?"* and *"What does recovery mean to you?"*

The final follow-up interview enabled the participants to clarify and/or elaborate on any of the issues previously discussed. Furthermore, it provided the participants with a sense of closure with both the interview process and with the interviewer.

CHAPTER 5

Results

Interpretation of Data

A case analysis is provided for each participant to offer an overview of their personal grief trajectory. An examination of what specific events/milestones are identified and the themes that were revealed within the individual accounts of the events are presented. As a test of the framework designed for the derivation of the major reported themes, both readers constructed an independent analysis of one of the transcripts and the accompanying story. Both readers agreed in theme identification. Subsequently, the primary reader analyzed the remaining transcripts and provided the second reader with the transcripts, the stories, and the results of the analyses as a check on interpretation. Again, there were no discrepancies other than the names by which the themes were identified. A list of these emergent themes and the temporal context in which they arose has been drafted, thus forming a template of the grief trajectories of these bereft gay men. The themes and their constituents are represented in tables 1 to 3 (see Appendix C).

Case Studies

David

The interview with David took place at his home in Vancouver's West End. David and the interviewer sat on the floor, relatively close together, and the tape recorder was situated between the two individuals. Both seemed comfortable with the context and the discussions that followed. David maintained eye contact with the interviewer, although he occasionally focused his eyes elsewhere when engaged in introspective thought. At one point David lay stretched out on the floor as he talked with the interviewer. David was eager to expand on his personal grief experiences that were noted on the timeline, and responded to the interview questions openly. During the interview David remarked that it "[felt] good to talk about it with [the interviewer]."

David reported losing the visual representation of the time line that had been provided and presented the interviewer with a hand written account of his grief experience. David structured his own bereavement experiences in six month intervals, as was indicated on his time line/list of milestones. Significant events were placed under the appropriate headings that were determined by David (i.e., first six months, second six months, third six months, fourth six months). In total, David reported eighteen milestones/significant events in his grief experience and his interview lasted a little over an hour.

Demographic, Personal, and Interpersonal Information

David is a fifty seven year old gay male residing in Vancouver's West End. At the time of the interview, David's partner Chris had been deceased for almost two years. Chris died at thirty years of age. David and Chris were together for approximately four years before Chris's death. For the first year of their relationship Chris lived in Edmonton so the two traveled back and forth to visit each other and kept in contact by telephone.

Chris was diagnosed with HIV prior to meeting David. When they met, Chris's cell count was down around four or five hundred. For the last couple of years of Chris's life he virtually lived without T-Cells. David does not recall Chris suffering from a lot of the debilitating illnesses that frequently accompany persons with AIDS (e.g., blindness, lesions). He recalls that Chris had a couple of bouts of *Pneumocystis carinii* pneumonia, which resulted in his being hospitalized for a couple of weeks at a time. Chris did suffer from Peripheral Neuropathy which caused him a lot of discomfort and pain, eventually affecting his ability to walk. This lasted about a year and a half until Chris's pain turned into numbness. Following this, Chris began suffering stroke-like seizures which lasted anywhere from 2 hours to 6 hours. David feels that Chris died in a tranquil manner as a result of one final seizure.

David thinks that his relationship with Chris started out as one of compassion rather than of passion. Chris's life story was one filled with tragedy and sadness and David felt that Chris needed to be loved and wanted to be the one to show him what unconditional love was. David recalls that their relationship was a very meaningful experience for him, as he stated, "It was genuine...It just seemed to flow in both directions. We just were able to give to each other without hesitation or restriction or resistance even. It was so mutual. Really a wonderful time." When Chris died, David felt a sense of satisfaction that he had done something worthwhile for someone else without any self interest, and he had no regrets regarding his behavior and involvement with Chris. David found that throughout the first year he really missed the companionship that he had shared with Chris and states that even now he can't go anywhere without remembering an experience/particular place that they had shared. David gave the example of his daily routine of going to work: each day as he goes to work he remembers how he hated leaving Chris alone each morning when he was ill.

When asked about his other experiences with loss, David reported that he had lost his mother at 21 years of age. Because his father lived in England, this was the only parent that he had as he was growing up. David believes that he did not deal with the death of his mother until the breakup of a relationship. At that point he feels as though he dealt with various losses including the loss of his mother, the loss from his divorce, and the loss of having children around. David believes that his friends helped him cope with his feelings of loss at this time.

David has lost over 30 friends to AIDS in 12 years. He feels that as a result of these losses there is a "general aura of loss that you live with after a while." David feels as though his previous experiences with AIDS-related loss have affected how he grieved/is grieving the loss of Chris: "I probably already had a jump start on innate sadness. I cry at the drop of a hat now...I'm on the emotional edge a lot. It's just under the surface, even when I'm really happy, it

can switch really quickly, with just a bit of stimulus. Yeah, I'm very emotional now." Much of David's support has come from what he describes as a "core group of close friends," including a group of Chris's friends that have remained close to David.

Elaboration of the Grief Time Line

Chris died at four in the morning on the Saturday of the Easter weekend in 1995. David had been lying in bed with Chris and holding his hand for the previous two days, knowing that the end was near. David recalls that Chris's breathing was sporadic from about midnight on, with Chris stopping breathing all together at around four a.m. When Chris died, David "went into action...straightened him out and straightened his arms, and covered him over and phoned the doctor right away." David also called his son and mutual friends of his and Chris's, Pritchard and Ann. The priest from the church came over to David's house at around seven in the morning and those present held a small vigil around Chris's body and the bed that he was in. David recalls that it was good to have the corpse there for a while in order to spend some farewell time with Chris; "we all spent time with Chris. I had spent some before people had arrived, and between peoples' visits. It was amazingly easy, and comforting, to hug the corpse, to kiss it, to talk to it." About six hours after Chris had died David wanted his body to be taken away, as Chris's appearance began to change. David remembers his emotions beginning to surface when the mortician placed Chris's body in the body bag and took him away. David then spent some time alone with Steven before beginning to do laundry and cleaning up his apartment. David recalls that then "[l]ife started to move on. It wasn't until the evenings of that week, when I was on my own that I did a lot of crying. But I also did a lot of talking on the phone [to notify people of the death and of the funeral plans]...So that first week was busy. There wasn't a lot of time to just think of me."

First 6 months after Chris's death. During the first six months after Chris's death, David identified seven milestones of his grief experience that he feels were significant: Chris's funeral, a trip with their friend, Steven, to Victoria, time spent alone, time spent on the phone, feeling Chris's presence, sorting through Chris's clothes and possessions, and his trip to Switzerland. David took Chris's wishes into consideration and carefully planned the funeral service, describing it as having "a very comfortable intimate feel to it." Furthermore, David was surprised at the support and sympathy that was received from people in his church as well as at work. Within a month after Chris's death, David and a mutual friend of his and Chris's, Steven, went to Victoria. Steven helped provide Chris's care in the last few months, and had become very close to Chris towards the end. David sees this trip as important because both men needed time to grieve and share their emotions: "we both needed time to just escape and talk and be with each other." David chose to spend a lot of time alone in the first few months after Chris's death: "I would come home from work and cook dinner and have a bath and crawl into bed at 6:30 or 7 at night and just lie there and think, and cry, and talk to myself, and listen to the funeral tape." Listening to the funeral tape brought David some comfort: "it just seemed to be good to hear the words over and over again, the support, the feelings." David also spent a lot of time on the phone, recalling that he did not like to be alone too long without talking to someone. Although he stated that talking on the phone was one of his personal characteristics, he noted that this need was especially strong after Chris's death. During the first couple of months after Chris's death David could sometimes feel Chris's hand holding his. For David, this was an amazing experience, symbolizing the last few days of Chris's life when they lay together in bed and David held Chris's hand as he gradually faded. Sorting through Chris's possessions was very difficult for David: "I was virtually crying through the whole day." David kept some of Chris's clothing, and recognizes the closure that he received by sorting through and keeping

some of Chris's things. The September after Chris's death, David went to Switzerland to visit a mutual friend of his and Chris's, hoping to both give and receive support. Unfortunately, David did not get the emotional support that he had hoped for, although he still had a reasonable holiday but notes that "it was still too soon for me...I was feeling very lonely despite the people around."

Second 6 months after Chris's death. During the second six months after Chris's death, David identified three milestones of his grief experience that he feels were significant: his first Christmas and New Year's alone, his trip to the Greek islands, and sending Easter flowers to the church. David recalls that the Christmas after Chris's death was the first year that he didn't get presents for anybody. Although he was invited to various parties and celebrations, he feels as though he was in "survival mode...not feeling very joyful." Furthermore, although David had a fun New Year's he was still feeling very lonely, since the person that he really wanted present wasn't there. The spring after Chris's death David went to the Greek islands for a vacation. He had visited the Greek islands before he had become seriously involved with Chris and had moved in with him. He saw this trip as another step in his closure process: being somewhere he had previously been although this time not looking forward to returning home. David placed Easter flowers in the church as a form of memorial for Chris, and felt that although it didn't bring a lot of emotions, and "it [was] the right thing to do...like one of those comfortable duties." Summing up the first year of his bereavement, David stated that "it was pretty hard to live it up and have fun...this constant cloud over your life."

Third 6 months after Chris's death. During the third six months after Chris's death, David identified four milestones of his grief experience that he feels were significant: his trip to California, the International AIDS Conference and the quilt, his trip to Regina, and meeting a potential new love. In June of 1996, David took a trip to California to go to his nephew's

wedding and to scatter Chris's ashes. He noted that this was his favourite nephew, one that he had always had a special emotional and spiritual tie with. David had decided to scatter Chris's ashes in California, where Chris was born. Furthermore, he and Chris had scattered Chris's sisters ashes there three years prior. David went to the same location that they had scattered Chris's sister and scattered Chris's ashes. He stated that it "felt meaningful to do that, that they were back in the same place together...when I did his ashes there, it felt really good to do them in the same place." David recalls that scattering Chris's ashes was a calm experience for him; he did not rush it, but rather slowly sifted through the ashes bit by bit. After scattering Chris's ashes, David felt "almost a metaphorical lifting of a spirit leaving me, felt this weight leaving my body...felt quite a big burden gone at that point...a major good-bye, I think." Prior to his trip to California, David was working on a panel for the Names Project (the AIDS quilt). He finished the panel before the International AIDS Conference and it was one of the panels from Vancouver that was consecrated during the conference. David found working on the quilt panel to be very therapeutic; he felt that the panel was a good way to leave a permanent record of Chris's life, "I think that just enhances the peaceful feeling of doing everything you can to recognize that a life was really worthwhile." David stated that there were no particularly strong feelings that accompanied the making of the quilt, but that it felt as though he was completing another part of his grieving process. In September 1996 David went to Regina to visit some of their friends and to visit one of Chris's aunts and her husband. David enjoyed hearing personal stories and about experiences with Chris from his friends and also visiting the places where Chris had lived, gone to school, and worked. He felt very content with his visit after he left Regina, and felt as though he was progressing along his grief experience. On his way back through Calgary, David met a new love interest. David feels as though he was making emotional progress and was in the right space to consider a new relationship. He connected very easily with him, and recognized in him

a lot of the values that Chris had had and appreciated them. David feels that from his experience with Chris he has learned to appreciate the real value in people, and who they are as individuals. David decided that this individual was worthwhile and is pursuing a relationship with him presently. When discussing this potential new relationship, David stated, "I recognize that this chap is a really really wonderful person, and I am ready to accept that again in my life. Cautiously."

Fourth 6 months after Chris's death. During the fourth six months after Chris's death, David identified four milestones of his grief experience that he feels were significant: finding comfort with his memories of Chris, sorting through cards and letters, his upcoming trip to Edmonton, and Chris's legacy. David recalls that the memories of Chris were at one point painful but have changed and are more comforting to him now, and the good times that he and Chris shared are stronger in his memory now. David felt as though this symbolizes that he was getting toward the final stages of his grief. Because David was feeling certain amounts of progress both in a new relationship and in his own grief, he felt that it was time to put some more of Chris's things away. He packed away all of the cards and letters that Chris had sent him during the first year of their relationship when they weren't living together, and he changed the pictures of Chris that he had in his apartment to smaller ones or placed them in albums; Chris has been placed "more into memory rather than in your face presence." At the time of the interview David had planned a trip to Edmonton for the upcoming week which he believed would be the final closure for him. He was going to the city where Chris had lived when they met and where they had spent much time together. He had never been there without Chris. David recognized that he had not been ready to visit Edmonton before this time, but that now he was looking forward to it. The final point on David's time line was Chris's legacy. David stated that Chris was "the best love I've ever experienced, so unconditional and generous, absolutely

unbeatable, a wonderful companion. He left me a legacy of good friends...I have an increased sense of my own self-worth...what I've experienced with Chris gave meaning to me and my life."

When asked what David thought his future would be like he stated that he now lives more day by day and doesn't plan too far in advance. He has a new appreciation of life and tends to take it more as it comes now rather than planning things. At the time of the interview, David's main focus was his potential new relationship and he felt that if that were to work out it would bring new direction to his life and new things to share with someone else as well as new things to work towards. David stated that "right now [the future] is a mystery" that he is willing to let it happen and he feels no sense of panic in it.

David sees the central issues of grief are not to avoid grieving. David feels as though he has really tackled his grieving experience, that he has indulged in grieving. "I've chosen to go through the steps and absorb them and not avoid them, and so there is more meaning in that for me...I've dealt with it all as intensely as I can." David feels that his grieving has enabled him to take the best of his experiences with Chris and use them to enhance his future life and relationships.

General Accounts of Grief

When asked if he had been able to make sense of his loss, David responded that he feels that death adds an intensity to living, it adds meaning and intensifies emotion. He stated that he wondered "if the relationship would have been as overwhelmingly wonderful if there weren't that expectation of death." He recognized that Chris made an effort to live and that his effort had enhanced their relationship. David does not feel that he has recovered from his loss, nor does he think it is possible to recover from such a loss. He doesn't think that a person ever really gets over the loss, but rather the loss becomes a part of who the individual is. To David, recovery means renewed strength to accept and move on. He feels that its very difficult and that "you tend

to look at life a lot more seriously, more intensely, but it adds more meaning, more satisfaction to a lot of aspects of life.” He feels that it increases individual wisdom to be able to talk about loss and sadness, and over time it becomes easier and actually feels good to talk about. Through his grief experience, David has learned that he is a stronger person than he originally thought he was. Furthermore, he has learned that he has “what it takes to be a good partner and to love and to give support and all.”

Ken

The interview with Ken took place at his home in North Vancouver. Ken and the interviewer sat in chairs in the living room and the tape recorder was situated on a table beside Ken. Ken seemed comfortable with the discussion that followed and was quick to expand on the points that he had noted on his time line. However, it was noteworthy that he required several prompts from the interviewer when responding to the interview questions. For the most part, Ken maintained eye contact with the interviewer, however, when deep in thought he focused elsewhere. During the interview, Ken became emotional; while talking about a visit to Revenue Canada, Ken cried as he recounted that he felt as though he was erasing his partners existence.

Ken reported losing the visual representation of the time line that had been provided and presented the interviewer with a hand written account of his grief experience. Ken’s time line was chronological and linear in its presentation; his grief experiences were numbered and he noted the months in which they occurred. In total, Ken reported nine milestones/significant events in his grief experience, and his interview lasted approximately an hour.

Demographic, Personal, and Interpersonal Information

Ken is a forty-six year old gay male residing in North Vancouver. At the time of the interview, Ken’s partner Pritchard had been deceased for about fifteen months. Pritchard died at forty-three years of age. Ken and Pritchard had been together for eleven years prior to

Pritchard's death. Pritchard was sick for about two and a half years before his death. He died on Christmas Eve in 1995 on the Palliative Care Ward at Lions Gate Hospital in North Vancouver.

Ken noted that Pritchard had always accepted the fact that he would get sick and die, which was something that Ken himself did not accept. Ken recalls that towards the end of Pritchard's life Pritchard was more concerned about Ken and how he would handle his loss, "he always wanted me to go out and do things...that's the hard part, is finding out what I want to do...it's like you're lost and confused...the other half is gone."

When asked about his other experiences with loss, Ken reported that his grandparents had died when he was young and he had little recollection of them. Ken has had other friends and co-workers die as well and noted that for the most part they had also died from AIDS. Ken doesn't feel that his previous experiences with loss have affected his present grief experience. However, Ken had hoped that current AIDS research and the medical field would have progressed enough to prevent Pritchard's death, but notes that new medications became available after he died. Ken feels that those individuals that he considered close friends of his and Pritchard's have remained so throughout Pritchard's illness and his subsequent death, "everybody you would have thought were close friends have been there since the very beginning to the very end and are still there." However, he notes that a few individuals whom he considered to be close friends "basically turned and walked away" when Pritchard became ill.

Elaboration of the Grief Time Line

For Ken, Pritchard's death elicited feelings of total desolation: "the center of my world died." He feels that Pritchard was his source of strength throughout his illness rather than things being the other way around. Ken recalls his competency at completing necessary tasks, but states that, "when things got really rough, he would hold me and tell me that things would be all right." Ken notes that he is surprised at how he still gets upset at times and notes that he tries to see the

positive side; that Pritchard fought as long as he could and then accepted his own death and became at peace with dying. Ken continued to note that it is up to him to accept and be at peace with Pritchard's passing, as his partner was.

Ken identified nine milestones of his grief experience that he feels were significant: joining a bereavement support group in January, bringing home Pritchard's ashes, Pritchard's mother's repeated request for the ashes, a 'letting go' dream, his road trip to Revelstoke, Pritchard's celebration of life, the international AIDS conference/making a quilt panel, his visit to Revenue Canada, and his trip to Hawaii and his dream about medications. After Pritchard's death Ken joined a bereavement support group: at first he joined one offered at the Lions Gate Hospital, but he found that it did not cater to his needs, instead it seemed to be predominantly for straight people; soon after, he joined the support group at St. Paul's Hospital which was geared towards gay men who had lost their partner to AIDS. He found that his friends and co-workers, although very supportive and caring, couldn't fully understand the magnitude of his loss; he feels that their lack of understanding can be attributed to their similarity in age and their lack of experience with such a loss. Ken found the support group to be very helpful to his grieving; "participating in the support group was a wonderful thing, I mean they understood everything, you didn't have to explain everything, and they knew when you were having a rough time." Ken found it helpful to have a place where he could go to talk to other people and share his experiences/feelings. He stated that joining the support group was an effort at working with his grief "rather than being run over by it."

There was a delay of about three weeks until Pritchard's ashes came home from the hospital, at which point Ken felt it was somewhat of a homecoming, and he felt a sense of peace in bringing Pritchard's remains home to their house. He stated that he had no other particular

feelings about bringing Pritchard's ashes home, as it wasn't him, but he felt a need to have the ashes at home.

Soon after Pritchard's death, his mother decided that she wanted some of his ashes, and began to contact Ken about her wishes. She sent cards and notes to Ken that would be completed with requests for a part of Pritchard's ashes. Ken feels as though Pritchard's mother thought that spreading the ashes was like scattering Pritchard's ashes into the wild. However, for Ken and Pritchard scattering the ashes was symbolic, "it meant to us it was the same as being prepared for birth and it was just not acceptable to part him up." After several letters of request from Pritchard's mother he became very frustrated and contacted Pritchard's sister and then his brother, "I'd had enough of the whole business...I was at the point of going and doing the ashes on my own and be done with dignity and respect." After speaking with Pritchard's brother the mother ceased her communications and requests. Ken feels that Pritchard's family didn't understand and he felt that no matter how he explained it to them, that they seemed not to want to understand. He felt that Pritchard's family had control over him that he did not want them to have and he finally had to take control and be firm about his and Pritchard's wishes. Ken remembered, "I mean, a week before he died he asked me to lie in the hospital bed beside him and said 'I want to be with *you*' and that meant *all* of him with *all* of me when I die...none of this [separating]."

Ken recalls that "I had always wanted more time...that I'd said more...or that I'd done more." One evening Ken had a dream that he feels was symbolic of his letting go of Pritchard. Ken awoke from sleeping and went out of his bedroom into the sitting room and saw a wheelchair in the place of the usual rocking chair. Pritchard was sitting in the wheelchair wrapped in a blanket. The two looked at each other, but exchanged no words and Ken felt as though he could read what Pritchard was trying to tell him; that Ken didn't want Pritchard alive

if it meant having to live with his illness, "it was my sub-conscious telling me that you can't have him the way he was...that he's gone ...and you have to let go of that." Although he sees this as a letting go dream, Ken stated that he still thinks of Pritchard on a regular basis, has pictures of Pritchard, visits special places and sometimes feels as though Pritchard is watching over him. Ken also reported that feelings of loneliness accompanied this dream.

The last trip that Pritchard and Ken took together was into the Rockies, when Pritchard was quite ill. The last part of their trip was somewhat of a let down and after Pritchard's death Ken decided that he would try to redo the same trip with hopes of a more positive outcome. However, Ken found that he couldn't deal with the emotions that accompanied retracing the steps that he and Pritchard had recently done together and decided to cut the trip short, and come home early. As he came home through Revelstoke and Roger's Pass, he found it to be a very emotional time. Ken decided to visit the hydrodam, as Pritchard had had a fascination with water throughout his childhood. He went up to the top of the dam and looked down into the water. Ken noted that this was the first time he felt any sort of anger: "that was the first time I had any anger about the whole death, not at him, but because he was cheated out of so much more...it was just a total rage." However, when Ken returned to his motel and thought about his trip he realized that he was trying to connect with Pritchard; he was looking for things and places that they had shared. Ken then realized that all the time he was searching for Pritchard, Pritchard had been with him and he hadn't realized it.

Pritchard had specified that he did not wish to have a funeral, rather he wanted a celebration of life. On June ninth, Pritchard's birthday, Ken held the celebration of life. Ken recalls that although Pritchard's family had wanted a traditional funeral service, they were pleased with the service as it was. Pritchard's ashes were scattered off of a pier at Porteau Cove, and almost everyone in attendance also had a flower to throw into the ocean. Ken recalled that

when he came home from the celebration, that a Christmas cactus that had never before bloomed on Pritchard's birthday had bloomed with one flower. Following the celebration of life Ken went fishing with his parents and siblings and noted that when he came home he felt as though he was coming home to an empty apartment, "because nothing of him was there anymore." He stated that this realization started his feelings of loneliness all over again, but also noted that these feelings were not continuous, but there were ups and downs to his loneliness.

Ken attended the International AIDS Conference in July with hopes that he might find answers to his questions of why things happened. He stated that the whole week was an incredible experience for him. He remembers attending one function that led him to another and then another; "it was like the whole week someone was planning it and organizing it around me." He met many interesting people and had many stimulating conversations with people that were working within the AIDS community. At the time of the conference, Ken had not yet decided if he was going to make a panel, in memory of Pritchard, for the AIDS quilt. However, when he saw the quilt and the panels that were presented he decided that he, too, wanted to create one in Pritchard's memory, "I want other people to see him, not just know his name or number, but to see what he was like as a person."

In November of 1996, Ken went to Revenue Canada to close some more of Pritchard's estate. He spoke with someone in the office and he realized that although he wasn't finished, he had done a lot more than he had thought in closing Pritchard's estate. When Ken left the building he recalls becoming quite emotional, "people don't understand that you're basically erasing someone else...so that hurt." Ken also remembers feeling very angry: at the way the system is set up, at the lack of equality for homosexual and heterosexual couples, and at the lack of recognition that he and Pritchard were indeed a couple, not 'close friends.'

The final point that Ken placed on his time line was his trip to Hawaii in February 1997, and a dream that he had about the new medications that are now available. He went to Hawaii with his parents for two weeks and recalls that he did not enjoy the first week at all, and then during the second week he had a dream. Ken always wondered what might have happened if Pritchard had had access to the new medications that were now available and appeared quite successful for people living with AIDS. In his dream he and Pritchard went to bed and Pritchard was very weak and on the verge of death. Ken recalls that in the dream when he awoke the following morning Pritchard was already out of bed and chastising Ken for sleeping in so late; Pritchard appeared to be healthy and strong once again. Ken then asked him if he could take the new medications at which point Pritchard turned to him and said no, that it was too late for him. Ken realizes that he needed to acknowledge that it was too late for the medications to help Pritchard, and that they could not change what had happened. Ken feels that this dream signifies that he was letting go a little more; he feels that he was finding more peace with Pritchard's death. Ken stated that he doesn't like the notion that 'closure' can take place, as he "[doesn't] think you're ever leaving it behind...you're a product of all the things you've experienced, whether they're good or bad."

When asked about what Ken thought his future would be like he stated that he has begun to think about that on a more regular basis. He stated that the only thing that he sees in his immediate future is the completion of the quilt panel. As for his long term plans, he has considered traveling, or going to the Gay Games in Amsterdam in 1998. Ken stated that for now, he is not comfortable with going too far away from home, "I don't do anything that I can't drive home from...I mean I can go for two or three days and if I need to I can bail out."

Ken sees the central issues of his grief experience as feelings of emptiness. He says that although he feels pain and sorrow, he has trouble with occupying his time, "what do you do with

all your free time? I mean, you can't sit around with couples all the time, you get tired of going by yourself, and you can't stay home either...it's like a hot potato."

General Accounts of Grief

When asked if he had been able to make sense of his loss, Ken responded that he doesn't feel that he has made sense of it per se, but has rather found peace with Pritchard's death. Furthermore, Ken feels that Pritchard helped him to achieve those feelings of peace, through "watching and listening to what he had to say, and reflecting back over what he did." Ken feels that he has recovered, in a sense, from his loss. To Ken, recovery means the ability to "get your life on course and go out and do new things." However, Ken noted that he doesn't feel that a person can ever leave such experience behind them, but rather is a product of all experiences, good or bad, and this leads to personal growth. Ken believes that he has changed as a result of his loss: whereas he used to see the individual as more important, he now views "the collective, the group of people, and people, family, friends, people who are sick are more important." Ken has learned that he is a stronger person than he originally thought he was.

Michael

The interview with Michael was carried out at his place of employment. The interviewer met with Michael on two occasions and the duration between the two interviews was approximately one week. In total, the interview with Michael was approximately four hours. During each interview, Michael and the interviewer sat at a small round table across from one another with the tape recorder situated between them. Michael maintained eye contact with the researcher throughout the interview. He seemed comfortable with the discussion that followed and elaborated on each point that he had placed on his time line, although he noted that some points were redundant as he had discussed them in accordance with previous points. A few times during the interview, Michael became emotional. Michael was uncomfortable in talking about

his partner's family and avoided speaking about that at the first meeting, opting to discuss the family at the second meeting with the interviewer. Michael also cried a few times during the interviews. He cried when remembering the final ambulance ride that they took to the hospital and at his realization that Joel was not coming home again, he cried when speaking about his first holiday season after Joel's death, and he cried while discussing his feelings of how unfair he felt Joel's death was. Michael stated however, that he felt as though the process of telling his story was somewhat therapeutic for him.

Michael completed the grief time line that had been given to him at the initial meeting. He wrote his significant events/milestones perpendicular to the line. The events began before the physical death of his partner and continued into the present time. Michael's time line was longitudinal; it was a continuum in which the significant events were connected through time and place. In total, Michael reported eight events before Joel's death and thirty events after Joel's death that were significant to his grief experience.

Demographic, Personal, and Interpersonal Information

Michael is a thirty eight-year old gay male residing in Vancouver's West End. At the time of the interview, Michael's partner Joel had been deceased for about fourteen months. Michael and Joel were together for approximately four years before Joel's death. On Thanksgiving in 1994, Michael and Joel had a blessing ceremony and exchanged rings in the presence of their family and friends. Joel died on May 14, 1996 in St. Paul's Hospital on the Palliative Care Ward. He was thirty-six years old.

Michael stated that in some ways he feels lost since Joel's death. He also noted that he feels as though Joel helped him through his grief: "he helped me emotionally and spiritually...as time passed...he grew more spiritual and shared that with me." He feels that the spirituality that

he gained from Joel eased his grieving experience. Michael also gains comfort from feeling Joel's presence in his life, even though he is deceased.

When asked about his other experiences with loss, Michael reported that he has lost friends as well as friends of friends to AIDS. He also noted that his brother had died suddenly eleven years prior in an automobile accident, and his father died of cancer seven years ago. Michael stated that although he has experienced other losses, no grief experiences have been close in magnitude to the death of Joel. Michael doesn't feel that his other experiences with loss have affected his present grief experience, although he notes that the other loss experiences tend to resurface somewhat. That is, he states that when he talks with other people that have/are experiencing losses, he is more apt to bring up the losses of his father and brother, as well as Joel's death. Furthermore, Michael feels as though he has a raised awareness of other people's losses, and is more willing to openly discuss his own personal loss with others and how the loss of Joel was different from his other losses.

Michael's mother accepted his sexuality and "didn't have a problem with it...loved me every bit as much," although they didn't discuss it. When Joel was ill and since he died, Michael noted that his mother has opened up: she asks him how he is doing and frequently talks about Joel. Michael also stated that his mother realizes that he has lost a partner with whom he planned to spend the rest of his life, and that she recognizes that this type of loss is qualitatively different from any other loss experienced. Furthermore, he noted that his brothers and sisters had reacted similarly. Michael has a core group of friends that he cherishes deeply. He recalls that after Joel's death one woman stayed at his house and slept with him for two weeks after Joel died. Michael also stated that "friends crawled out of the woodwork that I didn't realize cared so much." Michael found that people at work were supportive, although some difficulty ensued for

him because, "there came a time when...most people decided at some point that it's time for you to move on now, or it's time for them to stop bothering with it...it's over."

Elaboration of the Grief Time Line

For the three days before Joel died, the nurses at St. Paul's Hospital approached Michael everyday and quietly told him that they thought Joel wasn't going to make it through the night. Each time he was told this he would smile at the nurse and thank them, although he knew they were wrong, "I wasn't avoiding the fact that he was dying...I knew he was...it was obvious why they were saying this to me...but I just knew they were wrong...and they were"

Joel died on the fourth night. When Michael entered the hospital room where Joel's brother and Joel were he realized that this was the night that Joel was going to go. He asked the nursing staff to show Joel's brother to the family room so that he could spend his last moments with Joel alone. Michael stayed up all night and talked to Joel, who was unresponsive. While Joel lay in his hospital bed, Michael gave him permission to die, "I knew he was holding on for me...basically in a million different ways, told him that it was okay to go, that I was going to be okay, that I would see him soon, [and] that he didn't need to go on like this any longer." Michael stayed awake through the night, noticing that there were extended periods of time between Joel's gasps for breath. At about ten to seven Michael nodded off for about ten minutes. When he awoke he looked at Joel and waited for a breath, which didn't come. When he realized that Joel had died, he began to talk to him, only to stop mid-sentence because he realized that Joel was no longer there.

When Michael approached the nurses station, he was unable to respond when asked what the nurse could do for him, "I didn't respond. I just looked at her, I couldn't talk; I think I was afraid that if I said something that I would crack." The nurse realized what had occurred and accompanied Michael back into Joel's room for a brief moment. She then stayed with him while

he had a cigarette and a cup of coffee, and then accompanied him to the family room where he told Joel's brother. Michael packed up Joel's belongings that were returning home with him and brought Joel's clothes down to a ward that had advertised that they were in dire need of clothing etc. Until that point, Michael had not cried. When he dropped Joel's clothes off at the nursing station, the attending nurse seemed inconvenienced by him and her coldness caused him to 'crack,' "I cried and I went back to the elevator and I cried my way up the elevator." Michael was told by one of the nurses on the palliative care ward that Joel's bed was needed for another patient, and informed him that Joel's body needed to be picked up by noon or he would be taken to the morgue. Michael called the friend that was to take care of the body and he felt confident that it was under control; he then gathered up Joel's belongings and went home.

Michael had a friend pick him up at the hospital and take him home, although they were unable to stay with him as they had another commitment. When he got home he phoned some of his friends and paced in the silence of his apartment until they arrived, "it was really quiet, quieter than I ever remember my apartment ever being and I just paced, and paced, and paced...I just couldn't stand being alone." In order to pass the time and put an end to the silence, Michael hooked up his stereo (a job that had become a non-issue during Joel's illness) and began playing music. Soon after, people started arriving and by evening his apartment was full of friends offering their support.

Prior to Joel's death. Michael began his time line before the actual event of Joel's death. He identified eight significant milestones that occurred before Joel's death: the news, the doctor's appointments, the homecare, the ambulance rides, Rod Stewart, their last trip to Saturna, promises, and the last hospital stay. Michael noted that the news of Joel's illness was more shocking to Joel than it was to him. They had been living together for three months and Michael sensed that there was something wrong with Joel; he was complaining of ailments that seemed

not to go away. Since Joel didn't have a doctor, Michael took him to his. Upon Joel's diagnosis, Michael recalls that he recognized that his role was going to be to provide Joel's care, "it was just like in one instant I was caregiver...and it didn't stop...I was totally fine with that." The significance of the news to Michael was the feeling that their lives changed in an instant. Joel resisted going to his various doctors appointments, and it was difficult for Michael to get him to go. Michael usually accompanied Joel to his appointments to offer his support to Joel and to keep informed of Joel's health needs and/or concerns. Michael feels that going to the doctor was difficult for Joel because, "every doctors visit...was just a reminder of the reality." Joel resisted the homecare that was offered to him on several occasions. However, Michael eventually had to insist on homecare because he was working full-time and was unable to do the additional tasks that needed to be done. Once a routine was established, Joel adjusted to homecare. Michael recalls that the healthcare nurses were very helpful to both Joel and himself. They offered their support and their knowledge to Michael and gave him confidence that he was providing adequate care to Joel. Joel was taken to hospital by ambulance on three occasions; the last ambulance ride to the hospital was the most difficult because Michael knew that Joel was close to death. As Michael recalls, "I knew when I called the ambulance, um, that he wasn't going to come home. And when we got to the hospital and I got out of the ambulance...I'd never seen him look so awful, like he just looked like he was about to die, which he was...I got this immediate 'this is it' feeling." Michael stated that even now sometimes the sight of an ambulance or the sound of its sirens makes him recall that last ambulance ride and causes an emotional reaction.

Saturna island was a special place for Michael and Joel; they went on their birthdays and their anniversary, as well as any other time they could throughout the year. Prior to their last trip to Saturna, Michael took Joel to see the Rod Stewart concert at GM Place because he was Joel's favorite artist. Joel's health had deteriorated to the point that he was fairly immobile, and needed

assistance walking, but he attended the concert and enjoyed it immensely. Although Joel was quite ill on his last birthday, they went to Saturna island together for one last time. They had a small birthday celebration for Joel and enjoyed a peaceful week. Joel spent almost the entire week in bed, and on more than one occasion Michael wondered what he would do if Joel died on the island. Joel survived the week, although he was visibly weaker when they left the island. The day after they arrived home Joel went to the hospital for the last time. He remained in hospital for three weeks before he died in St. Paul's Hospital, as discussed above. Michael has struggled with promises that he made to Joel before he died. Michael promised Joel that he would not be with anyone else after Joel's death, and that he would not remove his ring. Michael still wears the ring that he exchanged with Joel at their Blessing Ceremony; he reported that it's "an ongoing struggle to this day."

After Joel's death. Immediately after Joel's death, a friend of theirs came to stay with Michael, offering him comfort and support. She stayed with him for two weeks, until he decided that it was time for her to go home, "I could have done that for the next year... [b]ut I realized that [I'd] have to experience the loneliness sooner or later and I felt strong enough to start facing it." Michael recalls that while Joel was alive he essentially had two full time jobs: his paid employment, as well as filling Joel's medical and health care needs, "I was running, running, running...from the time I woke up 'til the time I went to sleep at night...it was non-stop"

While Michael was packing up some of Joel's belongings he found a poem, written by Joel, amongst his belongings in his night stand. He was unaware that Joel had written such a poem, and feels as though it was written to read at his wake. Joel's wake was a significant event in Michael's grief experience. It was held at Michael's workplace, and a microphone was set up so that those in attendance had the opportunity to pay tribute to Joel. Michael was overwhelmed by the outpouring of love and support that was demonstrated at Joel's wake, "there were

beautiful flowers everywhere...I watched people come in and it filled up like I've never seen before...and hours went by and it was still going on."

After Joel's death Michael found that he didn't know what to do with his time and felt a sense of boredom set in, he therefore decided to return to work shortly thereafter. However, returning to work was difficult, as the sympathy that he received from his colleagues was hard to take and he found himself constantly having to explain to work acquaintances that Joel had died. Although Michael noted that he has always enjoyed a drink now and then, he noticed that he began to drink more after Joel's death and feels that this was due to the fact that he didn't want to go home and be alone. Michael recalls that sex and intimacy were difficult for the first year after Joel's death. He noted that he experienced guilt feelings when he was involved with other men and related these feelings back to the promises that he made Joel before his death. Michael would talk about Joel's death which often lead to discussing issues of his own health status, and he recalled that if the men didn't understand what he had gone through he wanted nothing to do with them. He also found that he missed the intimacy that he had shared with Joel: "it was so awful to have sex with someone that, um, wasn't going to curl up and go to sleep and be there the next day...so it became something that I really wanted to do and I always regretted doing...I can honestly say...that the entire first year was like that."

Michael noted that although he has felt lonely at other times in his life, he has never experienced that loneliness that he felt after Joel's death. He feels that this is a loneliness that will be with him for the rest of his life; it's not something that being with other people can cure: "you can be with all your friends, you can be with your mom...and there's a kind of loneliness that I believe I'm stuck with for the rest of my life...no one is ever going to be Joel."

Issues with members of Joel's family were significant throughout Michael's grieving experience, and were difficult for him to talk about. Joel had grown up in an abusive

environment, and when Joel and Michael met, Joel's parents had not had any contact with him for over two years. However, when Joel found out that he was sick, he felt as though he had to tell his family. Joel's family then became more involved in their lives, although Michael notes that this was not necessarily a positive occurrence. Joel's parents appeared to be concerned as to whether or not Joel had a will or any insurance policies; his oldest sister didn't become involved; a set of twin sisters came for four days, however, Michael felt that "they did more shopping downtown than visiting with their dying brother;" Joel had a twin brother that had a very difficult time dealing with Joel's illness; Joel's younger sister visited several times and Michael established and maintained a quasi-relationship with her, until upon Joel's death Michael feels as though she turned on him, severing the relationship that they had built; Joel's other brother frequently visited and was the only family member in town when Joel died. Joel's father never came to see Joel, whereas his mother did. Michael felt that Joel's mother interfered with their lives immensely: "they were being really evil...as long as Joel could speak for himself I was a really nice guy and they were glad I was with him...as soon as there was a point where Joel couldn't really react...I was a piece of shit." After Joel's death a lawyer representing Joel's parents contacted Michael contesting Joel's will; they wanted possession of Joel's ashes, whereas Joel had stated that he wanted Michael to scatter them. However, to avoid the legal hassles while he was trying to deal with his loss, Michael sent half of Joel's ashes to his parents, and scattered the other half on a mountain top on Saturna island. Michael stated that although he was angry at Joel's family, he found some solace in realizing that he was more of a genuine and caring person than Joel's own family had been.

Michael feels as though scattering Joel's ashes represented a stage of letting go. A number of friends accompanied him to Saturna island to share the experience and offer their support. He recalls that it took about fifteen minutes to scatter all of the ashes, and that when all

of the ashes were gone, he felt empty, "and it was even hard to walk away from that spot, it was like leaving him behind." Michael's first visit back to Saturna island was difficult because it reminded him of their last visit together on the island, and it also reminded him of how sick Joel had been at that time. He noted that he has been back several times since and feels that it is getting easier to be there without Joel, although his presence is still felt.

Although Michael has attempted to remove the ring that he received from Joel at their commitment ceremony, he has been unable to part with it thus far. He feels that although he has some guilt feelings about removing it because of the promises that he made to Joel on his death bed, he also feels a very strong spiritual connection to Joel through his ring and notes that he often touches it when he thinks about Joel or talks to him. Michael also noticed that a few plants that Joel had bought before his death began to bloom constantly after Joel's death, although they bloomed only once a year prior to this.

Each Year that Michael has lived in Vancouver, he has hosted a large dinner party on Thanksgiving (the smallest being 66 people, the largest was over 80 people). Joel and Michael had their commitment ceremony at one of these annual parties, but as Joel became sicker, the parties decreased in size. The Thanksgiving before Joel died, Michael had to cancel the party because Joel was admitted to hospital. The first Thanksgiving after Joel's death, Michael did not host the party as he didn't feel up to it, and feels that this demonstrates that he had difficulty getting his life back to normal. Michael also had a rough time the first Christmas after Joel died, "I'd go into a store and look at something and start crying...I was in some of his favorite stores and I just couldn't deal with it." Michael was unable to continue with his Christmas shopping that year because it was too difficult for him emotionally. He explained to his family and friends that he would not be participating in the holiday as he usually did, "[I] just skipped it...I had a very miserable Christmas." Christmas day was particularly difficult for Michael; he recalls that

he was very emotional and cried much of the day. Although he had a tree and cooked himself a Christmas dinner, he notes that “[it was] probably one of the few times where I just didn’t even want to live.” Michael’s first New Years Eve without Joel was particularly difficult when at midnight everyone appeared to be so happy, although he noted that his overwhelming feelings were gone as quickly as they had surfaced.

Michael mentioned that often when he has wondered what Joel might think of something that is going on in his life he envisions certain faces that Joel used to make when he was alive. He feels that these faces often “guide [him] as to where to go or the answers to the questions that are running through [his] mind.” When Joel became too ill to walk, he resisted using a wheelchair and instead bought a motorized scooter. Since Joel’s death, Michael has decided that he should sell the scooter, as it is worth a lot of money and it is something that he will never use. However, he notes that every time he thinks about selling it he avoids taking the appropriate steps to do so. He also notes that seeing the scooter and just going near it still upsets him. He feels that avoiding selling the scooter coincides with the notion that he has avoided much of his grief, “I feel like I do it on purpose...if I can possibly manage to postpone some of it so I can feel a little bit better, I will.” He also fears that when selling the scooter, he will be faced with a number of sick people, which is something that he finds difficult.

Michael really loved the home that he lived in at the time of Joel’s death and attempted to purchase it so that he could stay there. Unfortunately, he was unable to do so and was forced to move. He felt as though he wasn’t ready to move and was being forced to. He packed up his belongings, placed most of them in storage, and moved into a rooming house until his new place was ready. However, when Michael went back to his home to complete the final clean up before handing over the keys, he found that he did not miss it; this made him realize that he wasn’t leaving any memories behind, but that all of his important memories, treasures, and possessions

would be with him wherever he went. He recalls that what originally seemed to be a negative experience turned out to be a positive one.

Prior to Joel's death, Michael had considered creating an AIDS benefit inspired by the "Starry Night" AIDS benefit that occurs annually. After Joel's death he decided to create the benefit in his memory, and titled his project "And Then the Angels Sang." He began the plans in January 1997 in order to have the project finished and held around the anniversary of Joel's death. "[W]hen I started working on it...it was just good timing [or] it was the project itself, that did it for me but I started really feeling a lot better finally...that was my turning point." He recalls that everyone that was asked to participate in the production was honored to do so. Michael feels that promoting the show was a form of therapy for him because he told his story of why he was putting the benefit together many times, "to have to go around town to every person I know... I've seen before, and every stranger in some cases and explain to them what has gone on in my life to make me want to do this and how much this is needed...over and over again, couldn't do anything but help." To open the show, Michael recorded a monologue explaining to those in attendance why he had created the benefit, and dedicated it to Joel's memory. Although Michael wanted to create an uplifting show where people could enjoy themselves and the music, he didn't want them to forget why they were there; he wanted to give everyone the opportunity to remember loved ones. Michael recalls "it was truly wonderful, I must admit...it made me feel very proud."

Joel's birthday, as well as the anniversary of Joel's death were significant events in Michael's grief experience, although he notes that there were no specific stories about either event, just that they were emotional days. He recalls that although on the anniversary of Joel's death he remembered many positive things about Joel and their relationship, he was also plagued with bad memories of his illness, the hospital, and the negative family interactions.

Michael noted that the birth of his friend's baby was a significant event because it was the first time that he had had the opportunity to go into St. Paul's Hospital and be happy about something, and to feel fine with himself. However, he recalled that while he was holding his friend's baby and telling her how good he felt to be there for a happy reason, his mood suddenly changed and he felt the sadness again. This sadness was magnified when he went up to the rooftop garden to have a cigarette and saw the people in wheelchairs with their intravenous poles and he recalled being in a similar situation with Joel when he was in the hospital.

Michael recalled that after the three months of hard work preparing the benefit and the benefit itself was finished, he fell into a depression that lasted about one month. He noted that he was surprised by this depression because he thought that he was on an upswing, and he was also surprised with how long it lasted. He was considering going to see a professional when he was approached by an individual that had attended the benefit about participating in this research project; he recalls, "once again it felt like...this was the answer coming to me...what I had to do was go through the process and tell my story...[I'm] feeling that this is therapeutic."

Michael's birthday was also a significant event. He recalls that he was feeling very unspecial on his birthday, because he was missing Joel, and all of the special surprises that he used to prepare for his birthday. Rather than having a large birthday celebration, Michael went out with a close friend for a quiet dinner. Michael noted that, "it seemed so strange all these...Thanksgivings, and Christmases, and birthdays, and all these things have always been really big to me, like I always made the biggest and best of occasions like that...and I just don't seem to have it in me to do."

When asked about what Michael thought his future would be like he stated that he sees himself living at his current home for a few years and eventually moving to Saturna island to live. He also sees a significant person in his future, although he noted that he doesn't think that

he will ever have a relationship like the one that he shared with Joel. He hopes that he will meet someone who will be able to understand what he has gone through and respect that Joel will always be an important part of his life.

Michael sees the central issues of his grief experience as feelings of avoidance. He noted that prior to Joel's death he constantly focused on Joel and therefore didn't have time and also didn't choose to focus on himself and his feelings. He also noted that he now finds it difficult to go back and deal with feelings that he has avoided, "so I'm kind of burying stuff that I know is going to creep up." He hopes that his grieving will become easier as time passes, and feels that holiday times and birthdays (i.e. anniversaries) will become easier to cope with. Michael feels that although he had sufficient warning that Joel was going to die he feels that he didn't have enough time to prepare for it. Michael also recognizes that anger has played a central role in his grief experience. He says that "I really have a hard time thinking that someone that had such a rough life when he was a kid and was finally feeling happy and secure for the first time in his life had to lose his life...I have a hard time understanding why the people that did that to him wouldn't drop dead instead."

General Accounts of Grief

When asked if he had been able to make sense of his loss, Michael responded that it does not make any sense to him, nor does he think it ever will. However, he feels some comfort and understanding through his spirituality. Attempting to have it make sense to him, Michael believes that Joel is in a better place and that he was selected to die for a specific reason. Michael does not believe that it is possible to fully recover from a loss like he has experienced. He feels that although recovery to a certain extent is possible, a part of your grief stays with you for the rest of your life. He feels as though he has been scarred through his experience, "a lot of images that make me really sad...to watch someone that is a very healthy, strong, vibrant person

disintegrate before your eyes over a slow period^d of time...you're damn right it affects you...and no it doesn't go away, not for a second."

Michael feels that he has changed as a result of his loss. He feels that he has changed spiritually, noting that this is grounded in his belief that they will be together again one day. He also thinks that he is not as happy a person as he was prior to Joel's death and that he is more emotional than he previously was. He noted that one of the major changes was that he recognized that things he thought were important in his life are no longer as important, and he has adjusted his priorities to focus more on the importance of friends, family, and his personal life. Through his grief experience, Michael feels that he has learned about the art of caregiving. He has also learned that he is a stronger person than he ever thought he was. Furthermore, after losing Joel, he realized how strongly he felt about him and the relationship they had shared. Michael also feels that Joel was lucky to have him, "a nurturing kind of caregiving kind of person by nature...[what] people tell me was a really huge job, was nothing to me."

In his concluding remarks, Michael stressed that he believes that although he has shared his story, nobody can ever really fully understand his experience. He stated, "No matter what someone can say, you'll never get the slightest grasp as to what's going on in someone's head, in someone's heart...I can get you to know what happened, but I can't get you to feel how it feels...[no one] can possibly think that they know what it's like unless they've been through it, and I pray they never will"

Emergent Themes

Emergent themes were established predominantly by the areas/events where participants placed emphasis and/or repetition was demonstrated. Wherever possible, the words of the participants were used to categorize the themes.

David

Four themes emerged from the interview with David that characterized his grief experience: living the experience, connection/Chris's legacy, passing through stages, and closure. These themes are connected throughout David's grief experience. That is, David talked about his movement through several stages towards closure, which was achieved through personal experience and a sense of connection with Chris.

Living the Experience

Living the experience appeared to be important to David from the beginning of his relationship with Chris. David believes that "the central thing about grieving is [not to] avoid it...I've indulged in grieving...I've dealt with it all as intensely as I can and I've had to." David also feels that it is important to not be afraid of the grieving process, and believes that it can be very satisfying to "dive right in and experience it...it adds validity to the person's life who's gone, to give them that grief, that time, that energy and emotion...it validates that experience."

David knew that Chris had AIDS prior to their relationship, and he stated that his decision to begin the relationship was made out of compassion rather than passion. Chris died at home in their bed with David at his side, and up until his death, David had been very active in Chris's care. David's initial response to Chris's death is indicative of his desires to actively grieve his loss. David was aware that Chris's death was approaching and he chose to spend their last days together quietly offering his love and support to Chris. He recalls that at the moment of Chris's death he immediately went into action; he straightened out the body, and phoned the doctor and some family and friends, as well as the priest. David lit some candles and placed them on the headboard of the bed and played some Gregorian chants on the stereo while he, his son, two close friends, and the priest held a vigil around Chris's body. David also spent some time alone with Chris's corpse and recalled that he found it comforting to be able to talk to, hug,

and kiss the body. After Chris's death, David spent a lot of time alone and would frequently think about Chris, cry, and talk to himself. He also reported listening to the funeral tape on several occasions.

David found it traumatic to sort through Chris's personal effects and possessions. However, he felt it was important to choose what things of Chris's that he wanted to keep. He recalls that he and Chris were "the same size in everything, from shoes to trousers to shirts...I was trying on everything to see what I wanted to keep and what I wouldn't keep...I was virtually crying through the whole day as I went through all his clothes." David stated that the first major anniversary that he had to deal with was his first Christmas and New Years without Chris. He recalled that he was not feeling very joyful, and was in survival mode through the holiday season, "the first year it was pretty hard to live it up and have fun."

David planned to scatter Chris's ashes in California at the same place where they had scattered his sisters ashes three years prior to his death. He felt scattering Chris's ashes with his sister symbolized that they were back together and this was meaningful because Chris had missed his sister so much. David recalled, "I sifted the ashes bit by bit, I didn't rush it...it was very calming."

David noted that stimuli, or things that reminded him of Chris and made him emotional started to diminish after about a year and a half, "as I experience more of them there are fewer and fewer to go through as far as emotional hoops and memories...and each time they happen, they are less severe than they used to be; I deal with the emotion in a matter of minutes rather than days or hours." He also stated that the memories that were once painful have become more comforting with the passage of time.

Connection/Legacy

Maintaining a sense of connection with Chris was important to David throughout his grief experience. David stated that, "the person I am now is part of Chris, and everything that was good in him is really part of me in many ways now: the way I think, the way I analyze or judge or do things...the way I relate and feel...Chris is no threat to any relationship now; he is an enhancement to it." David also noted that Chris's memory permeates his every day life, "I can't go anywhere without remembering some experience...every town I go to, every neighborhood I go into, every walk I go on brings back his memory."

David stated that in the first months after Chris's death, he felt Chris's presence, and would sometimes feel Chris's hand holding his when he was laying in bed. He recalled that "it was an amazing sensation...blew me away" and felt as though this experience was linked to the last few days of Chris's life when David lay in bed with him and held his hand as he gradually faded.

David achieved a strong sense of connection with Chris by maintaining relationships with their mutual friends, as well as maintaining relationships with people that were close to Chris. David went to Victoria with Chris's friend Pritchard soon after his death. He noted that Pritchard had helped to provide some of Chris's care in the last few months and that Pritchard and Chris had become very close friends towards the end. He felt that it was nice to be away with someone who had been close to Chris and was also grieving his death. He also found it comforting to spend time with a close friend of Chris's, sharing personal stories and offering support to one another.

In the September following Chris's death, David went to Switzerland to visit a close mutual friend of his and Chris's. He felt that visiting a close friend of Chris's would be comforting, "they got along so well...and so I had to go over to see him." Unfortunately the trip

did not live up to David's expectations; he stated that although they had a reasonable holiday together, that it was too soon for him and he felt lonely despite the people around him.

About a year and a half after Chris's death, David went to Regina to see some friends of Chris's as well as one of his aunts and her husband. He recalled that the individuals that he visited were very important to Chris in the few years before he moved out west, and that they had been very involved in his life until that point. David felt that his trip was a success, stating, "all the personal stories, of all his friends, their experiences with Chris...when I left Regina...felt very content...felt really good."

Certain places also helped David feel connection with Chris after his death. The following spring, David went on a trip to the Greek Islands. David "identified [Chris] very closely with being there." He recalled that he had been there before he moved in with Chris and that on his previous trip he had looked forward to going home to Chris. This trip however, he did not have any reason to look forward to coming home, as Chris was no longer there. He noted that it was hard for him to have a good time and that he felt a "constant cloud over [his] life."

Also, at the time of the interview, David was preparing to leave on a weekend trip to Edmonton, where he and Chris had met. He stated that he feels that Edmonton is Chris's town, and that Chris had loved living there and sharing it with David. David felt that it would be interesting to experience the town without Chris, and noted that he felt as though he was "ready for [it]...I'm looking forward to going" (implicit in these accounts is evidence of his stage framework and links the interconnectedness of the themes).

Much of David's sense of connection with Chris is demonstrated by his desire to ensure that Chris's legacy continues, and that he is not forgotten. Each Easter since Chris's death, David has placed flowers at the church in Chris's memory, "it seems like the right thing to do...one of those comfortable duties...to make a statement." David also decided to make a quilt

panel in Chris's memory for the Names Project, and stated that creating the quilt panel was a way to leave a permanent record of Chris's life and that it enhanced "the peaceful feeling of doing everything you can to recognize a life that was really worthwhile."

David feels that Chris's legacy is a very important part of his life. He stated that their relationship, "was the best love I've ever experienced, so unconditional and generous, absolutely unbeatable, a wonderful companion...left me a legacy of good friends...I have an increased sense of my own self-worth...what I experienced with Chris gave a meaning to me in my life...overall, I'm more content."

Passing Through Stages

Throughout the interview, David mentioned his passage through various stages in his bereavement experience. As previously mentioned, this was also evident in the way that he structured his time line into four six month intervals. David spoke of his bereavement as though he moved through several stages that were necessary to experience. Each of these stages completed part of a process that validated his grief experience: "it felt like the completion of a process...part of a process that needed to be done." David spoke about stages throughout the interview, stating that he was "not at the right stage" that his grief "was progressing," that he "was getting towards the final stages, and that he had "chosen to go through the steps" to successfully grieve his loss.

Closure

The end result of David's progression through stages was closure with Chris's death. He stated that to him, closure included feelings of renewed strength and acceptance of the loss and an ability to move on in everyday life. David mentioned closure several times throughout the interview. He noted that he felt that sorting through Chris's personal effects and possessions was "an amazing closure process," although he recalled that this was a particularly traumatic and

emotional day. David also felt that scattering Chris's ashes was indicative of a part of his closure process: "when I had done it...I felt almost a metaphorical lifting of a spirit leaving me, felt this weight leaving my body...felt quite a big burden gone at that point; it was a major good-bye."

David sorted through a series of cards and letters that he had received from Chris during the first year of their relationship, and placed them all in a box and stored them away. He also removed the large pictures that he had of Chris on the walls in his home, and put them in photo albums or replaced them with smaller pictures. David stated that Chris has now been placed "more into memory rather than in your face presence," and that he feels as though "it's a time to move on."

Ken

Four themes emerged from the interview with Ken that characterized his grief experience: moving on/letting go, anger/regret, loneliness, and feeling Pritchard's presence.

Moving On/Letting Go

Ken noted that from the very beginning, Pritchard had accepted that he would get sick and die and that Ken was the one who had difficulty accepting this. He stated that after Pritchard's death, "your life goes on, and he always wanted me to go out and do things, even before he died...that's the hard part...finding out what I want to do; it's an up and down...but that's how it goes."

Initially, Ken joined a bereavement support group at Lion's Gate Hospital. However, he felt that it didn't adequately meet his needs, thus hindering his ability to move on, so he decided to join the bereavement support group at St. Paul's Hospital that was designed for gay men who were grieving the loss of their partner to AIDS. Ken felt that being a part of the bereavement support group helped him work with his grief rather than "being run over by it." He found it

beneficial to talk and share his feelings with people that he felt understood what he was experiencing.

Ken reported having two separate 'letting go' dreams. In the first dream, Ken walked from their bedroom into the living room and saw Pritchard sitting in a wheelchair with a blanket wrapped around him. Neither man said anything, and Ken recalled that when he looked at Pritchard, "it hit...I could read what he was saying: do you want me back from all this...and that was it." Ken felt that he was letting go of Pritchard; he was realizing that Pritchard had fought his illness as long as he could, and that he could not live any longer. In Ken's second dream, he and Pritchard had gone to bed. He recalled that Pritchard was very weak and near death when they went to bed, however, when he arose in the morning Pritchard was healthy again. Ken asked Pritchard about starting to take the new AIDS medications at which time Pritchard said that it was too late for him to benefit from those medications. Ken recalled, "I just needed to hear that, because it *was* too late." Ken thought that this dream signified that he was letting go even more, although he stated that he feels that he will never fully let go of Pritchard and that things will never be the same, he feels at peace with his loss.

In the Spring, Ken decided to attend the International AIDS Conference; "I was looking for answers to why things happened." He also saw this as a stepping stone in his letting go of Pritchard. He attended various different workshops and presentations and met many new and interesting people. Prior to attending the conference, Ken had not decided whether he wanted to make a quilt panel for the Names Project, however, upon viewing the sections of the quilt that were on display, he decided to create one in Pritchard's memory.

Regrets/Anger

Ken expressed regrets as well as some anger about issues surrounding Pritchard's death. Ken stated, "I always wanted more time, [I wish] that I'd said more, or that I'd done more." He

also stated that although he had hoped that the AIDS research and medications would progress enough to prevent Pritchard's death, the medical advancements were made too late to be of any benefit.

Ken recalled that he first experienced anger on his trip to the hydrodam. He stated that he was not angry at Pritchard, but he was angry because Pritchard "was cheated out of so much more...it was just a total rage." He feels that his anger was directed towards people who blocked the funding for AIDS research; if the fundamentalist Christians had not lobbied the Canadian and US governments to block funding for the research, the medical profession would have been one year ahead and this may have helped to prevent Pritchard's death. Ken also reported that he felt some anger toward Revenue Canada because he and Pritchard were not seen as equal partners. He feels that Pritchard's assets were taxed higher because they were a gay couple, and that this would not have happened if they had the same rights as straight couples.

Loneliness

Ken mentioned his feelings of loneliness at various points throughout the interview. He mentioned that his feelings of loneliness were not continuous, rather were a series of ups and downs. Ken stated that he felt lost and confused when Pritchard died and that he experienced feelings of "total desolation [because] the center of my world died." He also stated that a sense of loneliness accompanied his first dream about Pritchard after his death. Furthermore, Ken recalled that after he scattered Pritchard's ashes at Porteau Cove he felt as though he was coming home to an empty apartment because nothing of Pritchard was left there, and noted that this caused him to feel lonely as well.

Ken's final visit to Revenue Canada to close Pritchard's estate was a very emotional experience. He stated that he felt as though he was erasing Pritchard's life and existence, and recalled that this was very painful for him. Ken stated that overall he feels a sense of "emptiness

more than anything else...I mean, it sure hurts.” He also stated that when he was with Pritchard he felt as though he had a future and looked forward to retirement and spending their time together, however, now he doesn’t have that to look forward to anymore and feels somewhat lost and alone.

Pritchard’s Presence/Connection

Feeling Pritchard’s presence was an important aspect of Ken’s grief experience. He stated that he thinks of Pritchard on a daily basis, has pictures of him, he visits places that were special to them, and he sometimes feels that Pritchard is watching over him. Ken stated that although he knew that the ashes were not Pritchard, he felt a need to bring them home and achieved a feeling of peace when he finally had them at home. He chose to scatter them at Porteau Cove because this had been a special place for them. He noted that although Pritchard’s mother requested some of the ashes, Ken felt that it was unacceptable to part them up; he recalled, “my commitment was with Pritchard...a week before he died he asked me to lie in the hospital bed beside him and said ‘I want to be with *you*’ and that meant *all* of him with *all* of me when I die...none of this parting out.”

Ken’s visit to the hydrodam was an effort to feel some connection with Pritchard. He stated that Pritchard had had a fascination with water from the time he was a child and he visited the hydrodam in his honor. Ken was very emotional during this segment of his trip and stated that when he thought about his whole trip, he had realized that “I was looking for things and places that we had been to...and I guess I was really looking for him...I thought he was gone...but in a way he was with me and I just really didn’t realize it.”

When Ken attended the International AIDS Conference, he was unsure if he wanted to create a quilt panel in Pritchard’s memory. However, upon seeing the Names Project display, he decided that he would design a panel for the quilt. He stated, “I wanted other people to see

him...not just to know his name or number, but to see what he was like as a person.” Ken also noted that he occasionally feels Pritchard’s presence in his daily life, and that he can sometimes hear Pritchard talking to him in the background.

Michael

Five themes emerged from the interview with Michael that characterized his grief experience: caregiving that occurred prior to Joel’s death, emotional reactions, memories of Joel (both positive and negative), network support, and experiencing anniversaries.

Caregiver

Prior to Joel’s death, Michael was highly involved in providing and managing his care. He stated that he reacted differently from Joel when they heard the diagnosis and that he recognized his new role as a caregiver immediately. He recalled that “what actually when I look back on it, or when people tell me, was a really huge job, was nothing to me...I wanted to do what I did...half the time it didn’t feel like work or anything stressful.” Michael felt that Joel needed him very much, and that he was comfortable with that. However, he noted that his life changed in an instant and he became Joel’s caregiver.

Michael recalled that Joel resisted going to his medical appointments, and that his attempts to get Joel to go often resulted in arguments: “he’d fight until he was almost dead before he’d agree.” Joel also initially resisted homecare services although they were offered to him on several occasions. However, once Joel met the homecare nurses and accepted them, both he and Michael came to appreciate their assistance. Michael also noted that the homecare nurses were helpful to him and gave him confidence that he was able to provide adequate care to Joel.

The last time that Michael and Joel went to Saturna Island, Joel was very ill, and Michael felt that he was close to death. Michael recalled that he was afraid that Joel might die while they were on the island, and he was worried about what he would do should this occur. This fear

reinforced his notion as being Joel's caregiver. Michael recalled that Joel spent almost the whole week on the island in bed, and that when they left the island, Joel was visibly weaker than he had been when they arrived. Upon arriving home, Joel spent one night at home and then went to St. Paul's Hospital the next day, where he remained for three weeks before his death.

Emotional Reactions

Michael stated that the last few days prior to Joel's death were very painful. He recalled that he knew when Joel was going to die and spent that last night talking to him and giving him permission to die, "up until then I was encouraging him to live...I told him that it was okay to go, that I was going to be okay...that he didn't need to go on like this any longer." When he approached the nurse after Joel had died, he stated that he was unable to talk, "I was afraid that if I said something that I would crack," and that he felt like a zombie. Michael cleaned up Joel's personal belongings and left the hospital soon after his death because he felt like there was nothing that he could do.

Michael recalled that before Joel's death his life was very hectic, "I was running, running...running ragged...[after Joel's death] I realized how exhausted and run down I was." However, he stated that after Joel's death he felt as though he had a lot of time on his hands, and a sense of boredom set in. To avoid feeling bored, Michael returned to work less than a week after Joel died.

Michael noted that the first week after Joel's death was hectic and emotionally draining; Joel died on a Tuesday, the wake was held on the Saturday, and he returned to work on the Monday. Joel's wake was also an emotional event for Michael, and is discussed in further detail below.

Michael stated that he began to drink more than usual after Joel's death. He recalled that he found it difficult to go home from work and be alone, instead, he remained at work and had a

few drinks, and would go out to bars to avoid being alone. Michael also experienced guilty feelings around sexual encounters. He stated that sex "was pretty easy to find, but pretty difficult to deal with." He related this difficulty back to the promises that he had made to Joel that he would never be with anyone else, and stated that he felt like he was cheating on Joel even though he's gone. Michael also stated that for some time after Joel's death, he would feel anxious when passing hospitals, seeing ambulances, as well as when he saw sick men.

Michael stated that he felt a lonely feeling like nothing he had ever experienced before. He stated that the loneliness that he experiences as a result of his loss is not something that being around other people can cure: "this kind of loneliness, you can be with all your friends, you can be with your mom, and you can be laying in bed with someone...[it's] a kind of loneliness that I believe I'm stuck with for the rest of my life...no one is ever going to be Joel." Although he feels that he and Joel will be together again some day, he noted that until then he will be lonely for Joel, and he doesn't think that anyone or anything can change that feeling.

Michael expressed a lot of anger towards Joel's family, and he stated that he does not like to talk about them. Michael stated, "I still have anger towards them...I didn't need that at that time...I had enough to deal with." He stated that Joel had endured much abuse as a child, and that he had no contact with his family until he became ill. Furthermore, Michael feels that the family's concern was not for Joel's well-being, but rather for his possessions. Michael felt that the family did not care for him, nor did they respect the relationship that he and Joel shared. He stated that Joel's mother was at her home in Ontario when Joel died, and that he heard from her lawyer the day after Joel's death. He found that Joel's mother wanted to contest Joel's will, and entered into a legal battle with Michael over Joel's remains. The end result of this legal battle, much to Michael's disgust, was that he had to split up Joel's remains and send half of them to his mother. He also went through Joel's possessions and shipped anything that reminded him of

Joel's family (i.e., pictures, belongings that were from Joel's past) to one of Joel's brothers.

Michael also stated that he has had dreams in which he sees members of Joel's family, and stated that he has "woken up in the middle of the night shuddering because I've seen one of them in my dreams."

Michael recalled that scattering Joel's ashes was an emotional experience for him. He and a few close friends went to Saturna Island and scattered Joel's ashes at the top of a mountain. He recalled that because the ashes were in a vessel that was very bottlenecked, it took him approximately fifteen minutes of shaking the vessel to get all of Joel's ashes out. He noted that he found this a little humorous, and laughed, only to become angry at himself for laughing at a time when he was so upset. Michael recalled that when the vessel was empty, it made him feel empty as well, "it was so over...it was even hard to walk away from that spot...it was like leaving him behind."

Michael listed a number of milestones that he coined "rough spots." He stated that although there were no particular stories to accompany the events, they were emotionally difficult to deal with (e.g., holidays, birthdays, the anniversary of Joel's death). These particular events are discussed below.

Michael stated that throughout Joel's lengthy illness, he was too busy and exhausted to embrace what was going to happen and how he was feeling; "I had a fair warning that it was gonna happen, but it just seems like regardless of that, I didn't have enough time to prepare for it. Michael also feels as though he has avoided much of his grief, and that he has chosen to do this, "I feel like if I can possibly manage to postpone some of it so I can feel a little bit better, I will." As a result of this, he stated that sometimes his emotional reactions will catch him by surprise, and this reinforces his belief that he has put some of his feelings aside that he will have to eventually confront. Along similar lines, and perhaps related to these postponements, Michael

stated that his emotions change very quickly and unexpectedly sometimes, and he may switch from happy to sad in an instant; he feels that this has “heightened my awareness of how scarred I am.”

Michael stated that he became depressed after he completed the benefit. He recalled that after three months of hard work to produce the show, he was surprised when he felt depressed because he felt that his life was on an upswing. He recalled, “I got really depressed and didn’t snap out of it for almost a month...it surprised me.” Michael stated that in the midst of his depression the opportunity arose to participate in this study and he thought that it would be beneficial to “go through the process and tell my story...this is very therapeutic.”

Network Support

Throughout the interview, Michael identified his mother and a few friends that he feels were instrumental and supportive throughout his bereavement experience. He recognizes the importance of family and friends in times of need. He stated that he was surprised when he realized that a core group of friends “were taking care of me a little bit at first...I was really appreciative of what they were doing and I really needed them...and it wasn’t until I didn’t need them anymore that I realized that they were grieving too.”

Michael stated that his mother was aware of his sexuality and did not have a problem with it, although he noted that she did not discuss issues relating to this until Joel became ill. When Joel was ill and after he died, Michael felt his mother has opened up tremendously. He stated that his mother talks about Joel and recognizes the magnitude of Michael’s loss, “[she understands that] losing the person that you’re planning to spend your life with is different from losing any other member of your family, or any of your friends...she compares how I’m feeling to how she’s feeling about the loss of my father.”

Michael found that a core group of friends offered him a great deal of support. Michael recalled that soon after he returned home from the hospital on the day of Joel's death, a steady stream of friends came over offering their support and sharing in his grief. He stated that one woman friend in particular moved into his home with him that day, "[she] said good-bye to her boyfriend...for two weeks and slept with me every night...and didn't leave me alone." He recalled that the two lay together in bed that first night and literally cried themselves to sleep. The following day as they walked around the seawall, Michael recalled that he felt as though the world was standing still and that he was thankful to have the support of his friend, "there was one person that I found that was still alive with me." Michael also stated that this friend was instrumental in helping him plan and prepare for Joel's memorial; he told her what he wanted and "she took me by the hand to do it...[it was] beautiful."

Michael also stated that friends whom he didn't realize cared so much offered their support in his time of grief. The venue was decorated with Joel's favorite flowers, a memorial card that included a poem which Joel had written was made for those in attendance, various photos were on display, and a microphone was set up so that people who chose to could speak about Joel. Michael recalled, "one by one I watched people come in and it just poured in and filled up like I've never seen before." He stated that people said lovely things about Joel and sang songs in his honor. He was overwhelmed by the support and kindness that he received from his friends. Furthermore, when Michael scattered Joel's ashes on Saturna, he invited ten close friends to accompany him to the island. Sharing this intimate moment with close friends was what both Michael and Joel wanted and Michael was thankful for the support he received.

Memories of Joel

Michael has many memories of his relationship with Joel, both positive and negative. Negative memories stir up emotions and are painful for Michael. He noted, "I have a lot of

images that are really sad and make me really sad...and to watch someone that is a very healthy, strong, vibrant person disintegrate before your eyes over a slow period of time...it affects you [and it] doesn't go away."

Michael stated that he had a few memories that remain upsetting to him. He stated that he has flashbacks and visualizations that are very upsetting, "like a nightmare except while you're awake." One such memory is Joel's final ambulance ride to the hospital. He stated that when he called the ambulance he knew that Joel was not going to come home again and when they pulled Joel from the ambulance, he was visibly worse than when they had picked him up. He recalled that he had never seen Joel look so awful, and so close to death. He noted that occasionally when an ambulance drives by him he gets upset because it reminds him of that last ride and that he feels anxious in hospitals because it stirs up negative memories.

Shortly before Joel's death, Michael recalled that when Joel smiled, it looked as though it was physically painful for him. Furthermore, he stated this memory was very upsetting because it appeared as though Joel's teeth were wider than his face because he was so emaciated. Michael also stated that he has a difficult time looking at other sick men because it reminds him of Joel's illness. He stated that when faced with other sick men it "makes me nervous...it makes me anxious...it's hard for me." Along similar lines, Michael noted that he still owns the scooter that Joel used before his death. He stated that it was upsetting to look at and to go near because it is representative of Joel's illness and death.

Michael stated that before his death Joel was anxious and concerned that Michael would move on and find a new partner after he was gone. Michael recalled that Joel asked Michael to promise that he would never be with anyone else and that he would never remove the ring that they had exchanged at their blessing ceremony. Michael stated, "he didn't want to let go of me...and when you're looking at someone that's really sick and their dying, you'll promise

anything.” As a result of these promises, Michael struggles with some guilty feelings about being with other men, and has not removed his ring.

Michael also cherishes the positive memories that he has of Joel and the relationship that they shared. When Michael was sorting through Joel’s personal possessions, he selected and kept what he regarded as treasures of their relationship. Months later when he decided to move from their home he was surprised that there were no accompanying emotions of sadness because he was leaving their home. He realized that he was not leaving anything behind and that “all of my memories...treasures and possessions...are with me no matter where I go.” Also when cleaning up Joel’s effects, Michael found a poem that Joel had written in his nightstand. He stated that the poem was beautifully written and he felt as though it was perfect to be read at Joel’s wake. Michael decided to place the poem, along with a picture of Joel on a leaflet to hand out to those in attendance. The wake was designed with Joel’s tastes and desires; Michael had Joel’s favorite flowers, music, pictures, and other memorabilia displayed throughout the service.

Saturna Island was a special place for Michael and Joel. Michael stated that initially it was very hard for him to be on the island without Joel because it held so many memories for him; “a lot of memories, good or bad, they all upset me.” However, he stated that he has been back several times and he feels that it has gotten easier with the passage of time. Michael feels a strong connection with Joel when he is on the island. He stated that he thinks of Joel a lot when he is on the island, and often visits the mountain atop which he scattered Joel’s ashes.

Michael noted that although his ring has stirred up some negative memories of Joel’s last days, it is also very important to him. He stated that he feels a strong connection with Joel through his ring, “I’ll just touch it and instantly think of him...I know when I’m thinking of him I’ll look at it or touch it.” He also stated that he often touched and looked at the ring when he was talking to Joel. The ring also serves as a reminder of their blessing ceremony and the

relationship that the two men shared. Michael recalled that Joel often made funny faces and that he occasionally sees such faces, “[they] appear for me often times and they kinda guide me as to where to go or the answers to the questions that are running through my mind.”

Creating his benefit “And Then the Angels Sang” was extremely important to Michael. He created, promoted, and produced the show in Joel’s memory. Michael stated that he found it therapeutic to share his story and his reasons for wanting to put the show together with potential supporters. He dedicated the show to Joel and opened it up with a voice over explaining why he had chosen to do the benefit. He stated that the show was an important way to remember Joel and keep his spirit alive.

Anniversaries

Michael spoke of several anniversaries that were difficult for him after Joel’s death. Michael stated, “it seemed so strange all these...Thanksgivings, and Christmases, and birthdays, and all these things have always been really big to me...and I just don’t seem to have it in me to do.”

As previously stated, returning to Saturna Island without Joel was difficult for Michael. He recalled that he and Joel would visit the island several times a year and that it was difficult to be on the island without Joel. He stated that he felt that it was important to continue to visit the island and noted that he still stays at the same cottage that he and Joel stayed in on each visit. Michael stated that he is now comfortable with the memories of Joel that accompany being on the island.

The holidays were difficult for Michael after Joel died. He stated that although he used to host large Thanksgiving parties each year, he no longer feels up to continuing this tradition. Furthermore, he and Joel had had their blessing ceremony at one of these parties. Michael stated, “I’m finding it difficult...getting back to normal...having a bunch of people over and throwing a

party of Thanksgiving.” Michael stated that he had a hard time during his first Christmas without Joel. He recalled that Christmas shopping was so emotionally painful that he decided to stop shopping all together and informed his family and friends that he was not able to continue. “I just skipped it...I had a very miserable Christmas.” Although he tried to maintain a sense of normalcy by having a tree and a traditional Christmas dinner, he recalled that he spent most of Christmas day alone and crying. He noted that he was not even able to talk to his mother on the phone. Michael stated, “it’s probably one of the few times where I just didn’t even want to live.” Michael stated that New Years Eve was also difficult, although in a different way. He recalled that he felt fine for the majority of the evening until midnight. However, he noted that his emotional reaction to seeing everyone so happy disappeared almost as quickly as it had surfaced.

Michael noted that although there were no specific stories that accompanied both Joel’s and his birthdays, they were emotional days nonetheless. He stated that these were two more days that he didn’t want to face. The anniversary of Joel’s death was another rough spot for Michael. He recalled that he had a miserable day of sadness and negative memories, although he had hoped that the day would bring good memories.

CHAPTER 6

Discussion

The discussion that follows will address the themes previously discussed in both their substantive and structural forms. Additionally, comparisons of the approaches taken to the grief time line, the instrument through which these themes emerged, will be discussed. The inadequacy of current grief theory and conceptual literature, both as particularly focused on AIDS bereavement and more generally, will be addressed in the context of the findings of this study. This inadequacy is further supported by an analysis of some of the relevant comments offered by these participants but not encompassed by the forgoing themes, and observations of these participants in these interview sessions. This discussion will conclude with an evaluation of the strengths and weaknesses of this study and offer suggestions for future investigation.

Comparisons Among Participants

The themes characteristic of the grief experiences of the participants revealed both commonalities and distinct aspects. For example, all three participants focused on the importance of maintaining a sense of connection with their partner or keeping the memory of their partner alive. This was demonstrated by statements including feeling the presence of their partner (e.g., hearing their partners' voice, speaking to their partner, feeling as though their partner is watching over them), having dreams about their partner, expressed importance of remembering their partner, and keeping keepsakes of their relationship. Although Bowlby (1991) might refer to this as a phase of grief en route to resolution, Silverman and Klass (1996) would support these men's actions as a means to continue the bonds they have with their partner. This latter interpretation is supported by the claims of these men that their grief is not something from which they expected to "recover." It is worth noting that although the interviews with all three men demonstrated this connection, only Michael expressed any negative aspects within its

boundaries. Perhaps this suggests that, just as in life, relationships with the deceased are associated with positive and negative affect.

Attaining a sense of closure or feeling as though they were letting go/moving on was a commonality between David and Ken. This need was expressed in statements that included the desire to move on, to accept what had happened, and to 'let go' of their partner. This is what would be predicted from an attachment perspective (Bowlby, 1991; Parkes, 1972; Weiss, 1993). However, it is interesting to note that both men felt that their closure/recovery would be indicative of their ability to cope with life without their partner and learning to live without them—their bereavement has evolved into different forms and has become woven into the fabric of their lives (Schwartzberg, 1992).

As was expected, a range of emotional responses to the loss of their partner was demonstrated by all three men (Bowlby, 1991; Parkes, 1972; Weiss, 1993). Each participant was unique in the representation of his emotional expression. David actively encouraged any sort of emotional expression; recall he stated that he indulged in his grief and emotions. Ken's emotional expressions were more channeled into anger and loneliness and were evident throughout his interview. Finally, Michael's emotional reactions were more broadly stated throughout the course of his bereavement experience, including depression, anger, boredom, and guilt (Boykin, 1990; Martin & Dean, 1993a).

Michael's interview yielded three unique themes that were not expressed in the experiences of the other two men. First, Michael began the account of his bereavement experience prior to the actual physical death of his partner. He identified very strongly with his role as caregiver before Joel's death, and his caregiver theme was indicative of the time spent providing both instrumental and affective care to his partner. Perhaps this transition to the role of caregiver reflects the common knowledge of the course and consequence of AIDS in the gay

male community (Lovejoy, 1990). Recall that Mullan (1992) stated that it is not uncommon for the bereavement experience of caregivers to begin before the actual death; perhaps Michael's theme of caregiver is indicative that his bereavement began before Joel's death. The other two participants also touched on their roles in caring for their dying partners, although emphasis was not placed on their role as caregiver specifically. Furthermore, Michael stated that although he knew that Joel was going to die, he felt as though he was not prepared for his death (Martin & Dean, 1993a, 1993b). However, David wondered aloud if his relationship with Chris would have been as satisfying if there wasn't the expectation of death, noting that this aspect added an intensity to their living.

Secondly, Michael identified the theme of network support. Although this was unique to Michael, it was nonetheless expected based on Schwartzberg's (1992) notion that a greater sense of community exists within the bereaved gay male subculture. Although this was not a theme for David, he mentioned the roles of network members at various times in his grief experience. It appeared that Ken created a community through his involvement with a bereavement support group.

Finally, Michael placed significance on several anniversaries that followed Joel's death. This was in accordance with Wood's (1987) notions that holidays and other special times impact a person's bereavement experience. Along these lines, and in contrast, it was interesting that David and Ken did not indicate the importance of anniversaries given that their partners died at Easter and on Christmas Eve, respectively.

A unique theme for Ken was the focus and the expression of anger and regret, as discussed above. A unique theme for David was the structuring of his bereavement experience into distinct stages. This was his structural approach to the grief time line and evident in much of

his interview as well. This may be due, in part, to the popularization of current stage theories (e.g., Kubler-Ross, 1969) as a model for changes over time.

It is interesting to note the differences that exist between the participants with regards to the grief time line (i.e., the number of events, where the time lines began). There was a substantial range in the number of events listed as well as in the distribution of those events. Additionally, participants began their time lines either before the death or at the time of death. This may be seen as reinforcement of Schwartzberg's (1992) idea that grief is a highly individualistic experience in terms of form, substance, and nature.

Applications to Current Grief Theories

The findings of this study add voices to the questions about the adequacies of current grief and bereavement theories, particularly in the area of AIDS partner bereavement. Recall Schwartzberg's (1992) suggestions that four phenomena need to be addressed to fully understand the bereavement experiences of gay men. One of Schwartzberg's (1992) propositions stated that both the individual's orientation and illness play a role in the subsequent bereavement of their partner. This notion was not supported by the findings in this study. Perhaps this is due, in part, to the location where the study was conducted. That is, because the data were collected in Vancouver's West End where there is a large congregation of both gay men and AIDS services, this may not have been an issue. However, if such research was being conducted in another location (e.g., a small rural town), where services and support for gay men might not be present, the uniqueness would need to be examined.

Schwartzberg (1992) also suggests that bereavement among gay men who lost their partner to AIDS would be unique due to the prevalence of the disease within the gay community. It has been suggested that experiencing multiple loss would have an effect on how men grieved the loss of their partner (Biller & Rice, 1992; Schwartzberg, 1992). Although the participants

mentioned that they had lost friends, acquaintances, and co-workers to AIDS, this was not done in any thematic way. In fact, Michael stated that although he has experienced other AIDS-related losses, he felt none could compare to the loss of his partner, nor did they prepare him for such a loss. This may be seen as an implicit counter to Schwartzberg's (1992) statement. Further, none of the participants mentioned that they felt as though their partners' death was off-time or unnatural in nature, although Michael mentioned that he felt as though Joel's death was unfair.

The third notion that Schwartzberg (1992) suggests is that stage models are inadequate for various reasons. He argues that stage models cannot accommodate continual multiple loss and indicate that grief is a finite construct that can be resolved or recovered from. Further, Schwartzberg (1992) states that implicit in stage theories is the idea that bereft individuals progress through a sequence of stages towards an endpoint of recovery. Indeed, participants stated that they did not feel as though they would get over their loss, but instead would adapt to living without their partner. Schwartzberg's (1992) idea that grief is a highly individualistic process can be seen in the diversity of responses from the participants. In subtle contrast to this point is David's stage-like structure of his bereavement experience, as previously discussed.

The final notion discussed by Schwartzberg (1992) is that of the need to find meaning in the ongoing adversity of AIDS-related loss. He states that searching for meaning becomes a central focus "of grieving deaths and coping with life...a primary challenge to a grieving individual...is to find some meaning or sense in AIDS." Recall that the men were asked if they had been able to make sense of their loss and if they felt as though they had achieved a sense of recovery. Both Ken and Michael stated that they had not been able to make sense of their loss, although Ken noted that he had been able to make peace with it. However, David stated that he feels that death adds meaning and intensity to living and wondered if his relationship would have

been as wonderful without the expectation of death. In summary, Schwartzberg's (1992) theory receives modest support from these data.

David presented the account of his bereavement experience as multi-dimensional. This would fit into Weiss' (1993) stage theory approach to bereavement. Weiss' (1993) framework also suggests that successful grief is indicated by achieving a sense of recovery. All three participants indicated that they had not fully recovered, nor did they think that a full recovery was possible. David, Ken, and Michael felt that their bereavement experience had become a part of them, that they would never get over their loss, instead they would learn to live with it.

Relevant to the discussion of recovery and bereavement endpoints, Weiss (1993) mentions that "it seems necessary for individuals to develop a new image of themselves...the individual must make new commitments to new relationships" (p. 280). Recall that participants were asked if and how they have changed as a result of their loss. The responses to this question were fairly uniform in that all three men responded that they had changed; David reported a greater life contentment; Ken spoke of an increased sense of the collective and generativity; and Michael described himself as more spiritual and focused. Additionally, both David and Michael described themselves as more emotional and more willing to express emotions. These comments stand somewhat in contrast to the commitment to relationship focus anticipated by Weiss and perhaps suggest a broader spectrum of self-images following loss.

Further Comparisons

Although the themes were derived from consistency and recurrence of usage in all of the interview transcripts, several other notable points were raised across participants but with reduced emphasis, although they elicited noteworthy patterns. Primary among these were statements made by bereft partners proclaiming that they had gained some strength or learned from their experiences. David indicated that he came to appreciate a strong sense of mutuality

that he shared with Chris through his illness and death. Both Ken and Michael felt that they had learned from their experiences. This pattern appears to fit into the literature characterizing cognitive development and meaning in the reframing of traumatic events (de Vries, Blando, & Walker, 1995).

Another relevant issue surrounds the ideas of forgotten griever (Doka, 1989) and stigmatized relationships (Schwartzberg, 1992). Both Michael and Ken explicitly expressed the sentiment that they had lost a life partner; Ken made a particular point of emphasizing the difference between partner and friend. In fact, it was around this latter point that Ken expressed a great deal of anger. Together, these highlight salient aspects of the social and interpersonal context in which these losses have occurred. For these men, the term partner is interchangeable with the term spouse, although they noted that they did not feel as though this was the case in larger society, where both their lifestyle as well as the disease itself is stigmatized.

Interviewer's Reflections

Although qualitative research yields transcripts that are rich in narrative data, observations of the researcher can also add to this richness (Patton, 1990). As previously mentioned, the participants seemed very comfortable throughout the course of the interview. For the most part, each individual was eager to tell his story. Perhaps the participants felt that by telling their story they were validating the life of their partner. Both David and Michael stated that telling their story was somewhat therapeutic for them, and they enjoyed the story-telling process that they had gone through. Participants maintained eye contact throughout the interview, occasionally looking off when attempting to sort their thoughts. Also, two of the participants cried at some point during their interview, although this did not seem to make them uncomfortable. These points indicate that the participants were comfortable with both the interviewer and the surroundings in which the interview took place.

Michael's aversion to discussing Joel's family was interesting. Perhaps this indicates that even after Joel's death, Michael is protective of Joel's life. Michael's reluctance to talk about Joel's family may also be indicative of his need to keep Joel's secret about the abusive environment in which he grew up. Also, and perhaps relatedly, Michael's interview was considerably longer than those of the other two participants. One way to account for this might be the amount of time that has passed since Joel's death. However, both Ken and Michael had been bereaved for similar amounts of time. An alternative possible connection would be a relationship between the individuals' progress in their bereavement experience and the length of the interview.

Ken's interview was the shortest in comparison with the other two individuals. He also seemed to require prompting questions, such as "*what do you think this reveals about your grief?*" more often than the others. Perhaps individual difference variables played a role in this as with the other participants.

David expressed his grief experience very thoroughly. He was very responsive to the interview questions and appeared to have thought about each individual milestone. David appeared to be very in touch with his feelings, an observation that is supported by David's statements that he indulged in his grief.

Summary and Limitations

Following Weiss' (1993) framework of bereavement and Schwartzberg's (1992) proposal of the uniqueness of 'gay grief,' this study was meant to further examine the bereavement of gay men who had lost their partner to AIDS. The central themes of these participants included caregiver, living the experience, connection/legacy of the deceased partner, passing through stages, regrets/anger, loneliness, emotional reactions, letting go, network support, anniversaries, and closure. It is interesting to note that although support was offered to both Weiss' (1993) and

Schwartzberg's (1992) frameworks, neither offers a complete fit to the experiences of gay men. Although there was some cognitive and emotional evidence supporting Weiss' (1993) work, the participants reported adapting to their loss rather than fully recovering from it. Schwartzberg's (1992) notion of 'gay grief' was minimally supported. Although participants mentioned experiencing multiple losses, they did not focus on it nor mention it as affecting their current bereavement situation. Only one participant mentioned community or network support. Some evidence was found for Schwartzberg's (1992) proposal that grieving men search for meaning in their loss. These notions would also be supported by Weiss (1993) and other bereavement theorists (e.g., Bowlby, 1991; Parkes, 1972; Stroebe et al., 1993). The participants stated that they had adjusted to their loss, and learned to live with it rather than making sense of it.

It is important to acknowledge that limitations exist within the current study. The issues of the sample are one of the major limitations. That is, the sample is very small and select. It is also possible that the location of the study is a limitation. Data collected in a city where there is a high number of gay men, gay men with AIDS, and a large number of resources for persons living with AIDS may also affect the ability to generalize any findings to smaller communities. Furthermore, lacking other demographic information about the participants may also affect the interpretations of the findings. That is, because the socio-economic status of the participants in this study is not known, it is entirely possible that the results from this study are specific to one social class group. Without this demographic information, this remains to be determined. Finally, as with all research on stigmatized populations, self-identification restricts the composition of the group that is being studied.

Much of the current bereavement literature has focused on the loss of a spouse (e.g., Breckinridge, Gallagher, Thompson, & Peterson, 1986; Caserta & Lund, 1992). However, important differences exist between the bereavement experiences of gay men and of heterosexual

couples, such as the off-time nature of the bereavement in the case of the former, as well as the stigmatization of both the individuals and the disease. Schwartzberg (1992) has attempted to address these differences; his approach remains a less than adequate fit for these data. The lack of current theory research and empirical investigation limits the researchers ability to compare findings to other studies that have been conducted in similar fields.

Strengths and Implications

This study is the first known qualitative examination into the phenomenon of 'gay grief.' The nature of qualitative studies yields strong narrative results in which the interviewer is able to view the participant, as well as hear their voices as they answer the research questions. This study also indicates the need to question and perhaps refine and redirect the current model of gay grief that is proposed by Schwartzberg (1992). Furthermore, this study adds to the growing body of both the bereavement literature and the literature concerned with the lives of gay men.

Future research could examine larger samples in which gay men whose partners have died from AIDS-related causes. It would also be beneficial to carry out a longitudinal study in which both partners are interviewed prior to the death of the ill partner. This would offer insight into the nature of the relationship before the death and may add valuable knowledge beneficial to understanding the bereavement reactions of the grieving partner. Another area of research that could offer valuable input to the field of AIDS-related partner bereavement would include researching a partner dyad in which both partners have AIDS. This could yield novel results and have large implications for the study of AIDS-related survival guilt (Boykin, 1990; Murphy & Perry, 1988).

As the face of AIDS changes, the need for related studies, and in particular a focus on partner bereavement, becomes increasingly important. Issues that are important to those who have lost a loved one to AIDS need to be addressed in theory, research, and practice. Only then

can we begin to fully understand the ramifications of the AIDS epidemic. It is hoped that this study contributes to the areas of research and theory generation in the area of AIDS-related bereavement.

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APPENDIX A

Program Contact Letter, Participant Information Letter, and Consent Form

Dear <program leader/facilitator>,

I am a graduate student at U.B.C. and for my Master's thesis I am studying the bereavement experiences of gay men who lost their partner to AIDS approximately thirteen to eighteen months ago. In particular, I am interested in examining the experiences, issues, and/or feelings that bereaved individuals perceive as affecting their grief, and how these have evolved over the time period since the death of the partner.

In order to carry out my research, I require eight volunteers. Participants need to be gay men who lost their partner to AIDS between thirteen and eighteen months prior to this study. Participants will be asked to complete the Grief Time Line, a temporal representation of time since the death of their partner on which they will be asked to indicate any feelings, events, and/or occasions that have been of significance to them since their loss. An interview will follow that includes questions about the participants demographic background and an expansion and further discussion of the issues noted on the Grief Time Line. The interview will be conducted at either the participants' homes or another location requested by participants. The interview takes approximately one hour to complete. The Grief Time Line and all responses to the questions are kept strictly confidential, and participants have the right to refuse to participate or withdraw at any time without consequence.

If you are interested, I would be pleased to send you and your group a summary of the findings from the project when the study is complete.

I will be calling you in a few days to discuss further the study and to see if you may be able to identify any individuals that may be interested in taking part in the study. If you have any questions or would like further information, please feel free to contact either myself or Dr. Brian de Vries at one of the phone numbers listed below.

Sincerely,

Leigh Dustan
M.A. Candidate
School of Family and Nutritional Sciences
Phone: 264-1290

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Phone: 822-5672

Dear Potential Participant,

I am a graduate student at U.B.C. and for my Master's thesis I am studying the bereavement experiences of gay men who lost their partner to AIDS approximately thirteen to eighteen months ago. In particular, I am interested in examining the experiences, issues, and/or feelings that bereaved individuals perceive as affecting their grief, and how these have evolved over the time period since the death of the partner. It is hoped that this study will lead to a better understanding of some of the important issues involved in the grief experiences of gay men whom have lost their partner to AIDS.

Participants need to be gay men who lost their partner thirteen to eighteen months prior to the study. Participants will be asked to complete the Grief Time Line, a temporal representation of time since the death of their partner on which they will be asked to indicate any feelings, events, and/or occasions that have been of significance to them since their loss. An interview will follow that includes questions about the participants background and an expansion and further discussion of the issues noted on the Grief Time Line. The interview can be conducted at either the participants' homes or another location requested by the participant. The interview takes approximately one hour to complete. The Grief Time Line and all responses to questions are kept strictly confidential, and participants have the right to refuse to participate or withdraw at any time without consequence.

If you are interested in participating in this study, please call one of the telephone numbers provided below to arrange a convenient time for the interview. If no one is currently available to answer your call, please leave your name and telephone number and your call will be returned as soon as possible. Following completion of the study, I would be pleased to send you an informative summary of the projects findings.

Sincerely,

Leigh Dustan
M.A. Candidate
School of Family and Nutritional Sciences
Phone: 264-1290

Dr. Brian de Vries
Assistant Professor/Research Supervisor
School of Family and Nutritional Sciences
Phone: 822-5672

CONSENT FORM

This study involves exploring the bereavement experiences of gay men who lost their partner to AIDS.

Participants need to be gay men who lost their partner thirteen to eighteen months prior to the study. Participants will be asked to complete the Grief Time Line, a temporal representation of time since the death of their partner on which they will be asked to indicate any feelings, events, and/or occasions that have been of significance to them since their loss. An interview will follow that includes questions about the participants background and an expansion and further discussion of the issues noted on the Grief Time Line. The interview can be conducted at either the participant's home or another location requested by the participant. The interview takes approximately one hour to complete. Additionally, another hour will be spread over other meetings and tasks (i.e., the Grief Time Line). The Grief Time Line and all responses to questions are kept in a secure location and are treated as strictly confidential. No identifying information (e.g., the participant's name) is connected to the resulting information, and following completion of the project, the original subject data (e.g., taped interviews) will be destroyed. Participants have the right to refuse to participate or withdraw at any time without consequence.

The following is a statement of consent to participate in this study. Please read the following carefully and sign at the bottom if you agree to take part in this study.

I hereby consent to participate in the study entitled "Losing a Partner to AIDS: Bereavement in Gay Men," conducted by Leigh Dustan as a part of her Master of Arts degree, under the supervision of Dr. Brian de Vries, from the University of British Columbia. I understand that this study involves the tape recording of an interview, which takes approximately one hour to complete.

I understand that my participation is voluntary and that I am free to withdraw at any time without consequence. I further understand that the results will be kept strictly confidential. If I have any questions regarding this study I can contact Leigh Dustan at 264-1290 or Dr. Brian de Vries at the University of British Columbia at 822-5672. Also, if I have any concerns about my treatment or rights as a participant I may contact the Director of Research Services at the University of British Columbia, Dr. Richard Spratley at 822-8598. I also acknowledge that I have been offered a copy of the consent form for my own records.

Participant's name (print):

Witness:

Participant's signature:

Date:

APPENDIX B

Grief Time Line and Interview Schedule

Grief Time Line

Look back over the time since the death of your partner. Considering the things that have happened to you, the things you have done, and the things you have felt, place these on this representation of time. These could include things such as special times together, special occasions, and/or special places, as well as feelings and occurrences that are of significance to you since your loss.

death |-----| present

Part I - Demographic, Personal, and Interpersonal Information

1. What is your age (in years)?
2. How long ago did your partner die?
And how old was he?
3. How long had you and your partner been together?
4. How long was your partner sick before he died?
5. Where did the death of your partner occur?
6. Thinking back over the nature of your relationship how do you think it has affected your grief experience?
7. Have you had other experiences with loss?
Have you lost anyone else to AIDS?
Do you think that these previous experiences have affected how you grieve or are grieving the loss of your partner?
8. What has been your experiences with friends and/or family since your partner died?

Part II - Elaboration of the Grief Time Line

The interview will begin with the researcher asking:

What were your first reactions or feelings upon the death of your partner?

For each milestone indicated on the Grief Time Line, the interviewer will ask:

How was <milestone> for you?

Probing/Prompting questions will include:

What does this [*the milestone*] reveal about your grief?

Are there any other thoughts, feelings, and/or reactions surrounding this event?

Upon the completion of the discussion about the milestones, two final questions will be asked:

What do you anticipate your future to be?

Reflecting on your time line as a whole, what do you see as the central issues of your grief experience?

Part III - General Accounts of Grief

1. Have you been able to make sense of this loss? How have you done this?
2. Is it possible to recover from such a loss? If so, have you achieved this?
What does recovery mean to you?
3. Do you think that you as a person have changed as a result of your loss? If so, in what ways have you changed?
What have you learned about yourself through your grief experience?
How do you think the type of person that you are has affected your grief? For example, psychologically, physically, and/or spiritually.
4. Can you think of anything else that someone should know to better understand your grief experience?

APPENDIX C
Emergent Themes

Table 1:
David's Emergent Themes

Living the experience	Connection/Legacy	Passing through stages	Closure
<ul style="list-style-type: none"> - "it was a decision out of more reason of compassion rather than passion" - "I'd been lying in bed with him for two nights and a day just holding his hand and just being there" - "held a vigil around the bed...for about half an hour" - "amazingly easy, and comforting, to hug the corpse, to kiss it, to talk to it" - "I chose to be alone...[to] lie there and think" - "the central thing about grieving is don't avoid it... deal with it as deeply as you can...I've indulged in [it]" - "I think when you grieve properly, you take the best of your experience onward to the next person or the next place" - "never be afraid of [grief; it is a] very satisfying thing to dive right in and experience it. It adds validity to the person's life who's gone, to give them that grief, that time, that energy, and emotion. It validates that experience" 	<ul style="list-style-type: none"> - "I can't go anywhere without remembering some experience in a particular place...we did so much and went so many places...it permeates every day of my life" - "[Chris's] service had a very comfortable intimate feel to it" - the trip with Steven to Victoria; "[we] escaped together... they'd become very close towards the end" - "when I'd lie in bed I could actually still feel at times Chris's hand holding mine...it was an amazing sensation... I could still feel him there" - trip to Switzerland to see close mutual friend; trip to the Greek Islands - placement of Easter flowers at church - AIDS quilt panel; "one way of leaving some kind of permanent record" - visiting friends of Chris's - trip to Edmonton; "Edmonton to me is Chris's town and I've never experienced it like I experienced it when he lived there" - Chris's legacy; "the best love I've ever experienced, so unconditional and generous...a wonderful companion...an increased sense of my own self-worth... gave a meaning to me in my life... everything that was good in him is really part of me in many ways now" 	<ul style="list-style-type: none"> - "not at the right stage" - "it felt more like the completion of a process; one more part of a process that had to be done" - "[my grief] was progressing" - "I was getting towards the final stages" - "I've chosen to go through the steps" 	<ul style="list-style-type: none"> - "it's an amazing closure process to go through the personal effects" - scattering Chris's ashes; "I felt...a metaphorical lifting of a spirit leaving me, felt this weight leaving my body... felt quite a big burden gone at that point ...it was a major good-bye" - sorting through cards and letters from Chris; removing pictures from walls; "Chris has now been relegated...more into memory rather than in your face presence" - "renewed strength, to accept and move on"

Table 2:
Ken's Emergent Themes

Moving on/Letting go	Regrets/anger	Loneliness	Pritchard's legacy
<ul style="list-style-type: none"> - "he always accepted that he would get sick and he would die...I was the one who didn't" - "then your life goes on, and he always wanted me to go out and do things" - joined a bereavement support group; "it was a matter of working with it rather than being run over by it" - "I was letting go...you have to let go of that...it was my sub-conscious telling me that you can't have him the way he was" - "I went to the AIDS conference and again I was looking for answers to why things happened" - "that was the first time I ever felt like I was coming home to the home, to the comfortable peace, to that safe feeling" - "you keep wondering what if, should have, and all these could haves, well it was too late...you can't change what happened" - "I was letting go more...there's more peace with it, because I don't think you're ever leaving it behind" - "he fought as long as he could and he was at the end of his rope and he accepted it and he was at peace with it and now it's up to me to be at peace with it too" 	<ul style="list-style-type: none"> - "I had just hoped that they would progress to the point that they had medications and whatever and that he was doing the right thing, so that he wouldn't die...things changed just after he died" - "I always wanted more time, that I'd said more, or that I'd done more" - "first time I had any anger about the whole death, not at him - but because he was cheated out of so much more...it was just a total rage" - "when the new medications were beginning to come on the scene, and I began to wonder, oh what if he'd been on this...it was a little bit of anger not too much at traditional, but maybe if the fundamentalist Christians in the early days had not lobbied the Government in Canada and the U.S. to block funding, that would've been one more year ahead...so that's where the anger was" - anger at Revenue Canada; "anger that we're not seen as equal partners" 	<ul style="list-style-type: none"> - "you're lost and confused" - feelings of loneliness accompanied letting go dream of Pritchard - "it's never going to be the same" - when I came home [from scattering Pritchard's ashes] then it was coming home to an empty apartment because nothing of him was there anymore...it started the loneliness all over again" - "I walked out onto the street and then I got really quite emotional...people don't understand that you're basically erasing someone also...so that hurt" - reaction to Pritchard's death; "total desolation, really...the center of my world died" - "the emptiness...it sure hurts" 	<ul style="list-style-type: none"> - "I could almost hear Pritchard in the background" - bringing Pritchard's ashes home "was a type of peace" - "not acceptable to part [the ashes] up ...my commitment was with Pritchard...a week before he died he asked me to lie in the hospital bed beside him and said 'I want to be with you and that meant all of him with all of me...none of this parting out'" - "I think of him every day and I have pictures, and I go to places that were special and sometimes I almost feel that he is watching over me with the things that have happened" - visiting the hydrodam...I was looking for things and places that we had been to...and I guess I was really looking for him...I thought he was gone, but in a way he was with me and I just really didn't realize it" - scattering ashes at Porteau Cove where they had visited - AIDS quilt panel; "I want other people to see him...to see what he was like as a person" - "[I can] just be sitting at home...and feel him"

Table 3:
Michael's Emergent Themes

Caregiving	Connection/Memories of Joel	Network Support	Emotional Reactions
<ul style="list-style-type: none"> - "helped him as far as caregiving" - Joel's diagnosis; "I knew my role right away...I've got to take care of him, right now, and on" - "I was there to take care of him...it was just like in one instant I was caregiver...and it didn't stop" - getting Joel to doctor's appointments - Joel's resistance of homecare - last trip to Satuma before Joel's death; "I wasn't sure what one does when you're on an island that doesn't have a hospital or anything and someone dies because I was quite convinced that was [what would happen]" - "I learned a lot about the art of caregiving" - "when I look back on it, or when people tell me was a really huge job... was nothing to me...I mean it was something to me...I wanted to do what I did...didn't feel like work or anything stressful...it was just what I was doing" 	<ul style="list-style-type: none"> - Joel's final ambulance ride; "luckily there's only a few, but it's one of those pictures that kinda flashes back in my mind from time to time and really upsets me-like a nightmare but while you're awake" - Joel's smile; "his teeth were wider than his face" - promises made that he would not be with anyone else or remove his ring; "that's an ongoing struggle to this day" - passing hospitals; stirs up memories, feels anxious - seeing other sick men; reminders of Joel when ill - the scooter; "I can barely go near it... it just represents what happened" - "a lot of images that are really sad and make me really sad...it affects you... doesn't go away" - the poem; used at memorial - scattering ashes on Satuma Island - returning to Satuma Island - "there's a very strong connection with [Joel] and this ring" - seeing Joel's faces - moving; "made me realize I wasn't leaving anything behind...all of my treasures and possessions...are with me no matter where I go" - creating 'And Then the Angels Sang' 	<ul style="list-style-type: none"> - relationship with mother; "she compares how I'm feeling to how she's feeling about the loss of my father... [she] understood that losing the person that you're planning to spend your life with is different" - "core group of friends that are very close to me and very dear to me...very, very supportive" - support after Joel's death; "people started coming and by evening my house was full" - "Kerri stayed overnight and slept with me...she was with me for two weeks... and didn't leave me alone" - support at memorial; "Kerri basically was instrumental in everything...I watched people come in...filled up like I've never seen before" - bringing a number of close friends to Satuma to scatter ashes - recognizing the important roles of family and friends; "I was really appreciative of what they were doing" 	<ul style="list-style-type: none"> - at diagnosis; "feeling our lives change like that" - Joel's death; "I gave him permission to die...he was holding on for me" - reaction to the death; unable to speak; "I was afraid that if I said something that I would crack...I felt like a zombie" - sight of ambulances upsetting - boredom - drinking more to avoid loneliness - sex; "easy to find, but pretty difficult to deal with...I'd feel guilty...like I was cheating on him" - "loneliness I'm experiencing now is not something that being around other people can cure" - anger at Joel's family - scattering ashes; "when it was empty it just made me feel empty as well...it was even hard to walk away from the spot...like I was leaving him behind" - crying at Christmas time; unable to continue with Christmas rituals - avoidance; "I think I've probably avoided a good deal of my grief...if I can possibly manage to postpone some of it so I can feel a bit better, I will" - depression after benefit - awareness of buried emotions; - "heightened awareness of how scared I am"

Table 3: Cont'd

Anniversaries
<ul style="list-style-type: none"> - recurrent trips to Saturna Island; "I have gone back many times now...it's getting a lot easier" - annual Thanksgiving dinner party; "I wasn't ready for any kind of party...I'm finding it difficult...getting back to normal with it" - "I had a very miserable Christmas, and I love Christmas...it was a very rough spot...it's probably one of the few times where I just didn't even want to live" - New Year's Eve; "midnight hit I all of a sudden couldn't handle watching everyone be so...happy" - Joel's birthday - the anniversary of Joel's death; "a little bit too much came back to me that day...a miserable day" - Michael's birthday