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EXTRAORDINARY OUTCOMES ASSOCIATED WITH
AIDS-RELATED BEREAVEMENT:
AN EXPLORATORY STUDY

by

Joy Moon

B. A. (Honors), Simon Fraser University, 1984

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTERS OF ARTS (EDUCATION)
in the Faculty
of
Education

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ABSTRACT

This study investigated the effect upon survivors of the experience of bereavement due to an AIDS-related death. Using a self-report taped interview format twelve subjects (six males and six females) were asked to describe how their lives had changed following the death of a loved one. In addition, subjects were required to complete a questionnaire in order to provide personal data, information regarding the deceased, and insight into some aspects of the relationship between the subject and the deceased.

An examination of the personal narratives revealed that the bereaved typically experienced changes in the areas of relationships, employment, values, and attitudes toward living and dying. Themes of improved or concluded relationships, increased personal self-regard, movement toward jobs which provide a greater sense of satisfaction, a shift from material to spiritual values, a greater appreciation of life, and a radical loss of fear of dying were common. At the same time, subjects regularly indicated a general re-assessment of life priorities and a critical re-evaluation of traditional 'shoulds' originating from either religious doctrine or social expectations. All subjects attached a great deal of importance to their experience of bereavement concluding, paradoxically, that many valuable discoveries could be attributed to their unprecedented loss.

The implications of these findings are discussed for grief and bereavement counsellors in light of both facilitative pre-death counselling and follow-up bereavement work.

Finally, the present study suggests future research be designed to investigate the relationship between the bereaved and the person with AIDS prior to death, as well as the circumstances of the death. The relationship profiles emerging from this exploratory work indicate that variables such as the amount of openness in the discussion of death and dying, the degree of participation in care, the ability to express feelings, the length of the living/dying period, and the opportunity to be present at the time of death may all be associated with positive bereavement outcomes.

DEDICATION

I dedicate the merit of this thesis to Roy for teaching me about love, life, and God, and showing me that they are all the same thing. And I dedicate any future benefit of the work to Charles, Deryl, Garth, Jim, Joseph, Larry, Michael, Peter, Robert, and Roy - you continue to live in our hearts and our achievements.

And yet the compensations of calamity are made apparent to the understanding ... The death of a dear friend, wife, brother, lover, which seemed nothing but privation, somewhat later assumes that aspect of a guide or genius; for it commonly operates revolutions in our way of life, terminates an epoch of infancy or of youth waiting to be closed, breaks up a wonted occupation, or a household, or a style of living.

Ralph Waldo Emerson
From an essay on Compensation

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CHAPTER I BACKGROUND & STATEMENT OF THE PROBLEM

Background

I recently had the privilege of caring for a dear friend through the process of his dying. According to the literature on grief and bereavement much of what I experienced, at that time, was normal: despair, fatigue, weeping, and sleep disturbance. Yet, in addition to these emotional and physical problems my experience also included some undocumented aspects. Many of my values changed. Previous relationships either deepened or ended. I became very protective of my time and how I spent it. I began to see death as a genuine friend and I felt more alive than I could ever remember. Quite unexpectedly, I realized that in loving and losing this special person my own life was being transformed; that his dying was enriching my living.

Was my experience unusual? Had anyone else found such gifts in their grief? Could the human heart, in fact, break - open?

Two months after Roy's death I organized a support group for other people who had lost a loved one to AIDS. Testimony of personal gain through bereavement recurred from meeting to meeting.

That anything of value could be associated with AIDS is almost beyond comprehension. Not withholding hope for future medical advances, the AIDS virus has, to date, resulted in an epidemic of death. As of February 1990, 2122 of the 3509 Canadian men, women, and children diagnosed with AIDS are dead (Federal Centre for AIDS, 1990). Tragically, these many deaths represent only the first wave of the medical and psychological crisis that is AIDS. For each life lost there is a second emergency; a tidal wave of survivors: partners/spouses, parents, siblings, children, aunts, uncles, nieces, nephews, grandparents, friends, co-workers, neighbours, health care professionals, and more. The number of people affected by each death is substantial. Therefore, in its second wave, the AIDS crisis produces an epidemic of bereavement and grief.

Grief has always been a part of human experience. Each culture has developed and passed along grief lore to help its people cope with loss. Within the social network of family, friends, and church bereaved individuals have traditionally been supported by way of specific expectations, rituals, and theosophy. In most cultures, grief recovery has been seen as a natural process; one that time heals.

This conventional community approach to bereavement has generally been sufficient as long as certain conditions are met. Social support must be available and bereaved individuals must avail themselves of it. As well, the grief response must be uncomplicated.

Unfortunately, a number of issues associated with AIDS-related bereavement interfere with these basic conditions for unassisted recovery. These AIDS-specific issues tend to confound and/or compound the recovery process. The result for survivors can be the dual experience of insufficient support and a complicated grieving period.

The AIDS-specific issues which interfere with bereavement recovery fall into four categories. Societal attitudes towards AIDS and the actual nature of the syndrome are both issues that tend to confound the recovery process. Compounding issues are the problems of multiple losses and the possibility of HIV-related health concerns for survivors.

To begin, society's attitudes toward two of the affected populations, homosexuals and IV drug users, typically fall between suspicion and contempt. When the fear of contagion is

added to this existing prejudice the stigma of AIDS can exclude people from regular avenues of support. Families of origin may be emotionally, physically, and/or financially unavailable to those living with the disease and their caregivers. While certainly not universal, the withholding of customary family support is one hallmark of AIDS.

Societal attitudes also affect access to support when people choose not to disclose their experience of AIDS at work, school, or church. Due to the stigma of AIDS, employers, co-workers, instructors, and/or clergy may be told nothing of an individual's situation at home. The caring responses, special consideration, and/or compassionate leave normally extended at the time of serious illness and death are, therefore, often unavailable to those caring for a person with AIDS. At the same time, the intolerant doctrine of some religions may also exclude people with AIDS and their caregivers from spiritual support.

The second AIDS-related issue that can influence recovery from bereavement is the actual nature of the illness. According to Weiner's four point guide for determining the impact of a medical disorder on an individual, AIDS rates as high-negative on all counts. The syndrome typically appears abruptly; it is only moderately treatable but not curable; it carries a special stigma; and it requires hospitalization, special procedures and possible surgery (Weiner, 1982, p. 46).

While the disorder involves many difficult medical problems no one ever actually dies of AIDS. AIDS is a syndrome rather than a disease; a compromised immune system presenting as an idiosyncratic combination of secondary infections (See definition

of AIDS, p. 8). Patients suffer any combination of the following: blindness, cancer, dementia, neuropathy, pneumonia, and more. When the syndrome is fatal, death can be preceded by a rapid unexpected decline, a steady decline, a prolonged see/saw existence or long-term uncertain survival. Just as the syndrome presents a diverse set of medical problems, the range of associated bereavement issues also vary widely.

Choice of residence is another issue that is often dictated, in part, by the nature of AIDS. Due to the newness of the syndrome and the range of associated medical problems, the disorder is very difficult to manage. Patients, therefore, tend to seek medical attention in urban centres where AIDS-specific expertise, diagnostic testing, and treatments exist. In deciding to live near these specialized professionals and health care facilities patients from outlying areas often do so at the expense of family and community support.

Another aspect of the syndrome, as it presents itself today, is the age of those affected. The average age at the time of death is 33 years. Death that is seen as premature is one more bereavement issue for those left behind. The partners and friends who remain to grieve are, themselves, very often young; another unusual bereavement situation for modern times.

The third issue, multiplicity of loss, is another characteristic of AIDS-related bereavement which is unprecedented in recent times. Not only are many people being touched by an AIDS-related death, but numerous deaths are impacting upon a few people. As modern urban citizens, our participation in funerals

typically averages one day per decade and we can generally expect five or six major deaths in our lifetime (Kalish, 1985, p. 9 & 79). But, now, due to AIDS some people are experiencing far more loss. For example, eighty percent of Canadian haemophiliacs test HIV positive (Archibald, 1990). Their families are prone to multiple losses as several male members of one extended family unit may be both haemophiliac and, therefore, possibly HIV infected.

The problem of multiple loss is most pronounced in the gay community where it is not unusual for individuals to attend two AIDS-related funerals in one day (Callwood, 1988). For some this problem of multiple loss is a relentless one. A recent support group survey totalled 176 AIDS-related deaths for only seven members. Again AIDS presents a very difficult and unusual bereavement situation.

The last issue, the possibility of health concerns for the survivors, distinguishes AIDS-related bereavement from almost any other type of loss. Quite unique to AIDS, those who are left behind may be struggling with their own health worries. Unlike cancer, heart disease, or other medical problems that ultimately lead to death, a number of those who mourn an AIDS-related death are, at the same time, dealing with their own HIV infection. In conjunction with the grief they feel for the one who has died, survivors may be grieving about their own situation. In the case of an HIV positive bereaved partner, there can be feelings of grief for the loss of the loved one, grief for oneself, and the stress of knowing that if one's own health deteriorates that special person will not be present. The bereaved partner, in

this situation, is acutely aware of the loss of such an important source of support, having provided it so recently him/herself.

To compound the problem of the HIV positive survivor, it has long been established that bereavement adversely affects the immune system (Parks, 1964). If bereavement can suppress immune functioning in the general population, coping with bereavement is a matter of life or death for those whose immune system is already compromised.

There are many issues that make AIDS-related bereavement unique. Unfortunately, most of these issues serve to compound the grief of those who are left behind and confound their process of recovery. In the wake of the many problems specific to AIDS, conventional community based bereavement interventions may not be sufficient. The number of people affected by AIDS-related deaths is increasing astronomically and more and more of them are seeking professional help. It is likely that every counsellor, teacher, therapist, pastoral care person, and social worker will encounter people touched by AIDS in the near future.

Statement of the Problem

Counsellors have generally adopted a dynamic model for grief work; either concentrating on the client's movement through a series of emotions or their completion of various tasks. While the ordeal of unpleasant emotions and the chore of rebuilding one's life are both hallmarks of the grief experience, recent investigations have indicated that there may be a less onerous component. Beneficial outcomes for survivors have been discovered in a variety of bereavement situations. Bereavement

due to AIDS appears to be one situation where positive, life-enhancing outcomes can occur. A profile for this phenomenon, though, does not yet exist. In light of the influx of people seeking help to cope with AIDS-related deaths, there is an urgent need to understand all aspects of this type of bereavement. By examining the experience of those who have found something positive in their loss, counsellors may be better equipped to help those who are less fortunate. To that end, the present study asks the question "How is your life different now?" of people who have lost someone they loved to AIDS.

Definitions

A) Bereavement

To bereave means to "rob (or) deprive" (Fowler & Fowler, 1964). Bereavement refers to an event; the loss of a significant person through death. "If my father, to whom I am very close, dies, I am bereaved. If my mother, who has been both emotionally and psychologically absent from my life for 15 years, dies, I am also bereaved" (Kalish, 1985, p. 182). While implying nothing of the quality or duration of emotion associated with the event, the term signifies a date within a personal history.

B) Grief

Grief refers to the response to any loss or separation. A grief response can be all-encompassing, involving physical, emotional, and behavioural components. Historically, "grieving itself means pain and suffering" (Kalish, 1985, p. 182).

One can be bereaved and not grieve but grief is always

preceded by some form of bereavement or loss.

C) AIDS, PWA, and AIDS-related Bereavement

AIDS (Acquired Immune Deficiency Syndrome) is caused by a human T-cell lymphotropic virus. This virus preferentially infects and destroys certain white blood cells which control immune functioning in the body. Subsequently, the body becomes unable to respond normally to infectious agents and is, therefore, increasingly vulnerable to disease. Repeated severe and debilitating opportunistic infections and/or an aggressive form of soft tissue cancer result (Goldstone, 1985, p. 13).

There is no one profile for the syndrome. The patterns of infection and disease associated with AIDS are individual. Each PWA (person with AIDS) experiences a complex of health problems and each death is the result of individual circumstances. It is not the AIDS virus, per se, which kills but one or more secondary infections and/or cancer.

All deaths attributed to AIDS are contingent upon a compromised immune system rather than being directly caused by the AIDS virus. The phrase 'AIDS-related death' is, therefore, appropriate. For the purposes of this study, the experience of losing someone to an AIDS-related death is referred to as an AIDS-related bereavement.

D) Extraordinary Outcomes

extraord'inary 1. adj. (-ily). Out of usual course, additional, specially employed; exceptional, surprising; unusually great.

(Fowler & Fowler, 1964)

The outcomes investigated in this study are outside the usual

course of bereavement recovery discussed in the grief and bereavement literature. The loss of a loved one has historically been seen as an entirely unfortunate event in one's life; one of the most difficult of human experiences. The unwelcome aspects of bereavement are well documented. The possible existence of bereavement outcomes that are highly valued come as more of a surprise.

Organization of thesis

This first introductory section has presented the background of the present study. Chapter two reviews the death, dying, grief and bereavement literature, detailing the development of theory in these fields. Chapter three describes the method of the thesis; it introduces the subject population, the setting, the exploratory method, and the rationale behind the analysis of the data. Chapter four presents the findings of the study and an analysis of the data; it examines the emergence and prevalence of major sub-categories and recurring themes found in the data; interview excerpts illustrate the analysis and findings. Chapter five presents the conclusions and recommendations; it begins with a conceptualization of the dynamics involved, and proceeds with an exploration of the parallels found between the present findings and those of a somewhat related phenomenon. The chapter ends with several suggestions of ways to incorporate the findings into counselling interventions that could improve bereavement outcomes.

CHAPTER II LITERATURE REVIEW

The present review of the death, dying, grief, and bereavement literature begins by questioning the existing attitudes toward the topic of human mortality. Next, an early 'worst case' bereavement study is presented as it has selectively influenced our understanding of bereavement and grief. This study is followed by an outline of the historical development of explanatory models: first, stage models, then, various task models, and finally the most recent model; a personal growth model. The review also includes a discussion of the factors known to influence the grief process and some examples of bereavement outcomes. An overview of counselling interventions suggested in the literature concludes the section.

The existing attitudes toward the universal human experiences of death and loss are typically not positive attitudes. For example:

The attitude of the researchers seems to be that dying and death are psychologically 'bad', 'negative', and 'deteriorating' experiences in the existence of humanity (Zinker & Fink, 1966, p. 185).

But whereas birth is cause for celebration, death has become a dreaded and unspeakable issue to be avoided by every means possible in our modern society (Kubler-Ross, 1975, p. 5).

Illness is considered bad fortune. ... We only think we are O.K. if we are healthy (Levine, 1982, p. 2).

Principal fallacies persist in contemporary attitudes toward grieving ... that grief is a negative and diminishing factor in our lives, which must occasionally be endured and then forgotten as soon as possible (Murphy, 1985, p. 379).

This one-sided, negative bias interprets "grief as a

depressive reaction to the experience of loss" (Jansnow, 1985, p. 31) or "an indirect pathogen" (Sanders, 1982-83, p. 240). In an early attempt to understand the human reaction to loss, one particular piece of research espoused these negative attitudes.

In 1944 Erich Lindemann conducted an in depth study of the emotional, physical, and behavioral effects of bereavement. Lindemann interviewed over 100 people who had lost a family member in Boston's infamous Coconut Grove nightclub fire (Glick et al, 1974; Kalish, 1985). The experience of loss reported in this unexpected, youth-oriented, worst-case bereavement situation, was described by Lindemann as overwhelming "somatic distress ... (and) mental pain" (1944 in Kalish, 1985, p. 185). The problems associated with such a difficult bereavement circumstance are discussed later in the section under Factors Known to Influence the Grief Process. Here it is sufficient to note that the distress and pain reported by Lindemann in all likelihood significantly influenced our initial understanding of grief as an entirely negative experience.

During the two post-war, growth-oriented, baby-boom decades that followed Lindemann's study there was little interest in any aspect of human mortality. But in 1969, Elisabeth Kubler-Ross' daring endeavour to understand death and dying literally exploded the topics into public awareness. Her work indicated that the emotional aspects of grief parallel the emotional experience of dying; that an understanding of the psychology of one situation illuminates the other. Although the focus of this review is grief, the topics of bereavement, death, and dying are also

included due to their interconnectedness.

Stage Models

In 1965, defying opposition from the medical community, Elisabeth Kubler-Ross started to observe critically ill patients. In order to understand the psychological component of a terminal diagnosis, Kubler-Ross saw "the dying as teachers" (1969, p.28). In her landmark publication On Death and Dying: What The Dying Have To Teach Doctors, Nurses, Clergy and Their Own Families (1969) Kubler-Ross outlined a psychological process involving five sequential stages. This stage model has become the foundation for all subsequent work in the areas of death and dying, as well as grief and bereavement.

The five stages identified by Kubler-Ross as being "defense" or "coping mechanisms to deal with extremely difficult situations" (1969, p. 138) are: denial (and isolation), anger, bargaining, depression, and acceptance (Kubler-Ross, 1969).

These five stages are more specific than the little-known, pre-existing three stage model (shock, despair, and recovery) (Averill, 1968) or the four stage model (numbness, pining, depression, and recovery) later suggested by Parks (Kalish, 1985, p. 184). Of these three stage models, only the Kubler-Ross stages of coping have been widely recognized.

Even though Kubler-Ross clearly states that the stages "will last for different periods of time and will replace each other or exist at times side by side" (Kubler-Ross, 1969, p. 138) a general misunderstanding persists. A terminal diagnosis is not necessarily worked through to acceptance for one time only. For those patients who do experience denial, anger, bargaining,

depression, and acceptance, the stages can occur many times over the course of their illness. Patients often experience separate loss reactions to each phase of their decline. It is, therefore, common for the terminally ill to repeat the stages in a cyclical fashion; coming to accept one aspect of their deteriorating health only to repeat the process as new problems arise.

Another misunderstanding of the Kubler-Ross model concerns the universality of the stages. The five stages have been understood, by some, as "a rigid sequence through which people had to pass if their reaction was to be deemed normal" (Speck, 1985, p.90). In fact, the stages do not represent the experience of all terminal patients. For some patients a terminal diagnosis is preferable to continued uncertainty regarding the nature of their illness. For these people the experience of acceptance appears to be their first reaction. Still others, notably some elderly persons, those with certain religious convictions, or the newly bereaved, view death as a welcomed prospect. Again, acceptance is not preceded by denial, anger, bargaining, or depression.

The Kubler-Ross model is also restricted in the sense of presenting a limited and biased range of emotions. Denial, anger, bargaining, and depression all represent emotions traditionally viewed as negative, unpleasant, and unwelcome. The stage model specifically excludes emotions such as "hope, fear, curiosity, envy, apathy, relief, and even anticipation" (Kalish, 1985. p. 134), all of which can be part of the experience of dying.

Although the Kubler-Ross five stage model is flawed and has been misunderstood, it is the most widely recognized and respected framework for the psychology of dying. While the model was developed from conversations with terminal patients, "many people have applied the five stages of dying to the process of grieving as well" (Kalish, 1985, p. 183). Today, the Kubler-Ross stages are generally accepted as a model for psychological adjustment to bereavement as well as dying.

Whether the five stage model is applied to dying or grief, limitations exist. The Kubler-Ross inventory of emotions associated with grief is restricted to only five emotions while "grief is impossible to pin down. ... It is an amalgam, a mixture of all the emotions a human being can experience" (Murphy, 1985, p. 381). The 'funny bone' phenomenon provides an unlikely analogy: nerve bundles are semi-exposed at the elbow and an unexpected physical blow to the area results in an experience of all possible sensations (heat, cold, pain, and pressure). Similarly, the psychological blow of a bereavement can activate a range of human emotions.

Task Models

The word 'task' implies a degree of volition on the part of the bereaved. The identification of tasks associated with grieving suggests that the survivor take action; participating in the recovery process as opposed to surrendering to it. Task models generally call for the "reconstruction" (Kamm, 1985, p. 64) or "rebuild(ing)" (Potash, 1985, p. 83) of one's life following the death of a loved one. Worden (1982) and Parks &

Weiss (1983) provide examples of task models for bereavement recovery.

Four Tasks Necessary to Move Beyond Grief

- 1) Accept the reality of the loss
- 2) Accept that grief is painful
- 3) Adjust to an environment that no longer includes the person who has died
- 4) Withdraw much of the emotional energy once invested in the dead person and begin to reinvest it in other relationships (Worden, 1982)

The Tasks of Grieving

- 1) Intellectual recognition and explanation of loss
- 2) Emotional acceptance (when the survivor no longer feels the need to avoid reminders of loss for fear of being flooded by grief, pain or remorse)
- 3) New identity (a reasonably consistent set of assumptions about one's own self) (Parks & Weiss, 1983, p. 156-160)

These models evolved from research into spousal bereavement. When Parks and Weiss (1983) indicate that the final task is establishing a new identity, they refer to the transition from wife to widow or from husband to widower. Task completion results in the freedom "to take stock and to make a new start" (Parks, 1972, p. 94).

Task models and stage models are not mutually exclusive. They should, perhaps, be seen on a continuum for the process of bereavement recovery. The two task models outlined above each begin where the Kubler-Ross stages leave off; acceptance of the loss. In defining tasks subsequent to accepting a death, these models suggest that recovery involves acts of re-investment and re-definition. Task completion requires the bereaved to move beyond acceptance to rejoin the continuity of life; understanding

that "with renewed courage, one picks up the pieces of one's existence, and life moves on" (Kamm, 1985, p. 64).

Growth Models

As with stage models, growth models have emerged from observations of the dying. Although Zinker and Fink stated, in 1966, that "individuals on the brink of death or individuals who knew they were to die in the near future experience the greatest insights, the greatest joys, ... and sometimes grow" (Zinker & Fink, 1966, p. 186), the word 'growth' did not appear regularly in the death, dying, grief and bereavement literature until the mid 1970s.

Again, leading the field in understanding death and dying, Elisabeth Kubler-Ross introduced the idea of Death As The Final Stage Of Growth (1975). She suggested that dying can be a time of accelerated personal growth and insight; that positive outcomes may be associated with bereavement when the death is anticipated rather than unexpected. In Kubler-Ross' words "when you are dying, if you are fortunate enough to have some prior warning ... you get your final chance to grow, to become more truly who you really are, to become more fully human" (Kubler-Ross, 1975, p. x).

Steven Levine, another prolific author in the field of dying and grief (1979, 1982, 1984, & 1987), also maintains a growth model for these experiences. When he writes of the possibility of growth at the end of one's life he refers to "wellness" and "healing"; that terminally ill patients can "experience a greater wellness, (and) ... (that) they (can be) healed, more whole at

the moment of their dying than at any time in their life". Levine sees a potential for people to become "well ... during the weeks and months of their dying" (Levine, 1987 p. 5).

This prospect of growth exists not only for those who are dying but their caregivers as well. Kubler-Ross notes that those "individuals who have been fortunate enough to share in the death of someone who understood its meaning seem better able to live and grow because of their experience" (Kubler-Ross, 1975, p. 117). The growth model recognizes that "grief is both destiny and possibility for all who care. Inherent in the sadness of loss is the potential for emotional gain and a renewed contract with life" (Stern, 1985, p. 1).

While stage models for bereavement recovery imply passive transition from stage to stage and task models outline routes for active participation in the process, the growth model suggests the possibility of; emotional, behavioral and spiritual transformation.

In the grieving process acceptance is not the final stage. There has to be more. There has to be, or there should be, growth, fulfillment and what, for a better word, I can only call liberation ... in the sense of being freed, of finding self-direction and autonomy, of coming to rely on and to trust one's own resources, of coming to value oneself (Murphy, 1985 p. 381-2).

This opportunity to transcend one's pre-bereavement self explains why "one of the most demanding, and often one of the most rewarding, relationships that you can enter is that of caring for someone you love who is dying" (Kalish, 1985, p. 302). Bereavement can act as a catalyst. Survivors move beyond the last stage or task of grieving toward new experience; beyond recovery to discovery.

Factors Affecting Bereavement Outcome

A complex of factors affect the outcome of a bereavement situation. Circumstances existing both before and after the death can impact on the intensity and duration of the grief experienced by survivors. Other circumstances pertaining to the death itself determine aspects of the grief response. The majority of pre-existing bereavement circumstances are fixed and cannot be influenced. Others, though, are subject to volition. The favourable inclinations of both the dying person and those in attendance contribute to improved bereavement outcomes.

The following list, condensed from the literature on dying and grieving, outlines those circumstances shown to affect bereavement outcome. They are: who the person was (Worden, 1982), the pre-existing relationship (Kalish, 1985), type of death (Kalish, 1985), the response of the family and social network (Kalish, 1985), concurrent stresses or crises (Kalish, 1985), previous losses (Kalish, 1985), and sociodemographic factors (Raphael, 1983).

A brief description of the kind of influence each factor is reported to have over bereavement outcomes follows:

1) Who The Person Was

The personality of the deceased, what s/he stood for, and what s/he represented (i.e. security, identity, leadership), all influence the survivor's recovery process. Factors involving the character of the deceased and the nature of the pre-death relationship all impact bereavement outcomes.

A profound sense of loss is not necessarily contingent on the

survivor ever having met the deceased. For example, due to his personality and what he stood for, thousands of 'strangers' suffered the death of Martin Luther King.

In situations where a relationship has existed, regardless of the presence of an emotional bond, if the deceased represented security and/or an identity for the survivor then recovery will be more difficult (Worden, 1982, p. 29).

2) The Pre-existing Relationship

Paradoxically, the better the pre-death relationship with the deceased was, the better the bereavement outcome the survivor can expect. Survivors who have experienced ambivalent feelings about their relationship can expect a more difficult recovery (Kalish, 1985, p. 196).

3) Type of Death

Sudden, unexpected, and untimely deaths are the most difficult for survivors. "It appears that those whose loss is not anticipated have less likelihood of regaining full capacity for functioning and happiness" (Glick, 1974, p. 14). A death which is foreseen, on the other hand, allows for the experience of anticipatory grief.

"Anticipatory grief" (Lindemann in Kalish, 1985, p. 197) enables survivors to grieve in pace with the physical deterioration and loss of functioning exhibited by their loved one; piecemeal grieving rather than enduring a mass of emotion at the time of an unexpected death. In most cases, anticipatory grief is associated with greater calm and acceptance for the survivors (Fulton & Fulton, 1971), "although death from slow terminal illness may ... lead to difficult outcomes" (Kalish,

1985, p. 196). Long term illness may isolate caregivers as "nobody is interested in chronic" problems (Wilber, 1988, p. 145). Over an extended period, caregivers often lose their support systems and their regular routines. Satisfactory bereavement outcomes become more difficult as support dwindles and pre-illness life is all but forgotten.

4) The Response of The Family and Social Network

The bereaved person fares better if the family and the social network are supportive (Kalish, 1985). Specifically, "if family members and friends can identify parts of their own lives changed by their loved one, griefwork begins with a solid foundation" (Gaffney, 1988, p. 149).

5) Concurrent Stress or Crisis

Bereavement recovery is slower if there are other major sources of stress or crisis in the survivor's life (Kalish, 1985).

6) Previous Losses

If past losses were not well resolved, especially in the early years, then present losses may also be difficult to resolve. As well, series of losses can interfere with bereavement recovery. The term "bereavement overload" (Kaustenbaum, 1969) refers to the situation where one death is not resolved before another one takes place.

7) Sociodemographic Factors

The sociodemographic variables of "age, sex, religion, culture, occupation, and economic position" (Raphael, 1983, p. 62) can each influence the resolution of grief. An understanding

of these factors, though, is beyond the scope of this paper.

As well as the seven fairly stable bereavement conditions discussed above, there may also be two factors of choice. When the death is anticipated, both the attitude of the patient and the attitude of the survivor influence bereavement outcomes. Recovery is promoted when the patient is able to accept the prognosis and when those in attendance are able to maintain an attitude of willingness. Acceptance and willingness; two choices shown to benefit bereavement recovery.

Steven Levine has worked extensively with the terminally ill and has distinguished himself as an author in the fields of dying and grief (1982, 1984, 1987). His term 'healing' approaches what has been called 'acceptance' elsewhere; "a greater wellness (and) a sense of quiet completion". While 'healing' has typically referred to a restoration of physical health, Levine's definition is not confined to the physical realm. He has observed that some patients "experience their body returning to wholeness", while "others experienced the wholeness of death". The latter group Levine understands to have "healed into death" (1987, p. 5).

Several other authors have noted that a patient's attitude of acceptance can be contagious. It may also be very beneficial to those attending a death and therefore, acceptance has been seen as a favorable factor in healthy bereavement recovery. As Kubler-Ross has found, "having been close to a person who accepted death with inner peace was a positive factor in emotional adjustment, while having been close to a dying person who was angry and upset was a negative factor" in subsequent bereavement adjustment (Kubler-Ross, 1975, p. 79). Nichols

observes that "many patients ... arrive at a sense of dignity and a state of composure or acceptance. (And) such patients are often great help to others" (Nichols, 1983, p. 103). It appears that the patient who is reconciled to the reality of the situation may model acceptance for those who are closest. This can be a real gift to survivors as "acceptance is (seen as) the net result of a healthy grief process" (Schiff, 1986, p. 212).

The budding AIDS-related bereavement literature provides evidence of this type of communication between people with AIDS and their caregivers. Psychotherapist Lu Chaikin writes of her colleague and close friend, Gary Walsh: "... he was transformed and he transformed other people" (Chaikin in Nungesser, 1986, p. 180). Jim Geary, Executive Director of Shanti Project, San Francisco remembers a friend, Paul, who "died healing. Healing himself and others ..." (in Moffatt, 1988, p. 73). And, sharing these two experiences, Steven Levine recalls, "a sign of Bill's healing, and many of the healings we have shared in, is that those friends and attendants closest were healing as well" (Levine, 1987, p. 128). If people with AIDS can find peace of mind and acceptance at the end of their lives, then those who are with them appear to benefit.

While the patient's attitude is important, the survivor's own attitude is also a crucial factor in post-death recovery. Independent of any external influences, the survivor's personal thoughts about the situation can affect bereavement outcome. An attitude of willingness, expressed throughout the dying period, appears to promote adjustment to the death. Specifically, the

following types of willingness are believed to improve bereavement outcome:

- 1) willingness to risk the unknown (Kubler-Ross, 1975)
- 2) willingness to let go of control (Levine, 1987)
- 3) willingness to become vulnerable (McCarroll, 1988)
- 4) willingness to experience fully (Zinker & Hallenbeck, 1965)
- 5) willingness to be overwhelmed (Levine, 1987)
- 6) willingness to trust the process (Levine, 1987)
- 7) willingness to learn (Tatelbaum, 1985)

Although these suggestions of willingness have come from a variety of sources, a pattern emerges. First, Kubler-Ross suggests that caregivers find the "willingness to risk the unknown, to venture forth into unfamiliar territory" (Kubler-Ross, 1975, p. 145). A willingness to risk the unknown can combat feelings of inexperience, uncertainty, and fear. The decision to risk moving beyond the familiar requires a willingness to "let go of control" (Levine, 1987, p. 110). Speaking about AIDS nurse Cassandra Christenson states that "when we're there, ... (it is important) to not have any idea of what we're going to do" (in Moffatt, 1988, p. 141). With little idea of what will happen and no plan for what to do, what remains is a "moment to moment way of living" (Geary in Moffat, 1988, p. 72).

By living in the moment, "everyone seems to break free of normal, self-centered preoccupation and become voluntarily vulnerable to one another (McCarroll, 1988, p. 63). The willingness to be vulnerable enables everyone to participate more fully. As Zinker and Hallenbeck report in Notes on Loss, Crisis and Growth:

While change and growth are continuous in human experience, there are certain events that stand out as being especially important in challenging the possibility of change or growth. When a man allows himself to experience fully an important event, he takes the risk of 'becoming'. If the event fully permeates his being, his entire inner life, it aids him to restructure or revise his experiencing (Zinker & Hallenbeck, 1965, p. 248).

The willingness to experience fully and not "shy away from experiences, emotions, (and) situations" (Hodgson, in Moffatt, 1988, p. 66) leads to recovery. Levine believes that if people are not willing to fully experience their pain they will always be in pain (1987). He suggests that everyone concerned "just let the pain in" (Levine, 1987, p. 125). Tatelbaum, author of Courage to Grieve, agrees: "Open mourners are a select group, willing to journey into pain and sorrow and anger in order to heal and recover" (Tatelbaum, 1985, p. 9).

There is a "tendency to want to shut down and run away" but "death only has victory over you if it causes you to shut down" according to Marianne Williamson, pastoral care person working with people with AIDS (in Moffatt, 1988, p. 203 & 211). Therefore, along with the willingness to experience fully one must also be willing to "allow (oneself) to be overwhelmed" (Levine, 1987, p. 110). In order to surrender control voluntarily and allow oneself to be overwhelmed, one must also be willing to "trust the process" (Levine, 1987). Nurse Christenson holds that "the process that occurs is a process that I think needs to occur in order to facilitate ... a healthy way of dying" (in Moffatt, 1988, p. 52).

In addition to trusting the process, a willingness to learn

from the experience can also affect the eventual bereavement outcome. "Since pain is unavoidable, we can learn to make pain our teacher instead of our enemy" (Tatelbaum, 1985, p. 10). In fact, "we strive to find meaning in the fact that someone so dear (has) left us. We search for lessons to learn" (Taylor in Ruskin, 1988, p. 7).

A healthy, healing dying/bereavement experience appears to rely, in part, on the choices made by those involved. Deborah Duda, author of Coming Home: A Guide to Home Care for the Terminally Ill, remarks that "when someone is dying, we tend to focus on sadness, not joy. But it's a choice. We can allow joy into this often most painful experience of our lives" (Duda, 1984, p. 16). Seeing the choices that exist in a painful situation enables one to change the perception of a threat into one of a challenge. "We can either give up or grow from the experience. We can succumb to adversity or, use adversity to transform our lives ... From our pain we can learn and grow" (Tatelbaum, 1980, p. 138). Bereavement recovery, then, is partly a matter of choice.

Bereavement Outcomes

The grief and bereavement literature has only recently begun to acknowledge any features of grief resolution beyond acceptance (Kubler-Ross, 1969), new relationships (Worden, 1982), and a new identity (Parks & Weiss, 1983). Neither stage theory nor task theory identify specific bereavement outcomes. Some early studies of widowhood did note that the experience "brought most widows close to their families" and "change(d) the intensity

of friendships" (Glick et al, 1974, p. 185 & 200) but most often, only vague references to change and growth have been reported. For example: "Having weathered a crisis, expect to discover: a stronger you, a different you, a more evolved you" (Colgrove et al, 1981, p. 112).

Over the last five years specific references to the results or outcomes of bereavement have become more common. Most reports of personal change have been unorganized; usually anecdotal segments embedded in first person accounts of a bereavement experience. Only one study, in Beyond Endurance - When A Child Dies (Knapp, 1986), systematically presents a number of bereavement outcomes for parents who have suffered the loss of a child. Knapp's six findings follow.

Findings Associated With The Death Of A Child

- 1) To never forget. Parents express the need or desire never to forget.
- 2) The wish to die. Following the death of an older child, particularly a sudden death, parents contemplate their own death. Knapp also notes his belief that living with no fear of death or dying may become a permanent characteristic for a majority of parent survivors.
- 3) A religious experience. All surviving parents seemed to have a need to fit death into some kind of recognizable context. Even those bereaved parents who before the loss rejected the idea of a heavenly God, who rejected belief in an afterlife, who believed firmly in the reality of life and the finality of death, after suffering for a period of time were unable to sustain these attitudes.
- 4) A change of values. This was particularly true for those who struggled through a long terminal illness with the child. The death itself, coupled with months of heroic effort in ministering to the needs of a dying child, tended to shake attachments to traditional values and goals of success and personal achievement. New commitments to more intangible values were brought into play. Parents tended to become more concerned with cultivating and strengthening family relationships. Time became more

precious.

- 5) More tolerance. The event of losing a child tended to make a parent more tolerant of other people and more sensitive to and understanding of the problems and suffering of others.
- 6) Shadow grief. This refers to the fact that parental grief may never be resolved. Shadow grief does not manifest itself overtly; it does not debilitate; no effort is required to cope with it. Shadow grief reveals itself more in the form of an emotional 'dullness', where the person is unable to respond fully and completely to outer stimulation and where normal activity is moderately inhibited (Knapp, 1986, p. 28-40)

At this point in time, the AIDS literature offers only single case, interview, or personal story evidence of the consequences of an AIDS-related death for survivors. For example, When Someone You Know Has AIDS (Martelli et al, 1987):

Inexorably, whether you notice it or not, your interests will change, your needs and wants will change, even your values will change. Soon you will wonder, 'What is happening to me? Why do so many of my conversations seem silly to me? Why is my job less interesting? Why am I so restless? Why do I always seem to want to leave where I am to go somewhere else, usually to where my friend with AIDS is just then? ... You will have begun to live a life probably more intense and painful than anything you know before, but a life certainly richer and more rewarding (Martelli et al, 1987, p. 21)

This review notes a number of such examples from a variety of AIDS specific sources: Epidemic of Courage - Facing AIDS in America (Nungesser, 1986), Quilt Stories from the NAMES Project (Ruskin, 1988), and Morning Glory Babies - Children with AIDS and The Celebration of Life (McCarroll, 1988). These first person accounts of change are presented, here, under the nine headings used by Moffatt in Gifts for the Living - Conversations with Caregivers on Death and Dying (1988). Moffatt's work offers the first attempt to structure the phenomenon of AIDS-related

bereavement outcomes. She presents a collection of personal narratives under nine chapter titles; each announcing 'a gift' for caregivers. The nine chapter headings are:

- Chapter One - The Gift of Adventure
 - Chapter Two - The Gift of Generations
 - Chapter Three - The Gift of Honesty
 - Chapter Four - The Gift of Healing
 - Chapter Five - The Gift of Understanding
 - Chapter Six - The Gift of Guidance
 - Chapter Seven - The Gift of Caring
 - Chapter Eight - The Gift of Unconditional Love
 - Chapter Nine - The Gift of Transformation
- (Moffatt, 1988, p. xiii)

Due to the similarity between the idea of a gift and a positive bereavement outcome, Moffatt's nine headings are used here to structure the following examples of personal change attributed to AIDS-related bereavement. Examples of bereavement outcomes associated with AIDS are:

1) The Gift of Adventure

A theme of adventure or venturing into the unexpected has been part of McCarroll's experience of caring for babies with AIDS. He states that "those with AIDS and those caring for them must learn to float on random waves of misfortune and blessing" (McCarroll, 1988, p. 2). Another example of adaption to uncertainty credited to AIDS, is reported in the experience of "learning to be a good follower in a dance where the music changes rapidly" (Nungesser, 1986, p.228).

2) The Gift of Generations

This particular set of outcomes has to do with first seeing oneself clearly, then developing a sensitivity to others, and finally viewing oneself as part of the larger context of

humanity. Examples of this pattern are:

When you are close to death, it makes you look at your own life (Chaikin in Nungesser, 1986, p. 177).

When you have suffered, it gives you an x-ray vision into other people's suffering (Williamson in Moffatt, 1988, p. 214).

We are entering a new level of consciousness in recognizing the bonds within the human family (McCarroll, 1988, p. 70).

3) The Gift of Honesty

New found honesty associated with AIDS losses involves being honest with oneself. Examples of this type of honesty are:

The presence of AIDS in so many of our lives helped us to be ourselves (McCarroll, 1988, p. 52).

I am now "very impatient with superficialities and superficial people" (Williamson in Moffatt, 1988, p. 215).

And from a submission to the guilt book: "I don't spend energy on people or activities I dislike" (Ruskin, 1988, p. 131).

4) The Gift of Healing

One example of healing within a family follows the death of a baby due to AIDS.

It seems that in death Aaron had brought about a healing with his family. People who had been estranged were now reaching out to one another in compassion (McCarroll, 1988, p. 146).

5) The Gift of Understanding

An understanding that "the dying do teach the living about life" (in Nungesser, 1986, p. 229) is common. A survivor's understanding of life can be a multi-faceted experience.

Time is so much more precious to me. The dying do teach the living about life, I think. And I'm more congruent. I mean, I don't do many things I don't want to do ... it makes us look at all the issues that everybody puts off till they're seventy or eighty years old ... I've grown spiritually, I've grown emotionally

... my values are different (Chaikin in Nugesser, 1986, p. 228-229).

The survivor cannot always describe the understanding obtained via an AIDS-related death. The experience may be ineffable. For example:

I have no words to explain what I do not understand (McCarroll, 1988, p. 132).

I don't know how to explain it (Nugesser, 1986, p. 228)

6) The Gift of Guidance

Moffatt used this heading for an interview with a nurse who works with people who have AIDS and their families. No other examples of this service-oriented outcome were found in any of the other sources.

7) The Gift of Caring

Examples of caring involve caring about life, oneself, loved ones, and all people involved with AIDS as well as "recognizing the bonds within the human family" (McCarroll, 1988, p. 70).

The tension in which we lived awakened in us an appreciation of the preciousness of life. We grew up fast (McCarroll, 1988, p. 18).

From the guilt: "It (AIDS) has forced us into a realization that we must cherish every moment of the glorious experience of this thing we call life. We are learning to value our own lives and the lives of our loved ones as if any moment may be the last" (in Ruskin, 1988, p. 7).

The feeling of community is strong among all people involved with AIDS (McCarroll, 1988, p. 88).

8) The Gift of Unconditional Love

These passages need no further explanation.

He made me confront my values, my motives, and my desires. As my love for him grew, so did my love for myself (Ruskin, 1988, p.27).

An example from Epidemic of Courage: Facing AIDS in America: "our relationship provided me with the experience closest to unconditional love that I'll probably ever have in my life" (Chaikin in Nungesser, 1986, p. 179).

'Love really is the answer' Gary wasn't sure what the question was but he was sure that as simple as it sounded, love was the solution (Jim Geary - Executive Director, Shanti Project, San Francisco in Moffatt, 1988, p. 76).

9) The Gift of Transformation (Moffatt, 1988, p. xiii)

Moffatt has used this title to introduce spiritual matters. Therefore, examples of spiritual changes are presented here.

I've grown spiritually, I've grown emotionally ... (Nungesser, 1986, p.228).

The presence of AIDS changes people's spiritual lives (McCarroll, 1988, p. 2).

I must stumble along with only the awareness that there are experiences that transcend time and space (McCarroll, 1988, p. 132).

Counselling Interventions

The use of counselling interventions specifically targeted at grief is a fairly new enterprise. Initially, counselling strategies were developed to facilitate coping in the post-bereavement period. More recently, pre-death counselling has been proposed as a means of improving the quality of the dying experience for everyone involved, as well as enhancing bereavement outcomes for survivors. At present, AIDS-specific counselling interventions are in a developmental stage.

Counselling for grief recovery has typically been a post-bereavement endeavour. Whether counsellors were stage-oriented or task-oriented, the goals of counselling were "generally to encourage the expression of grieving affects and promote the

mourning process" (Raphael, 1983, p. 368). A framework for the objectives of post-death counselling is offered by Worden in Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner. Worden's ten counselling objectives are as follows:

- 1) Help the survivor actualize the loss
- 2) Help the survivor identify and express feelings
- 3) Assist living without the deceased
- 4) Facilitate emotional withdrawal from the deceased
- 5) Provide time to grieve
- 6) Interpret 'normal' behavior
- 7) Allow for individual differences
- 8) Provide continuing support
- 9) Examine defenses and coping styles
- 10) Identify pathology and refer (Worden, 1982, p. 39)

Where possible, this ad hoc approach to the problem of bereavement is being replaced by a pre-death approach. "When there is knowledge beforehand of the terminal nature of illness and the impending death, psychotherapy, counselling, and anticipatory guidance can help the family's adjustment, both during the illness and subsequent to it" (Raphael, 1983, p. 395).

Anticipated death situations provide the best opportunity for counsellors to influence bereavement outcomes. One proposal for pre-death counselling requires the counsellor to:

- 1) facilitate anticipatory grief,
- 2) provide optimal care and control of symptoms for the dying, and
- 3) encourage the survivor to be present at the time of death and to view the body subsequently (Cameron and Parks, 1983, in Speck, 1985, p. 92).

Another approach involves the use of time progression techniques as "it may be possible to develop strategies which effect the quality of the experience of dying by preexperiencing dying" (Gamble & Brown, 1980-81, p. 354).

Regardless of the type of pre-death counselling intervention

adopted, "it can not be emphasized enough how very significant for bereavement outcome are the events and interactions with people during the time leading up to the death" (Stroebe & Stroebe, 1987, p. 240).

Counsellors who deal with problems associated with AIDS-related bereavement are using existing grief theory and interventions, modifying these with experience. Very little AIDS-specific grief information is available.

For example, counsellors are aware of AIDS-related bereavement overload: that "it is not uncommon for people to be grieving or anticipating the loss of more than one person to AIDS" but, "as of yet, there are no simple guidelines on how to cope in these circumstances ... We do not yet know what 'normal' grief is under these circumstances" (Schoen & Schindelman, 1983, p. 3).

General guidelines for AIDS bereavement support have been put forward in an article called AIDS and Bereavement: Diagnosis/Treatment/Prevention (Schoen & Schindelman, 1983). The authors suggest that counsellors:

- 1) provide information, as information helps to normalize the experience and gives the person permission to grieve,
- 2) encourage talk about feelings and,
- 3) encourage peer support (Schoen & Schindelman, 1983, p. 3).

CHAPTER III METHOD

Sample

Twelve subjects, self-selected from a population of individuals bereaved by AIDS, were interviewed for this study. The six men and six women ranged twenty years in age, while the range in age for the people with AIDS they had known was thirty years. The sample was also diverse in the nature of each subject's relationship with the deceased, the length of time each subject had known the PWA, and the subject's own personal reference to the AIDS virus.

The individuals who participated in this study volunteered from a variety of sources. One half of the sample originated from the AIDS Vancouver Coping With Loss and Grief Support Group. These subjects were twice self-selected, in that they first chose to attend a support group and subsequently volunteered for this project. The balance of six subjects came forward from various other arenas. These individuals became aware of the study through some form of AIDS-related involvement and/or association with AIDS Vancouver (e.g. providing care for a PWA, or participating in an AIDS Vancouver volunteer training program). These last six subjects offered to be interviewed on learning the nature of the proposed study.

The subjects, six men and six women, ranged in age from 27 to 47 years. The average age for subjects was 33 years. All of the PWA's referred to in this study were adult males; average age 36 years; range of 25 to 55 years of age.

The relationship between each subject and their PWA was

catagorized by one of four terms; partner (4), friend (4), sibling (2), or buddy (2) (otherwise known as an AIDS Vancouver emotional support volunteer). Of the four partners, three subjects were male and one female. The subjects who had been a friend of the PWA were divided equally; two males and two females. Both of the siblings were sisters, and the two emotional support volunteers were one male and one female.

The duration of the relationship between subject and PWA ranged from six months for one of the emotional support volunteers to an entire lifetime for both of the siblings. The time from the PWA's diagnosis of AIDS until his death averaged thirteen months with a range from three weeks to two and a half years. An average of thirteen months also represented the length of time from the AIDS-related death to the interview with the survivor/subject.

The subject's personal reference to AIDS also varied in regard to the number of deaths each subject had experienced, as well as personal HIV status. Subjects ranged from knowing only one PWA to having known 36+ people who had died as a result of AIDS. The average number of AIDS-related deaths known to members of this sample was 12+.

Three quarters of the twelve subjects reported themselves as antibody negative or uninfected with the AIDS virus. The remaining three subjects reported testing antibody positive or HIV infected. Of those individuals who were infected, one subject had been diagnosed with ARC (AIDS-Related Complex, a pre-AIDS condition).

Subjects provided the above data via their individual

completion of a Subject Information Sheet (Appendix A). This information has been condensed on the Summary of Subject Information Sheet (Appendix B). A brief biographical sketch of each subject, drawn from the Subject Information Sheets, follows.

SUBJECT F1

When her brother's health began to deteriorate, Subject F1 left her job in Eastern Canada to come and stay with him. She had been aware of his diagnosis for a year and a half. He had known of it for three years. F1 and her brother's partner cared for him, at home, until his death ten months before the interview. She noted that there had been complete two-way communication of their emotions, during that time, with totally open discussions of death and dying. She also stated that they did not experience bargaining in their otherwise full range of emotions. F1 was in her mid-twenties at the time of the death. Her brother, who was the second person she had known to die of AIDS, was slightly older.

SUBJECT F2

Subject F2 became a member of a care team following her assignment as an AIDS Vancouver Emotional Support Volunteer. She was in her late forties and he was in his early twenties. Their relationship lasted two years until his death, at home, one year before the interview. F2 indicated that they experienced a complete two-way communication of their emotions which included "love, sadness, and joy" in addition to the list of emotions provided on the questionnaire. They had also

discussed death and dying openly. F2 reported having known more than twenty people who had died of AIDS.

SUBJECT F3

Subject F3 was in her mid-twenties when her brother, who was one year older, died. He was the only person she had known to have AIDS. He was diagnosed at the time of his admittance to hospital. There was little opportunity to assist in his care as he spent his entire stay in an intensive care unit. From the beginning, medical procedures made any kind of verbal or physical communication for her brother impossible. He was not expected to die, as he did, after only three weeks in hospital. The subject indicated that she experienced "devastation" as well as the other listed emotions. The interview took place five months after the death.

SUBJECT F4

Two and a half years ago Subject F4 became the room-mate and primary care giver for a friend with AIDS. She lived with him during his last six months. They had complete two-way communication of their emotions. He expressed "fear, rage ... and hopelessness" and he was "frequently suicidal". She remembered feeling "guilt". During their time together, they discussed death and dying openly. F4 reported knowing more than thirty people who have died of AIDS.

SUBJECT F5

Subject F5 married her long time friend after he was diagnosed with AIDS. She cared for him, by herself, during the

last 22 months of his life. She then returned to her family overseas. She responded to the interview questions, by mail, four months after his death. F5 indicated that their communication was open and two-way and that it was "with R's help I got over all that I was feeling about his leaving me". In responding to the question about the number of people one has known to have died of AIDS, F5 reported knowing "3 dozen, at least". Both she and her husband were in their early thirties.

SUBJECT F6

Subject F6 was also in her early thirties, as was her friend when he died. They met six years earlier, at work, although they didn't particularly care for one another at that time. After several years of no contact they met again by chance. Where his good looks had once brought him fashion-related work on three continents, he now appeared to be twice his age. His personality seemed to have changed for the better, though, and the subject began to visit him. He had the help he needed to die at home so she did not participate in his care. F6 stated that they did not talk about death and dying, that he "mostly helped me with my feelings". She was with him when he died and he was the only person she had known to have AIDS. The interview took place four months after his death.

SUBJECT M1

Subject M1 had known twenty people to die of AIDS. He was in his early thirties when he became an AIDS Vancouver Emotional Support Volunteer for a man in his mid-fifties. The

relationship lasted for a year until the buddy died. They developed complete two-way communication of their feelings with a moderate degree of discussion of death and dying. The man was very angry and depressed. The subject experienced "sympathetic pain and turmoil" as he provided "emotional and practical support" for his buddy and the buddy's friends. The death occurred one year before the interview took place.

SUBJECT M2

Subject M2 had known his friend for 12 years before he became his primary care giver. He maintained his full-time job and his long term, live-in relationship during the eighteen months he cared for his friend. They talked openly about death and dying. Their communication of feelings, though, was basically one-way; the patient shared his feelings but the subject could not. The subject was with his friend, in his own apartment, when he died. This was a year and a half before the interview. M2 had known three other people to die of AIDS.

SUBJECT M3

Subject M3 had known twelve people who died of AIDS. He left his job to become the primary care giver for his partner of ten years. The subject was in his mid-thirties, his partner was in his mid-forties. The death took place, at home, nineteen months after the diagnosis. They experienced a complete, two-way communication of emotions and totally open discussions of death and dying. The interview took place nine months after the death.

SUBJECT M4

Subject M4's partner died fourteen months before the interview. They had been together for ten years and the subject was primary care giver for the five months his partner was ill. The symptoms of the illness did not fit any of the typical patterns associated with AIDS. An AIDS diagnosis was, therefore, not made until just a month and a half before the death. The subject reported that they experienced complete two-way communication of emotions with a somewhat limited discussion of death and dying. In addition to their own personal set of emotions, M4 noted that they both experienced "love" during the illness. He had already known ten people who had died of AIDS.

SUBJECT M5

Subject M5 and his partner of six years were both in their mid-thirties. They shared their emotions completely over the year and a half from diagnosis to death. They also discussed death and dying openly. The subject was the primary care giver and his partner died at home, "eleven months and one day" before the interview. M5 had known six other people who died of AIDS.

SUBJECT M6

Subject M6 was in his mid-twenties, as was his friend of ten years at the time of his death. The subject was primary care giver for the nine month period between diagnosis and death. M6 reported accepting the situation only on the "last day" of

his friend's life. The death occurred at home. They had discussed death and dying before the diagnosis but communication of their feelings and thoughts later became limited. M6 had known three other people who had died of AIDS.

Setting

The twelve individual interviews were conducted independently between December 14th 1988 and February 11th 1989. Two thirds or eight of the twelve interviews were audiotaped in the subject's own home. Three audiotaping sessions took place at the researcher's office and the one remaining interview was received in written form. The subject who replied in writing had moved from Vancouver to Australia following the death. In each situation steps were taken to ensure a quiet and undisturbed environment. All interviews were carried out in private.

Every interview began with the subject reading and signing a Consent and Release Form (Appendix C). Subjects were then reassured verbally, or, in the case of the overseas respondent, in written form, of the guarantee of anonymity, as well as each subject's right to withdraw their co-operation at any point. It was also restated, that in the event of a subject's withdrawal from the study, the destruction of all recorded material would be automatic.

Following the subject's signing the Consent and Release Form and the researcher's verbal statement of commitment to the document, each subject was requested to fill in the Subject Information Sheet (Appendix A).

After these pen and paper tasks had been completed, subjects

were asked if they had any questions. These questions were answered and then the audio taped portion of the interview began. Taping lasted from one hour to one and a half hours depending upon the length of each subject's response to the interview questions. At the 45 minute point, signaled by the end of one side of audiotape, subjects were given an opportunity to take a short break.

At the end of each interview, after the tape recorder had been turned off, subjects were asked to evaluate their experience. They were asked "How has it been for you to do this interview?". This debriefing segment of the interview was designed to give subjects an occasion to talk about their experience. It also provided closure for their participation in the project.

The day following each interview the subject was telephoned and thanked for his/her co-operation. This call provided a second opportunity for subjects to talk about any concerns resulting from their participation. A card of thanks was also mailed to each subject.

Data Collection

The format for the data collecting interviews was derived from information presented by qualitative research authors Glaser & Strauss (1967), Miles (1984), Strauss (1987), and ethnographers Hammersley & Atkinson (1983). The research method drafted from these sources considered the suitability of a qualitative approach, the recognition and inclusion of the researcher's experience, and the formulation of the research questions.

In support of a qualitative approach, it was noted that theory

building "require(s) first of all that they (theories) be conceived, then elaborated, then checked out ... induction, deduction, and verification" (Glaser & Strauss, 1987, p. 11 & 17). The idea of positive outcomes being associated with bereavement and grief is only alluded to in the literature. There is no theory. Before the process of induction or initial theory building can be undertaken, some knowledge of the fundamental characteristics of the phenomenon must be obtained. These "crucial elements of ... theory are often found best with a qualitative method, that is, from data on structural conditions, consequences, deviances, norms, process, patterns, and systems" (Glaser & Strauss, 1967, p. 35). A qualitative approach was, therefore, adopted to determine the crucial elements of the consequences of an AIDS-related death for survivors.

The next aspect of concern in the construction of the data collection instrument involved the possible effect of the researcher's bereavement experience. In this study, the researcher had prior personal experience of the phenomenon under investigation. But it is understood that "any researcher ... comes to fieldwork with some orienting ideas, foci, and tools" (Miles, 1984, p. 27).

The researcher's background was recognized, in this case, as both a liability and an asset. Previous experience is a liability for researchers in that their expectations may influence the composition of interview questions, as well as, the direction of the responses. A qualitative research method is susceptible to the tailoring of interview questions, in effect

limiting the scope of the study to a revisitation of the researcher's original experience. There is also a concern that the researcher may, via his/her reaction to the subject's responses, unintentionally direct the collection process; communicating that one type of information is preferable to another. Both of these errors are selective in nature and both would have the capacity to restrict and contaminate the findings.

The existence of these potential problems was acknowledged and measures were employed in the design of the research questions and the interview procedure to counteract their effect. Through the use of open questions and the neutrality of the researcher's reaction, the potential effect of the researcher's experience was minimized. All questions were open questions as "a question which sharply defines a particular area for discussion is far more likely to result in omission of some vital data which ... the interviewer (has) not even thought of" (Hammersley & Atkinseon, 1983, p. 113). The researcher was also aware of the fact that there are no 'right answers'; that every piece of information is as valuable as any other. Therefore, the researcher made no judgmental comments during the procedure. Regardless of the content of their replies, respondents were only encouraged to continue. As well, the researcher consciously remained as neutral as possible in body position and non-verbal cues.

On the other hand, a researcher's sensitivity to the research problem can also serve as an asset to the investigation. As Hammersley and Atkinseon indicate, researchers need "not decide before hand the questions they want to ask, though they may enter

the interview with a list of issues to be covered" (Hammersley & Atkinseon, 1983, p. 113). The experience of the researcher was included in the forming of interview questions; the intial question being a general open question and the source of the remaining questions being issues originating from the researcher's own experience.

Each interview began with the general question, "How did the death of _____ affect your life?" (Appendix B). Subjects were requested to take all the time they needed to answer this question as Glaser and Strauss advise initially allowing respondents "to talk with no imposed limitation of time" (Glaser & Strauss, 1967, p. 75). This beginning question was designed to generate information completely uninfluenced by researcher partiality.

The remaining nine questions attempted to generate supplemental information with a minimum amount of guidance. These open questions invited additional responses using four determinants: who, what, when, and why, in conjunction with significant issues the researcher had identified as being associated with the phenomenon.

- a) who - relationships
- b) what - what you value
 - what you do for a living-
 - your attitude about dying
 - your belief in an after-life
 - philosophy of life/meaning or purpose of life
- c) when - how you spend your time

d) why - what makes this experience different

- to what do you attribute the changes

In cases of vague, undefined reports of change, subjects were asked to provide concrete examples of the change they had experienced.

All interview tapes were transcribed in full.

Data Analysis

The analysis of the interview tapes involved the examination of only those segments reporting subject change. One at a time, as the transcribed interviews were read, seven specific areas of change became apparent. As these areas or categories of change emerged they were each assigned a colour. A system of coding was employed, highlighting the transcribed segments with the appropriate colour. Next, these coloured segments were examined for common properties or sub-categories. Only those sub-categories mentioned by at least half of the subjects were included in this analysis.

Although the research questions specifically asked for reports of change, subjects also provided a great deal of material inconsequential to this study. Subjects related a range of information about their experience; for example, how they met the PWA, what they missed most about the deceased, and descriptions of their experience of grief. Many subjects showed the researcher photos of the PWA taken at a time of health; one subject produced a photo taken shortly after the death. Most subjects recounted the death scene in detail. As a result of these extra activities the interview evoked an emotional

catharsis for virtually every subject.

In order to be included as an aspect of personal change, a segment was either qualified as such:

The change in me has just been ... (Sub. F3)
I have become ... (Sub. F5)

or included a suffix indicating change:

... my relationships are generally healthier (Sub. M1)
I started seeing ... (Sub. F4)

or included a change-related modifier:

I'm not afraid any more (Sub. F1)
I now think ... (Sub. F6)
I appreciate more (Sub. M6)

Once identified, the segments reporting change were colour coded according to category. Categories were created, one by one, until no new categories were needed to fit the material. The six emerging categories were: values (blue), relationships (pink), time (yellow), death issues (orange), employment (purple), and change (green). These seven categories accommodated all of the reported aspects of change and were defined as follows:

1) Yellow Category - Time

Any reference to time was included in this category; spending time, planning, being busy, here and now, past/present/future. As well, this category covered responses to interview question # 3.

2) Pink Category - Relationships

This category covered responses associated with relationships. Reports of a change in relation to one's self, friends, family, intimates, the people who were involved with the

death, and people in general were included under this category. Answers to interview question # 4 also were recorded here.

3) Blue Category - Values

This category covered statements containing words like 'important' and 'valuable'. It also included segments referring to materialism and the responses to interview question # 5.

4) Purple Category - Employment

The fourth category covered any responses pertaining to the subject's job or career. Answers to interview question #6 were registered in this category.

5) Orange Category - Death Issues

This category included all comments on death, dying, grief and bereavement. Thoughts on one's own death, fear of dying, remarks about an afterlife, and all references to grief were noted here. As well, the answers to questions # 7 and #8 were recorded in this category.

6) Green Category - Change

This last category served as a repository for all reports of change described by subjects that did not fall under the five established headings. Responses referring to the degree or importance of change were filed in this category, as were descriptions of the experience and the pre-death relationship between the subject and the deceased.

Following the assignment of each account of change to the appropriate category, cluster of similar responses within categories were identified. These common groupings within each category were designated as sub-categories if they contained

reports from six or more subjects; that is, at least fifty percent of the sample. Sub-categories were, then, scrutinized for discernible patterns. Predominant themes emerging from the data were noted and a metaphor was chosen to represent the overall picture drawn from the findings.

CHAPTER IV FINDINGS

The six categories for subject responses were divided into a number of sub-categories as a result of the data analysis described in Chapter II. Each of these twenty-one sub-categories were substantiated by at least half of the sample. Four discernible themes emerged from these popular responses. The themes running through the data were understood in terms of one all-encompassing metaphor.

The twenty-one sub-categories that delineate the most common responses provide a concise representation of the findings. An inventory of these predominant sub-categories follows as the majority of subjects reported: spending more time alone, being more concerned about wasted time, improved relationships with self and family, being more selective about friendships, and having an increased sensitivity to others. They also said they were less materialistic or money-oriented, appreciated life and nature more, and placed a greater emphasis on love. Re-evaluations of social expectations and religious beliefs were described, as well as changes in employment. Subjects expressed less or no fear of death and a new or stronger belief in an afterlife. They believed that they would see the deceased again and that their experience of losing a loved one had been a very important one. Respondents also provided statements summarizing the event, naming it, and indicating the type and degree of importance it had for them. Descriptions of the nature of the pre-death relationship were also supplied.

The interview excerpts that established these twenty-one sub-

categories are presented, here, under the six data collection categories (Time, Relationships, Values, Employment, Death/Grief Issues, and Change).

Yellow Category - Time

Two sub-categories were found in the responses referring to time; spending more time alone and an increased concern about wasting time.

i) More Time Spent Alone (6 reports)

I can spend time alone now and be really happy ... which is something I never thought I'd say. (Sub. F1)

I have quiet times. (Sub. 4)

I'm trying to have more time to myself ... because if I don't do it I won't be happy. ... The experience taught me to have time by myself. (Sub. M2)

I've not gone out much. Once I'm in my apartment I ... enjoy my comfortable surroundings. ... I've been taking some real time out. (Sub. M3)

I spend a lot more time alone by myself. ... Some people say that I have become a social recluse and in a certain way I have. I have moved away from crowds. (Sub. M5)

I now spend time alone. Before I always had to be with somebody. (Sub. M6)

ii) More Concern About Wasting Time (6 reports)

Why am I wasting so much time with anger? (Sub. F2)

I don't waste it (time). If I want to do something I do it. (Sub. F3)

(laughing) I get more done in a day than I used to get done in a month. (Sub. F4)

I don't like my time wasted. (Sub. M1)

I find I don't waste my time. ... I spend less time with trivia. (Sub. M5)

Now! There are no more delays. There is no more postponing. (Sub. M5)

Pink Category - Relationships

Statements referring to relationships established four sub-categories. These sub-categories are: improved relationships with self and family, becoming more selective about friendships, and an increased sensitivity to others.

1) Improved Relationship With Self (12 reports)

I've stopped apologizing for myself. ... I was such a sad person. There were no goals. There was no real ambition. There was no real happiness and I wasn't looking forward to ever being happy. ... I'm able to take care of myself which I wasn't able to do before. (Sub. F1)

I claimed or reclaimed parts of me that were dead. ... That allowed me to see more of my strengths. (Sub. F2)

The other thing that it's done is it's made me decide to live happier; to not be concerned with things that are mundane. (Sub. F3)

He was the guy that taught me that I didn't have to explain myself to other people. I didn't have to justify my existence. I didn't have that ability before because I wasn't comfortable around feelings and I wasn't comfortable around me. ... I don't beat myself up; put myself down. (Sub. F4)

I have become very in-touch with myself and grown through R's death. ... I try to be good to myself. (Sub. F5)

I try to treat myself better. (Sub. F6)

I'm learning to value myself more. I had to be hit over the head with the fact that other people did before I could begin to do it myself. I realized with C that there wasn't anything wrong with me. ... It's getting easier to love myself and give myself a break. ... My self-esteem has changed a great deal. ... Coming face to face with death and coming to terms with my own mortality has given me greater appreciation for me with all my weaknesses. (Sub. M1)

I try to make more time for myself. (Sub. M2)

I'm taking better care of myself than I ever did before. (Sub. M3)

Accepting the way I look and feeling good about it.

(Before) I was the last person I would think of. (Sub. M4)

There is a part of me that died with him. There has also been parts of me that have been dead - put away or maybe the word is 'deadened' - through certain living experiences. ... But you drag it out and you better deal with it now if you are going to live. ... Basically, (I) really, really take care of myself; loving myself. ... I'm determined to bloom like those six cherry trees by the beach that bloom in the wintertime and I am going to be the best that I can be. (Sub. M5)

It's no longer okay to have a drink or a joint. I am learning to value my body. Like a car I have to keep it tuned. I used to abuse my body. ... I learned about who I really am. (Sub. M6)

ii) More Selective About Friendships (7 reports)

I've weeded a lot of people out of my life. (Sub. F1)

Having 1,000 friends is not important. ... I guess I choose the people that I hang out with. (Sub. F3)

Its important to maintain those relationships (friends) ... I need people to know me well and I need to know them well. I need that kind of closeness. ... I'm selective who I spend time with. (Sub. F4)

I have let a lot of people in my life go. ... Since I have done this I have attracted so many special people. People who are at peace with themselves. (Sub. F5)

My relationships are generally healthier. ... I have very much less patience for bullshit from people. I don't feel the need to waste my time on people who mistreat me. (Sub. M1)

I just have a handful of people (now) that I call and see. I stay away from a lot of people actually. I don't have an address and telephone book anymore. (Sub. M5)

More selective as to who friends are. (Sub. M6)

iii) Improved Relationships With Family Members (7 reports)

It's amazing to me because it wasn't a good relationship (daughter/mother) but it's a wonderful relationship now. ... I love them (parents). I like to spend time with them. ... It's been a healing experience for my entire family. (Sub. F1)

It's helped my relationship with (my surviving brother)

... Now we do things together. ... I make sure that I tell my parents that I love them. That's one thing that's changed. (Sub. F3)

My ideas around family are starting to shift. I'm starting to want to re-establish relationships with family. (Sub. F4)

I have a much closer relationship with my family. (Sub. F5)

My dad and I have a profound understanding and a better relationship; much better than it ever was. ... I'm starting to discover things about my younger sisters that I didn't know before. ... We're kind of growing together. There's a real healing bond there. (Sub. M3)

The urge to go back there (to family of origin) is a lot stronger and it's not them pulling me there. It's me wanting to live with them; to have them in my life a lot more and being in their lives. (Sub. M4)

I purposely isolated myself from my family. I've been abusive to my family and I truly love them. I'm going to let them be there. I don't want to hide the fact that I love them. (Sub. M6)

iv) Increased Sensitivity To Others (6 reports)

I have more understanding and tolerance than I ever did before. ... I even like street people now. I understand them. Maybe they don't want to live in a house. I can let them do whatever they want to do. Instead of giving them some money (I) give them fruit. (Sub. F1)

I started seeing that we're all the same. ... The people in my life are part of me and I'm part of them. And I have this - I don't like to call it sensitivity ... (Sub. F4)

... understanding and love for our fellow man. (Sub. F5)

And by feeling more connected to people I am more connected to people. (Sub. M1)

It's made me more aware. I can appreciate what they (the patients at work) are thinking and feeling. It's made me more sensitive and given what I went through with J I can understand now what it must be like to be in pain constantly or be sick constantly; to have your body react in a way that's not normal. ... I've got another AIDS patient right now. ... I know where he's coming from. ... God, I really feel for him! (Sub. M3)

A mother on T.V. was telling about her daughter who had

been raped and murdered. She was trying to keep control and I was telling the T.V. 'It's okay. Let it out'. When she broke I broke. I know the pain. (Sub. M6)

Blue Category - Values

Four sub-categories were found in the data referring to values. Subjects reported becoming less materialistic or money-oriented, having a greater appreciation for life and nature, placing more emphasis on love, and re-evaluating social expectations and religious beliefs.

i) Less Materialistic or Money-oriented (8 reports)

Not to value materialistic stuff. ... There's more to life than money. ... I have no money but I have quite enough money. (Sub. F3)

I used to value the material more than anything else. ... If I had the job, the house, the car, the toys, ... and I looked okay, people would look at me and say (she's) really got it together. I had to have lots of money. I had to have mega-holidays. ... Its the inside stuff now, rather than the outside stuff. (Sub. F4)

(The deceased) and I were very materialistic. (Sub. F5)

I don't think it's so you can buy a house and a car anymore. ... I used to think you had to look good; dress good. ... I used to think you had to get a good job. ... I mean I'm still working along those lines because I want to be self-sufficient but I think, now, that there's a deeper purpose. (Sub. F 6)

My idea of success has changed. As much as I resented it, I felt success was shown by financial stability, by external recognition and, most importantly, it was something that happened in the future, if at all. (Sub. M1)

Instead of coming from the pocket book, coming from the heart. And it means so much more. (Sub. M3)

You can have all the money or the nicest place in the world but if you have no one to share with I think you're really poor then. (Sub. M4)

It has (changed) in the way of material things. For example, if my car falls apart I just laugh. ... I don't get caught up in those things any more. (Sub. M 5)

ii) Greater Appreciation of Life/Nature (7 reports)

I look at flowers different and it sounds so smarmy and corny but it's true. ... Freesia is so important to me. Its one of my favourite things in the world. ... But that will change. I go through flower-of-the-month. ... Its just so amazing to me to be around; to be surrounded by so much beauty. And if I would have been here two years ago I never would have seen it. 'That's a nice plant' and keep walking. It just fills me - everything just fills me. What I value in life is life! (Sub. F1)

We're not going to be around for a long time so why aren't we going for a walk in the park. (Sub. F3)

It doesn't matter how many days, weeks, or years I live. It matters how I do it. ... Not just be, but live. (Sub. F4)

In every life there is beauty to appreciate; from the greatest mountain to the smallest flower. ... I try to absorb life in every way. ... I appreciate the finest things in life and don't take life for granted as I used to. ... I take time to ... appreciate whatever it may be from the scent of a flower to the sounds of nature. (Sub. F 5)

Even on a drive around Stanley Park before he got sick - 'Okay. That's great. Let's get it done and over with.' - and then all throughout his illness; everytime we did (go to Stanley Park) it was just wonderful because we slowed down and took in everything. ... And I still enjoy going down and sitting by second beach ... in the grove where squirrels seem to gather. Feeding the ducks. ... I still enjoy walking the seawall. More into it than I ever was. (Sub. M3)

I think that in a very simple summary kind of way ... I value the opportunity to be here; of life itself. ... To be able to see different beauties in different things and appreciate them. ... It's opened my eyes to beauty. (Sub. M5)

I appreciate more (that) I am one hell of a lucky person. ... I still have life. I can walk; smell the roses. (Sub. M6)

iii) More Emphasis On Love (6 reports)

Two days before he died he said he was really happy and he ... said 'I love you. Be happy for me'. And I said 'J I love you so much'. He said 'It's too bad we didn't know this before'. And it is. ... I'd like to do it better, I really would. I'd like to tell him every day that we're together or show him just how much I love

him. So what I'm doing this time, is to make sure that the people that are still here with me know, know deep down in their deepest being, that I love them and they are important to me. (Sub. F1)

For me it's a matter of always being aware of what's going on in here (points to heart region) and when it's not loving, begin to deal with it. (Sub. F2)

I loved the guy. I hadn't even known him that long. ... I'd never until I was 27 ... said to anybody 'I love you' and it was so scary. The first time I did it I was shitting bricks. And now most of my (telephone) messages will say 'I love you'. ... Completely different! (Sub. F4)

The incredible love we shared. ... This growing love is with me today. ... The effect on my life through R's death is to continue ... so others may understand more about the gift of love. (Sub. F5)

I was able to learn that just by listening, by being mindful, we both learned things about love and about caring that we wouldn't have learned otherwise. (Sub. M1)

It was like making love to him ... but really intense and for a long long time ... up until the end. ... We all learned something really important there. (Sub. M4)

vi) Re-evaluation of Social Expectations (6 reports)

I spend my time doing what I want to do more than what I think people want me to do or what I should be doing. Where, before, I was 'You have to do this. You hafta, hafta, should, should, should'. ... I used to have to be what people wanted me to be. (Sub. F1)

I'm dead when I'm caught in what I've been taught I am as opposed to who I am in the moment. (Sub. F2)

Do be, do be, do. (Sub. F4)

He wasn't caught up in social pressure ... what you should do and what you shouldn't do. It feels good because ... I've always done what I thought I should do, always. (Sub. F3)

I wasn't too thrilled about having to wear 'whites' (uniforms - back at work after the death). (So) I took a couple of weeks off. ... (Now) 'whites' are out. Casual but nice dress. They (the patients) are responding so much better. (Sub. M3)

Working in the moment. Really there now. (Sub. M6)

vii) Re-evaluation of Religious Beliefs (6 reports)

There was always this God thing that didn't make sense. ... I couldn't buy it. It had no basis in reality for me. ... 'It's a plague from God' Excuse me! No God I know. ... And my dad looked at me and said 'You know I don't think any more that you have to die to go to hell. I think sometimes you have to die to get out of it.' and that just made so much sense. ... And now, from before - kinda floundering and not knowing what I believed - to not even believing but knowing. (Sub. F1)

Shame and guilt. Shame and guilt. I was raised on shame and guilt. What can I say? I should have been Jewish. I'm Catholic; it's close enough. ... God isn't the God that the Catholic church gave me. ... God is love. ... and people are - they're God. They're part of God. ... The guys with AIDS were the ones that helped me the most to understand that it was inside me. (Sub. F4)

The effect of the Christian upbringing that I've been exposed to ... (in) analyzing my feelings on it I was able to realize that all the rules on personal conduct and ethics were not absolutes. That just because someone is breaking the ten commandments doesn't mean they are doing something wrong. ... That narrow perspective wasn't binding me anymore. (Sub. M1)

There was another fairly big change on religion. ... I was never into organized religion of any kind but I always had this - seeing as you were brought up that way - I always had this little thing in the back of my mind. Well, maybe, just maybe, you do have to believe in God a certain way. ... I always had this little thing. Well, what if they were right? R was brought up more on a spiritual level with no organized church and I watched him die. He didn't have any uptight things like heaven and hell to deal with. ... Yet he died peacefully. Like he wasn't scared that he was going to hell. He didn't seem to care if he was going to heaven. He just knew that he was going somewhere that would be nice and he died extremely peacefully. ... So that cleared up everything in my mind about dying and worrying about heaven and hell. ... I'm comfortable now knowing that you don't really need a religion to get to wherever you are going on the other side. (Sub. M2)

I think a closer relationship to God. Definitely. Living a spiritual life. I'm not religious or anything. I don't go to church. (Sub. M5)

More value on spirituality ... more of it happening. ... I think heaven and hell are what we live now. Death is going beyond that. We can all live in heaven if we

choose to. It's not by going down on your knees to
repent. It's how you live your life. (Sub. M6)

Purple Category - Employment

One quarter or four of the twelve respondents returned to their pre-bereavement employment. Of these, three returned to health care positions and reported improved performance. The fourth returnee indicated a new determination to evolve and find more satisfaction in the workplace. Five subjects changed jobs. In four cases the new position involved less remuneration but more personal fulfillment. The remaining three subjects went back to school; one return was planned before the death; the other two decisions to return to school were influenced by the death.

i) Change in the Workplace (12 reports)

Now that it's over let's go on. ... So I what I looked for was something that I already knew how to do. I started applying there and I got a job really fast. ... It's working out great. (Sub. F1)

I'm a better therapist. (Sub F2)

I do want to do my Masters. Not just for my parents. And this is what I want to do it in. I've struggled more on why I'm going to school but I think of D too because he would have wanted me to do this. He was always one of my big supports when I went through university. (Subject returned to school) (Sub. F3)

I wasn't going back to work in a hospital with all that lifting because I had reached the point where I loved myself enough that if I was going to work, it only had to be something that I enjoyed. ... It had to be healthy for me in all other areas. (Subject went back to school) (Sub. F4)

(Subject returned to health care position) (Sub. F5)

(Subject went back to school as she had planned to do before R's death) (Sub. F6)

(Subject began work for an AIDS organization) (Sub. M1)

(Subject found a less stressful, lower paying job in the same field) (Sub. M2)

(Subject re-opened a closed ward and is now working with the terminally ill) (Sub. M3)

I would like to find out if there's anything else I can do with this company. ... I want to move ahead in the sense of evolution and satisfaction. (Sub. M4)

I just want(ed) a job to do. Yet a job to do in the way of a physical sense but also connected with the heart; a simple expression of lovingkindness. And that's exactly what I do. ... Complete change of career; income bracket. Total complete change. Fifty percent income loss but I'm not any less wealthy. (Sub. M5)

Now I'm doing something I enjoy a lot more at one third the wage ... I'm doing what I really want to do. I don't have to bring it home. ... Feeling a sense of personal accomplishment. (Sub. M6)

Orange Category - Death And Grief Issues

There are four sub-categories associated with death and grief issues. Subjects reported less or no fear of dying and a new or stronger belief in an afterlife. Respondents were also confident that they would see their loved one again and they valued their experience of bereavement.

i) Loss of Fear of Dying (9 reports)

I was always scared of death. ... And then to get on the bed beside what used to be my brother and just hold him and talk to him. He wasn't anything to be afraid of when he died because it was so much like a birth. It was like 'God. He's gone! Its so great!'. ... I'm not afraid anymore. (Sub. F1)

When I was in my nursing days (and) people started talking about dying I'd cut them off. I didn't want to hear it. ... Before I'd run even if I didn't leave the room. ... (Now) I'm not really afraid of dying. (Sub. F4)

I don't have any fear of death ... R's death was so peaceful and to experience it with him, how can one have fear? (Sub. F5)

Basically the acceptance of death and not really fearing it. A lot of fear is diminished. ... I guess more than anything it's made me really not afraid to die. (Sub. F6)

I still have fear about losing my mind or losing control of my body but the actual idea of dying is not overwhelming. ... 'Death has lost its sting' is about the best way I can put it. (Sub. M1)

Watching R die I really came to the conclusion that death is not that 'big a deal' ... The dying process bothered me because I was losing someone but the death - like one minute he was here and the next he was gone. And I didn't freak out and I didn't cry. There was no change other than the sense that it wasn't that bad. You know, dying isn't that bad. (Sub. M2)

Not being afraid of it. ... I was very surprised at how, in this case, his death was very peaceful. (Sub. M4)

I value my understanding of death. That it makes me absolutely fearless. When I'm in a plane and somebody says 'What if we crash?' (laughing) I say 'Hallelujah!'. (Sub. M5)

My attitude to death has become more positive. I was always afraid before. I now realize its part of life. (Sub. M6)

ii) A New or Stronger Belief in an Afterlife (7 reports)

There was just this shell of this person that I just loved so much. He wasn't there anymore! That was the biggest realization in coming to terms with death; that what was lying there on the bed wasn't my brother any more. He was gone. He was somewhere else ... and I believe in reincarnation. I used to have no thoughts. There was no afterlife. (Sub. F1)

It's reinforced my experience and my learning over the years that we are first and foremost spirit. (Sub. F2)

There is a definitely a soul. I don't know whether it leaves a person. Because when I saw him dead he was there but he wasn't in that body and I knew that. That body could have been this kleenex box. That's all it was. It was just matter. So there is more. There is something that makes you up but I don't know what it is. (Sub. F3)

My belief in life after death is so much stronger. (Sub. F5)

But with proof that B was actually going somewhere. You

could see when he was laying there that he was looking at something that we couldn't see. Yet he was aware of us. But he was looking off somewhere even though his eyes were glassy and watery. He was looking at something. I mean his eyes were open and I don't think you go blind when you die. ... When I go I just go with me and whatever I have learned. (Sub. F6)

I have always, since I was a little boy, said 'There must be more than what I see; what meets the eyes. There must be another reality'. However this might constitute only 5% of my belief system and 95% is the reality we live in. And that slowly changed and I'd say that toward J's death the picture totally turned around. That 95% of my belief is that there is more than we can see; 5% is our reality. (Sub. M5)

I'm positive there is an afterlife. ... You go and live elsewhere when you die. (Sub. M6)

iii) Seeing The Deceased Again (6 reports)

It brings me a lot of pleasure to know that at some point in my life ... I'm going to meet him again. ... Oh, I know he'll be there laughing because that's what J did best. (Sub. F1)

I know I'll see him again. (Sub. F6)

Now I know that when I die I'm going to have someone waiting for me ... there's going to be someone on the other side waiting for me. (Sub. M2)

Or little birds. When a little bird lands near me and they kind of stare at me I can't help but think 'Is that you?'. (Sub. M4)

I look forward to the meeting again. ... If I were going to die that would be one of the things to look forward to; that I was going to see J again. (Sub. M5)

I'm not afraid because I have someone on the other side waiting for me. Whenever I die he's going to be there waiting for me. One big bonus in dying. He'll be there! ... If I live 'till I'm 90 he's going to wait for me. (Sub. M6)

iv) The Importance of Experiencing the Grief (6 reports)

I just wish everybody could understand that, everybody that's experienced a loss. I wish they could just understand and do the work and feel the feelings. ... I may have to go through it again. I may have to go through it with people I love because some of the people that I love are HIV positive. But I'm prepared and I

know the way. As long as I can keep those feelings out and not bottle anything up. (Sub. F1)

I felt like I was dying in lots of ways. ... And this layer accepts and then this layer accepts and then this one. (Sub. F2)

Its was the first time I went through the whole process because I didn't like to feel before. ... I just stayed in denial. ... I didn't understand that it - **get on with your life** - meant there was work to do around healing. I just chose to ignore it. ... I went through anger, denial, resentment, rage, the whole nine yards; all those stages with L. (Sub. F4)

Through the awariness of R's condition we were able to talk openly and freely on life and death. (Sub. F5)

This was the only death where I was emotional. ... I was crying and I was sad and I was upset. I couldn't control my emotions. ... A lot of emotions came out when R was dying. Those kind of emotions that normally don't come out in me. I didn't have any say in it.. (Sub. M2)

During the grief process was the willingness to totally let go. To really understand that the only control is letting go. So I let go. I let go and I started falling in my drifting process. And falling like a leaf. Just drifting in the air. Fall. Fall. Fall. And hit the bottom. Hit just the darkness of the darkness. Hit bottom and stay there. And then that is when the magic happened. When I hit bottom a trap door opened and I fell into the light. (Sub. M5)

Green Category - Change

The Change category heads five sub-categories that represent common responses not included under any of the other major categories. These five sub-categories contain: statements summarizing the experience, naming it, indicating the type and degree of importance it represented, and describing the nature of the pre-death relationship.

i) Summing The Experience (11 reports)

He started me on a road to a happier life. ... Feb 13th my life stopped and the world went on. Nothing about the world changed but everything about me changed. (Sub. F1)

One of the gifts of all of this ... has been that every death ... mirrors for me the parts of me that are not living ... and each time I become more alive. (Sub F2)

The change in me has just been to take life more seriously but less seriously ... You've got to cut off a finger before you appreciate the four you've got left. (Sub. F3)

Living with someone with AIDS changed my life. (Sub. F4)

I was honored that I helped his spirit move to another place and that I witnessed part of it. (Sub. F6)

The whole experience of AIDS in my life has caused me to view the world quite a bit differently and caused me to change my priorities. (Sub. M1)

The experience has brought only good changes. ... I can't think of anything negative other than losing him. And then if I wouldn't have lost him I wouldn't have all these positive experiences; sort of like a double-edged sword. (Sub. M2)

Instead of being a negative experience it was a very quiet positive experience. (Sub. M3)

Some things you just can't change or control. So you let those things happen. There's no reason why you can't transform; rearrange. It's like an interior. You start with something awful. You can't control the shape of your walls but you can transform; do something. You are still with the same thing but you've done something. (Sub. M4)

The world didn't die that day. It blossomed. (Sub. M5)

I lost my best friend but that was the only negative thing ... so many positive aspects. (Sub. M6)

ii) Naming The Experience As Gift or Lesson (10 reports)

The word gift was mentioned five times in this sub-category.

Terms referring to learning were also mentioned five times.

There was something to be learned and it was your job to learn it. ... It was a gift. (Sub. F1)

J provided many mirrors. ... I regard him as a teacher. ... So for me it was such a gift. (Sub. F2)

He was sort of like my mentor. (Sub. F4)

It was just a learning experience to learn that if love

isn't unconditional, it probably isn't there at all.
(Sub. M1)

It's been a very intense learning experience. (Sub. M4)

His mission was to give me this gift. (Sub. M5)

Thank you for giving me the gift of dying on me! (Sub. M6)

iii) Degree of Importance of the Experience (8 reports)

I'm totally different... It's an experience that I wouldn't give up; ... the time that I spent with J and the fact that I was there when he died. ... The biggest most important event in my life. (Sub. F1)

My whole life is different. (Sub. F3)

I'm not the same person. ... Everything's different. You wouldn't have wanted to know me three years ago. (Sub. F4)

The whole thing is really important to me - being with B. (Sub. F6)

The most anything's changed in my life since I've been born. (Sub. M2)

His dying would mean a new change for me; a new lease on life. Thank you kiddo! (Sub. M3)

I was appreciating it as it was happening and even right after. And I can appreciate it a lot more now. (Sub. M4)

I think it has effected my life and changed my life completely; ... a dramatic, absolute change happened. ... I think it's profoundly changed how I live! (Sub. M5)

iv) Reports of Growing Up or Accelerated Learning (6 reports)

I'm light years away from where I was before. (Sub. F1)

This was like using rocket fuel instead of using unleaded gas. (Sub. F4)

I've grown so much. (Sub. F6)

It's been a time to grow up in lots of ways. (Sub. M2)

... like this evolution or this trajectory. (Sub. M4)

This made me grow up. (Sub. M6)

v) Type of Pre-death Relationship With The Deceased (6 reports)

He was my favorite person in this world. I can't think of anyone I loved more than J. (Sub. F1)

I loved that man. ... We were closer than family. (Sub. F4)

You know, he really did understand me. (Sub. F6)

All this thing about best friends. ... There has to be a better word for it. It's some hookups. (Sub. M2)

I was his best friend. I think when you are a lover and can be your lover's best friend you've got something pretty good there. (Sub. M4)

It's someone I chose to love. That says it all. (Sub. M6)

The sub-categories above have condensed the range of subject information into twenty-one common responses. The data is further reduced as four predominant themes emerge. Themes of locomotion, contradiction, inconsistency, and paradox were found to connect various sub-categories.

The first theme, locomotion, refers to the experience of a shift from external sources of influence to an internal source. Subjects typically reported a relocation of the locus of authority in their lives. They re-evaluated previous external motivations and became more inclined to look inside themselves for guidance.

External motivations such as money, material goods, and popularity gave way to job satisfaction, caring for others, and selective socializing; all internally motivated. As one subject stated. "It's the inside stuff now rather than the outside stuff" (Sub. F4).

Subjects noted improved relationships with themselves; the

reclaiming of lost parts, acknowledging their strengths, valuing and accepting themselves. They reported that they got in touch with who they really were and began to treat themselves better. In conjunction with this new hospitality toward themselves, subjects began to question traditional sources of authority. They came to respect their own judgement and relied on it more.

Evidence of internally-driven decision-making was demonstrated in the area of employment as the majority of subjects changed their career focus following the death. A full two-thirds or eight of the sample of twelve either assumed a new position or returned to school. Of the five who chose a different line of work, four accepted placements that paid less but afforded a reduction in stress and a greater sense of personal accomplishment. The three subjects who returned to school apparently choose to invest in themselves following their bereavement.

A shift away from materialism toward caring for others was also reported by two-thirds of the subjects; "instead of coming from the pocketbook, coming from the heart" (Sub. M3). Most of the subjects who returned to their previous jobs (three out of the four) worked in the health care field. This is consistent with the trend of increased caring for others. Other evidence of a movement toward caring is seen in the reports of improved relationships with family members and a heightened emphasis on love.

Another example of the shift from external to internal motivation was seen in reference to social activities. A diminished need to be popular resulted in subjects spending more

time by themselves and becoming more selective in the social interactions they did have. "It pulls one percent closer and pushes the rest further (away)" (Sub. M5).

Subjects also reported a re-evaluation of social expectations and religious beliefs. Half the sample described a move away from external centers of authority to a personal decision-making. Social pressure became less effective as 'shoulds' internalized over time were replaced by a personal "tuning in" process (Sub. F1). As one subject reported, "I spend my time doing what I want to do more than what I think people want me to do, or what I 'should' be doing" (Sub. F1).

The external authority of early religious instruction was challenged and a more personalized concept of God was adopted. Subjects tended to internalize their religious beliefs, coming to "understand that it was inside" themselves (Sub. F4). Traditional concepts such as heaven and hell were redefined in terms of present conditions and possibilities. And "living a spiritual life" (Sub. M5) became a goal having little to do with established religion.

The second theme to emerge from the data, a theme of contradiction, involved human relationships. Subjects reported an increased sense of connection to all humanity, and yet they spent more time alone. Increased levels of empathy, caring, and love for one's fellow man and seeing "that other people were just the same as me" (Sub. F4) coincided with an increased screening of actual social contacts. While family relationships improved, following the bereavement, subjects frequently curtailed other

social activity. Many relationships ended and new friendships were carefully selected.

The third theme to appear in the data was one of inconsistency; a greater participation in life was reported at the same time as death became accepted as a welcomed prospect. Subjects acknowledged a new appreciation for themselves, others, nature, and life in general, yet they also experienced a diminished fear of dying. Reports of a new passion for life, "doing, seeing, and being the best" (Sub. F1) seem to be inconsistent with "welcom(ing) death" (Sub. F6). Subjects commonly valued both life and death simultaneously, two apparently diametric and mutually exclusive states. An appreciation of one state did not seem to depreciate the other.

The final theme involved paradox. Subjects indicated that they had an exceptionally close relationship with the person who died. Paradoxically, they also saw the loss of this primary person as a valued experience. Although the deceased were portrayed in terms of "best friend (and) lover" (Sub. M4), "favourite person in this world" (Sub. F1), and "someone I chose to love" (Sub. M6), three quarters or nine of the twelve subjects described the death as a gift or learning experience. Several subjects suggested their experience had been the most valued one of their lives. They used phrases like: "an experience I wouldn't give up" (Sub. F1), "a new lease on life" (Sub. M3), and "the most loving gift anyone will ever give me" (Sub. M5). Paradoxically, the loss of a precious relationship was seen as a highly valued experience.

In an attempt to define the dynamics involved in these

positive bereavement situations, the four themes noted above have been drawn together into a single metaphor. The life cycle of a flower was chosen as references to flowering plants were common in the data. For example: "weeded a lot ... out", "flowers", "freesia" (Sub. F1), "smallest flower", "scent of a flower" (Sub. F5), "bloom", "blossom", "leaf", "cherry trees" (Sub. M5), and "smell the roses" (Sub. M6). The following metaphor is offered to represent the phenomenon of personal growth through loss.

Plants live best outdoors, connected to the earth. In most gardens they grow and bloom in clusters, appreciated, at a glance, for their collective effect. But when we bring a single flower home, its unique beauty is ours until it dies. There is a trade-off though. By bringing one flower close, we enjoy it more but for a shorter time.

The beauty of one special flower can initiate an interest in gardening. We learn that plants all have the same basic needs: soil, water, and sun. As we begin, we come to appreciate the variety of species that exist. Yet, to protect the health of an individual sprout we weed out certain types. We learn that plants need room to grow. They need space from even their own sort. And if their needs are met, their simple mission is to live and blossom and die. Their season done, we find our favourites are perennial. And this pleases us.

CHAPTER V
CONCLUSIONS & RECOMMENDATIONS

There are as many ways to cope with the turmoil of losing a loved one as there are people left behind. A bereavement permanently shatters some lives. Other times, people come to discover a life they never dreamed possible. The majority of bereaved individuals, however, experience some degree of each: both falling apart and finding a better way.

In order to discover how to assist people facing bereavement, this study has examined those individuals who not only survived their crisis, but who also, reportedly, thrived as a result of it. The sample was selected with a philosophy promoted by Abraham Maslow (1971): study healthy psychological functioning as opposed to pathology. Maslow chose "the use of selected good specimens ... for studying the best capability that the human species has" (Maslow, 1971, p. 5). Just as Bernie Siegle's (1986, 1989) recent interest in ECaPs, or exceptional cancer patients, has furthered our understanding of optimal functioning in dire medical situations, this work featured exceptional bereavement survivors to better understand the bereavement recovery process.

The present exploratory study established that valued bereavement outcomes do exist and that they are found in recognizable patterns. These findings are discussed in relation to parallel results drawn from research in a related field. The findings of the present study are also discussed in regard to their power and limitations. Implications for counselling are noted and a number of pre- and post-bereavement counselling

strategies are suggested. Recommendations for future research are provided and these are followed by a brief closing comment.

The interview data, from the present study, revealed two points. First, some people do experience very positive bereavement outcomes. And second, there appear to be patterns to the phenomenon.

While positive bereavement outcomes are certainly an enigma, the present study shows that they are also a reality. The fact that some people find anything of value in the death of a loved one is an important finding in itself. Subjects reported beneficial changes in the areas of; time, relationships, values, employment, and death/grief issues. They also used terms such as 'growth', 'learning', and 'gift' to describe their experience.

The twenty one positive changes, described by at least half the sample, correspond with the reported aftereffects of a near-death experience (NDE). Raymond Moody (1975) surveyed individuals who, having been clinically dead, were revived and survived to describe their experience. Moody found that near-death experiencers (NDEers) undergo substantial value transformations and a decreased fear of death. In short, "their lives have been totally, completely, and permanently transformed" (Moody in Flynn, 1986, p. xiv).

Kenneth Ring further investigated the phenomenon of NDEs and classified his findings under the following headings: Aftereffects I - Personality and Value changes and Aftereffects II - Attitudes Toward Religions and Death (Ring, 1980, p. 138 & 159). Ring's more recent work, the Omega Study (1984), continued

to survey NDEers, this time focusing on the meaning of their experience.

The findings of this last study provide a detailed inventory of NDE aftereffects. In the area of Personality and Value Change the findings were: A Greater Appreciation of Life (appreciation of ordinary things and nature), A Greater Concern for Others (helping others, compassion, patience, tolerance, love for others, insight into others, understanding and acceptance of others), Less Concern with Impressing Others (good impression, well-known, what others think), Less Materialism (material things, 'living the good life', high standard of living, material success) and, A Quest for Meaning (higher consciousness, 'what life is all about', purpose, inner meaning, self-understanding, personal meaning) (Ring, 1984, p. 300 - 311).

Attitude changes towards religion and death found in Ring's Omega Study were: a tendency to characterize oneself as spiritual rather than religious per se, a feeling of being inwardly close to God, a deemphasis of the formal aspects of religious life and worship, a conviction that there is life after death, an openness to the doctrine of reincarnation, a belief in the essential underlying unity of all religions and, a desire for a universal religion embracing all humanity (Ring, 1984, p. 146).

More recently, Charles Flynn (1986) examined the emotional transformation experienced by NDEers. Flynn added two more experiences to the known aftereffects of NDEs. First, NDEers tend to experience a "deep sensitivity to the suffering of others and their empathy for all forms of life reflect a profound reverence of life" (Flynn, 1986, p.39). Flynn's subjects also

came to believe that "love is the central meaning of life" (Flynn, 1986, p. 50).

The integrated findings of these three researchers provide a detailed account of common NDE aftereffects. These results closely parallel the present findings: a transfer from an external to an internal orientation, greater appreciation of both life and death, greater connection to humanity with increased selectivity for social contacts, and the over-all valuing of a very grave experience.

A research link exists between NDEs and the present AIDS-related findings. A study of survivors who had "come close to death" revealed that a life threatening experience can also produce changes similar to those of a NDEs (Noyes (1982). Evidently, one does not have to actually die and be resuscitated to experience the aftereffects. AIDS author BettyClare agrees. She observes that "we are never the same again after ...the pass through to the mystery of death, whether it is a near death experience or holding the hand of a dying patient" (Moffatt, 1988, p. xii). AIDS caregivers apparently experience a close encounter with death as opposed to the personal encounter of the NDEer, yet the consequences are similar.

While the interview responses in the present study were quite consistent, there is no evidence to suggest that the findings of this study are restricted to AIDS-related bereavements. Positive bereavement outcomes are not necessarily an AIDS-related phenomenon. Nor are the outcomes discussed here to be generalized to all AIDS survivors. The sample was twice self-

selected; most subjects volunteering from a support group they chose to attend. Therefore, for generalization purposes, the sample represents only itself.

The study realizes strength through the nature of the interview questions. The similarity of the subject's responses to nonspecific open questions generates confidence in the findings. In addition, the fifty percent report criteria per sub-category serves to further increase the power of the study.

The present research indicates that there are similarities between some bereavements and near death experiences. One of the main differences between the two situations is that individuals can often prepare themselves for a bereavement. NDEs, on the other hand, are usually quite unexpected. Individuals facing the death of a loved one can benefit from pre-bereavement strategies that facilitate communication, as well as follow-up integrative work.

"Why is it so difficult to console? The quickest answer is that we have no language of the heart to express our deepest feelings" (Roth, 1987, p. 111). Counsellors can help survivors develop 'a language of the heart'. By seeding such words as 'gift', 'lesson', and 'teacher', counsellors offer a positive framework for survivors to shape meaning around their experience.

Another means of providing influential language to those coping with a terminal diagnosis involves the use of metaphors. Counsellors can collect valuable information about how individuals perceive their situation by asking them for a metaphor. Then, replacing fearful images of approaching death such as a 'headless horseman' and 'night of the living dead'

characters, counsellors can suggest natural, process-oriented metaphors like the winding down of a clock, a sunset at the end of a beautiful day, and the gradual withering of a flower.

Another valuable strategy counsellors can offer during the pre-bereavement period is modeling. Actually planning to work without an agenda, attempting to be in the moment, letting go of expectations and control, and expressing genuine feelings may be more useful than a discussion of the same ideas. Similarly, the possibility of a situation being seen as a learning experience is realized when the counsellor discloses what s/he has personally learned from the client.

The present findings suggest that post-bereavement recovery is a "resocialization" period (Flynn, 1986). Just as NDEers have shown that "the experience itself becomes a part of the individual and becomes part of his or her life" (Clarke in Flynn, 1986, p. 19), the newly bereaved often find re-entry into the world difficult since "nothing about the world changed and everything about me changed" (Sub. F1). As NDE researchers have observed, "... you cannot expect NDEers to take up life as usual after an NDE; their outside circumstances may have to be changed to meet their internal changes" (Greyson & Harris in Grof & Grof, 1989, p. 210).

Bereavement recovery involves more than learning to live in the absence of the deceased. Survivors may find it easier to adjust to the loss of their loved one than to re-enter the world with the changes they have experienced. Post-bereavement work involves helping survivors learn "how to incorporate newfound

values, beliefs, attitudes, and behavior patterns that have suddenly replaced old familiar ones" (Flynn, 1986, p. 27). As crisis researchers Stanislav and Christina Grof suggest:

The most important task is to give people in crisis a positive context for their experience and sufficient information about the process they are going through. It is essential that they move away from the concept of disease and recognize the healing nature of their crisis (Grof & Grof, 1989, p. 192).

Future research suggestions in the area of bereavement outcomes: Do positive outcomes extinguish over time? Do locus of control measures change from pre- to post-bereavement? What is the effect of cultural differences? Valued outcomes - who's values? What is the effect of the degree of participation in care? What is the effect of the degree of openness of expression: thoughts and feelings? What are the effects of counselling, specific readings, peer support groups, and multiple losses on bereavement outcomes?

More than any other factors, good bereavement recovery seems to depend on the attitudes of acceptance and willingness. The adoption of these attitudes involves personal choice.

You decide you are going to plan your life and you plan on taking this trip. And you're going to go to France. And you get off the plane and you're not in France. You are in Holland but you didn't want to go there. That's not where you planned on going. And that's not where I wanted to be. But then you realize there are things about Holland that you don't know. And its a beautiful place to be. Its the same as a loss. Its not what I planned and its not what I wanted to happen but there are some really beautiful things about it. ... Before J died, if I would have landed in Holland I would have been right pissed off. Take me to France! I want to see the Eiffel Tower! (Sub. F1)

"There is nothing good about this plague, but there's alot of good in the way people respond to it" (Jones in Ruskin, 1988, p. 18). This paper does not aim to romanticize AIDS or death. The death of a loved one and the subsequent bereavement experienced by survivors are never beautiful, but, in some situations, the experience can be a vehicle for personal growth and transformation.

Bereavement is a time of letting go. While survivors strive to release the person who has died, the experience of bereavement may also include letting go of previously held judgements, fears, self-criticisms, and feelings of separation. These acts of letting go do not diminish the survivor for, as this study has shown, a new sense of confidence, compassion, and communion can appear.

Perhaps, love is the most contagious aspect of AIDS; love of self, love of others, and love of all that is. Even death may be thought of with affection as one survivor proclaimed: "Death has lost its sting" (Sub. M1). Of course it has! The bee is love making for a plant!

It was like making love to him ... those days together were like an intense session of lovemaking ... up until the end. (Sub. M4)

And in the end, a lesson to be learned by heart: The human heart can, indeed, break open. Something of value can be found the processes of dying and grieving. And to understand that "an open heart is a much greater blessing than death is a tragedy" (Bill, Person With AIDS, in Levine, 1987, p. 127) - one graduates to life.

The world didn't die that day. It blossomed. (Sub. M6)

APPENDIX A

SUBJECT INFORMATION SHEET

Subject: (Ident. Code) _____ Age _____ Sex _____
 Person who died of AIDS Age _____ Sex _____

- 1) What was your relationship to the deceased? _____
- 2) How long ago did he/she die? _____
- 3) How long had you known the deceased? _____
- 4) What was the length of time from diagnosis (AIDS) until death?

- 5) Length of time from disclosure of AIDS diagnosis (to you personally) until death _____
- 6) What was the degree of your participation in patient's care:
 - no participation in care
 - limited participation (i.e. patient in hospital)
 - member of a care team
 - primary caregiver
 - other _____
- 7) How did the two of you communicate the emotions you were experiencing to each other?
 - complete two-way communication
 - one-way communication (explain: _____)
 - limited communication (explain: _____)
- 8) To what degree did the two of you discuss death and dying?
 (circle one number)

No talk									Open talk
[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]
- 9) Mark the emotions that you believe the PWA experienced during the course of his/her illness.

<ul style="list-style-type: none"> <input type="checkbox"/> denial <input type="checkbox"/> anger <input type="checkbox"/> bargaining <input type="checkbox"/> depression <input type="checkbox"/> hope <input type="checkbox"/> acceptance <input type="checkbox"/> other _____ 	Mark the emotions that you yourself experienced during the course of the illness. <ul style="list-style-type: none"> <input type="checkbox"/> denial <input type="checkbox"/> anger <input type="checkbox"/> bargaining <input type="checkbox"/> depression <input type="checkbox"/> hope <input type="checkbox"/> acceptance <input type="checkbox"/> other _____
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- 10) Total number of people you have known to die of AIDS _____
- 11) What is your HIV status? antibody neg. antibody pos.
 untested ARC AIDS do not wish to answer

APPENDIX B

SUMMARY OF SUBJECT INFORMATION SHEET

Subject: (Ident. Code) _____ Age 33 Sex 6M/6F
 Person who died of AIDS Age 36 Sex 12M

- 1) What was your relationship to the deceased? _____
 - 2) How long ago did he/she die? 13 months
 - 3) How long had you known the deceased? range: 6 mon - 29 yrs
 - 4) What was the length of time from diagnosis (AIDS) until death?

 - 5) Length of time from disclosure of AIDS diagnosis (to you personally) until death _____
 - 6) What was the degree of your participation in patient's care:
 - [1] no participation in care
 - [1] limited participation (i.e. patient in hospital)
 - [2] member of a care team
 - [8] primary caregiver
 - [] other _____
 - 7) How did the two of you communicate the emotions you were experiencing to each other?
 - [7] complete two-way communication
 - [1] one-way communication (explain: _____)
 - [4] limited communication (explain: _____)
 - 8) To what degree did the two of you discuss death and dying?
 (circle one number)
- | | | | | | | | | | |
|---------|-----|-----|-----|-----|-----|-----|-----|-----|-----------|
| No talk | | | | | | | | | Open talk |
| [1] | [2] | [3] | [4] | [5] | [6] | [7] | [8] | [9] | [10] |
| 2 | | 1 | | 1 | | 1 | | 1 | 6 |
- 9) Mark the emotions that you believe the PWA experienced during the course of his/her illness.
 - [] denial
 - [] anger
 - [] bargaining
 - [] depression
 - [] hope
 - [] acceptance
 - [] other _____
 - Mark the emotions that you yourself experienced during the course of the illness.
 - [] denial
 - [] anger
 - [] bargaining
 - [] depression
 - [] hope
 - [] acceptance
 - [] other _____
- 10) Total number of people you have known to die of AIDS 12+
 - 11) What is your HIV status? [9] antibody neg. [2] antibody pos.
 [] untested [1] ARC [] AIDS [] do not wish to answer

Appendix C

CONSENT AND RELEASE FORM
SIMON FRASER UNIVERSITY
FACULTY OF EDUCATION
BURNABY B. C. V5A 1S6
(604) 291-3395

I, the undersigned, agree to take part in a study sanctioned by the University Research Ethics Review Committee of Simon Fraser University. My participation has been explained to me as:

- a) the completion of a questionnaire and
- b) one audiotaped interview of approximately an hour and a half in length.

I understand that:

- 1) the recollection of my experience of losing a loved one to AIDS may cause me emotional distress and that I have the right to discontinue my co-operation at any time. By doing so all material recorded to that date will be destroyed.
- 2) all questions regarding the study will be answered by the researcher following my participation. The researcher will make a follow-up call to discuss any effect this study has had on me. And the researcher will remain accessible to me after I have made my contribution.
- 3) my personal anonymity and the anonymity of any person(s) I may refer to shall be protected by the changing of names and circumstances in the text of the completed document(s).
- 4) the audiotape of my interview will be destroyed at the end of the project.
- 5) I will have access to the completed document(s)
- 6) I may register any complaint I might have about this study with the chief researcher named below or with Dr. Adam Horvath, Chairman of the Counselling Psychology Department, Simon Fraser University.

I, also, give my consent for written portions of my interview to be published in whatever form(s) the researcher sees fit.

Signature of subject/participant

Thankyou for your participation!

Joy Moon B.A. (Honors Psychology)
Researcher/ M.A. Candidate
Simon Fraser University

APPENDIX D

INTERVIEW GUIDELINES

PRIMARY OPEN QUESTION

- 1) How has the death of _____ affected your life?

ADDITIONAL AREAS OF INTEREST

- 2) How has the death affected your philosophy of life or your understanding of the meaning or purpose of life?
- 3) How do you spend your time differently since the death?
- 4) How has the death affected your relationships with others?
- 5) How has the death affected your values?
- 6) How has the death affected what you do for a living?
- 7) How has the death affected your attitude about dying?
- 8) How has the death affected your belief in an afterlife?
What experience formed these beliefs?
- 9) What makes this experience different from the deaths of other people in your life?
- 10) To what do you attribute the positive consequences this death has had for you?

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