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The sun always comes out after it rains: Exploring the experience of AIDS caregivers (Immune deficiency)

Susan Cadell
Wilfrid Laurier University

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The Sun Always Comes Out After It Rains: Exploring the Experience of AIDS Caregivers

BY

Susan Cadell

M.S.W., Wilfrid Laurier University, 1990
B.A., University of Waterloo, 1986

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ABSTRACT

The Sun Always Comes Out After It Rains: Exploring the Experience of AIDS Caregivers

Susan Cadell

This research was designed to explore the growth of people who have cared for or about someone who has died of Acquired Immune Deficiency Syndrome (AIDS)-related illnesses or complications related to Human Immunodeficiency Virus (HIV) disease. It consists of a cross-sectional study of 176 bereaved caregivers of people with HIV disease, some of whom themselves are HIV-positive. Measures were selected to assess demographics, creativity, spirituality/religiosity, social support, depression, traumatic symptomatology and posttraumatic growth. A research model is tested which examines the relationship of psychosocial resources and stressors to the post-traumatic growth of the bereaved participants. In addition, seven caregivers participated in unstructured interviews in order to provide descriptive data with which to supplement the quantitative results.

The results demonstrate that individuals scoring highest on measures of spirituality, reported the greatest positive changes after trauma. Support for the role of spirituality was found in all the statistical tests as well as in the structural equation model. The interview data further substantiated the importance of spirituality in the process of growth. The structural equation model and the interview data also demonstrated confirmation of the hypothesis that the carers with higher reported levels social support would demonstrate higher post-traumatic growth. The results further demonstrated that those individuals with higher levels of post-traumatic stress symptoms reported the most growth after the death of the care recipient; this result was the opposite of the hypothesized relationship.

This study provides a portrait of bereaved HIV carers in Canada and the realities associated with that situation. The findings confirm the literature that suggests that, in contrast to carers of people with other diseases, HIV caregivers are younger, more often male, not necessarily a family member and are often HIV-positive themselves. This portrait and the relationship of spirituality, social support and trauma to growth have implications for social workers in all practice areas. The importance of spirituality mirrors an emerging area of interest in social work. The knowledge of factors that can play a role in post-traumatic growth can contribute to the work of social workers and others at any level of intervention.

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To these friends I dedicate this work. And I would gladly trade it in to have them back.

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CHAPTER ONE

Introduction

Overview

This research was designed to explore the growth of people who have cared for or about someone who has died of Acquired Immune Deficiency Syndrome (AIDS)-related illnesses or complications related to Human Immunodeficiency Virus (HIV) disease. More specifically, it examines the role of social support, spirituality/religiosity and creativity in the personal growth of AIDS caregivers after the care recipients have died and investigates the role of stress in growth outcomes. It consists of a cross-sectional study of 176 bereaved caregivers of people with HIV disease, some of whom themselves are HIV-positive. A research model is tested which examines the relationship of psychosocial resources and stressors to the post-traumatic growth of the bereaved participants. In addition, seven bereaved caregivers participated in unstructured interviews in order to provide descriptive data with which to supplement the quantitative results.

Rationale

For every person who dies of AIDS-related complications there is at least one person left behind who cared for or about that deceased individual. The experience of caring for someone who is dying can be a devastating and life-altering occurrence. The pain and suffering involved in such an undertaking are understood by anyone who has experienced it and uncomfortably imagined by those who have not.

However widely understood the consequences of caring for someone and being bereaved in the context of any disease may be, the issues surrounding HIV disease make the situation considerably more complicated. The stigma of AIDS, while lessened in recent years, is still enormous and touches those who are associated with an infected person as well as those who are infected (Caruth & Keenan, 1995; Herek & Glunt, 1988; Powell-Cope & Brown, 1992). The unpredictable nature of the progression of HIV and AIDS provides extra stress (Siegl & Morse, 1994; Weiser, 1996). In Canada, the gay male population has suffered the greatest impact of HIV. The losses in the gay and lesbian community reach well beyond the number of people who have died to the loss of leaders and the loss of dreams, to name a few (Klein, 1998; Nord, 1996a, 1996b, 1997, 1998). In addition, those who care for a person with AIDS are often not in relationships that are recognized by society (Rowe, Plum & Crossman, 1988; Worden, 1991). Because the people dying tend to be in their 30's and 40's, the people providing care for them are often in this age group as well (McCann & Wadsworth, 1992;

Turner, Catania and Gagnon, 1994). It is common for those who care to be HIV-positive themselves (Clipp, Adinolfi, Forrest & Bennet, 1995; Folkman, Chesney, Collette, Boccellari & Cooke, 1996; Wrubel & Folkman, 1997) and to have lost dozens of friends and associates (Shernoff, 1995, 1997b).

Despite the pain and suffering, there is great variability in the reactions to bereavement (Calhoun & Tedeschi, 1990; Wortman & Silver, 1992). One possible outcome of caregiving and bereavement is personal growth (Tedeschi and Calhoun, 1995). While the literature on AIDS caring and bereavement is scarce, especially those studies which investigate positive outcomes, there is some indication that carers grow from the experience (Folkman, 1997b; Garfield, 1995; Moskowitz, Folkman, Collette & Vittinghoff, 1996; Viney, Crooks, Walker & Henry, 1991).

Definitions and Disclaimer

The Human Immunodeficiency Virus is often referred to as the virus that leads to AIDS. However, there is debate about the existence of such a direct relationship (Duesberg, 1996). While such a debate is beyond the scope of this dissertation, the lack of agreement concerning the relationship between HIV and AIDS requires a careful use of terms. Thus, HIV-positive is used to denote a person who has tested positive for the presence of HIV antibodies; HIV-negative indicates that a person has been tested and no HIV antibodies were found. HIV serostatus is the general term used to indicate the presence or absence of HIV antibodies in the bloodstream: HIV seropositivity being HIV-positive and HIV seronegativity being HIV-negative. A person who is HIV-positive may be symptom-free or may be ill with related conditions. As such, being HIV-positive does not necessarily indicate that someone is ill or has AIDS. The term AIDS is technically used to classify individuals who have developed one or more of an evolving list of opportunistic infections. Because HIV weakens the immune system of those infected, individuals succumb to opportunistic infections to which they would not, had their immune systems not become compromised. When death occurs, it is due to opportunistic infections. One never dies of AIDS, but dies of AIDS-related complications. Since the term AIDS is a technical one as well as the word used to denote the whole disease, many have started to use the term HIV disease to indicate the whole disease. Consequently, the terms 'AIDS' and 'HIV disease' are used interchangeably within the dissertation to represent the disease itself.

The focus of the research is on adults who have cared for or about other adults who were HIV-positive and have died. The term most often used in North America to denote these individuals is caregiver, often with the terms 'informal' or 'unpaid' preceding it. However, it is often confused with professional caregivers: those who are paid or who have a professional role in the life of the person with AIDS. The term carer is used by some (McCann & Wadsworth, 1992; Pakenham, Dadds & Terry, 1995) and better suits this study. The participants who were sought out for this research included anyone who had cared for or about the person who died. This expands the notion beyond the few who may have provided physical care to anyone who has cared about an HIV-infected individual. Although this distinction could arguably be made concerning any disease, it is especially relevant in relation to HIV disease because the stigma of AIDS extends beyond those who are infected to those who are affected. Individuals who care, whether physically or emotionally, generally experience a change in their relationship with the care recipient who was previously interdependent or independent (Folkman, Chesney & Christopher-Richards, 1994). Nonetheless, most of the research that has been done refers to caregivers and consequently the two terms, 'carer' and 'caregiver', will be used interchangeably in this dissertation.

The focus of the dissertation is upon the benefits that may arise from coping with a stressful and traumatic situation. However the concentration on transformational growth is not an attempt to diminish the negative effects of AIDS caregiving. Nor does it constitute an attempt to glamorize HIV and AIDS by claiming that the purpose of the disease is to make those affected stronger (Maitland, 1990). Instead, it is an exploration of the factors that enhance the ability of the bereaved to grow from their experiences.

Theoretical Framework

Understanding the processes by which an individual grows from trauma first requires comprehension of how trauma impacts on an individual and how one can make sense of the experience. The transactional theory of stress and coping (Lazarus & Folkman, 1984) proposes that the appraisal of a stressful event and the coping strategies that result occur through the transaction between the individual's personal resources and the environment. The original model included the possibility of positive psychological outcomes only when the situation was resolved successfully. A new model of the transactional approach to stress and coping rectifies this, allowing for positive psychological outcomes for the individual regardless of the outcome of the stressful occurrence (Folkman, 1997b). Further, Calhoun and Tedeschi (1998) propose a model of growth after trauma that fits within the transactional framework because of the interplay among the environment, personal resources, appraisal, and coping responses. The creation of significance, or how an individual understands the stressful situation, plays a central role in the process of coping with trauma.

Implications

The concept of post-traumatic growth has been developed recently and while it has been observed in diverse populations, it has not been explored within the context of HIV disease. In addition, little research has concentrated on the factors that contribute to or enhance growth. Many of these traumatized individuals are transformed through their experiences with little or no professional intervention. Knowledge of such factors can be used to inform and strengthen the work of social workers and other professionals who work with bereaved and other traumatized people in order to aid in the recovery process. A broader understanding of the specifics of caring within the context of AIDS will also lead to more powerful interventions for social workers and other health professionals working with this population.

This dissertation is presented in seven chapters, the second and third of which explore the theoretical framework of the research. Chapter two examines coping and post-traumatic growth in general and these are explored within the context of AIDS in chapter three. The methodology is reviewed in chapter four. The fifth chapter presents the quantitative results and the sixth, the interview data. Discussion of the findings and implications for all levels of social work practice are developed in the final chapter.

CHAPTER TWO

Coping and Post-Traumatic Growth

Introduction

This chapter begins with an overview of the transactional model of coping, the theoretical framework of this dissertation, and proceeds to a discussion of the development of the transactional approach. Traumatic stress and the development of the Post-Traumatic Stress Disorder diagnosis are then reviewed. Meaning-making is explored as a coping mechanism to deal with traumatic stress. Finally two models of positive psychological outcomes of coping are reviewed and placed within the theoretical framework.

The Transactional Model of Coping

Coping is widely used to mean that individuals are dealing well with stressful circumstances. At its origin, the use of the term coping arises from a fascination with heroics and the strength of those who overcome obstacles (Aldwin, 1994). However, the psychological use of the term encompasses coping mechanisms that may be beneficial or detrimental to the individual regardless of the success of the outcome. Coping is defined as the cognitions and behaviours that manage stressors which are considered to strain or exceed the resources of the individual (Lazarus & Folkman, 1984). Coping is an important moderator of stressful circumstances (Pearlin, 1991). The exact relationship of coping to distress and well-being is not yet fully understood, but it is generally conceived of as a process. An historical overview provides some insights into coping theory.

Coping is a concept that has arisen in two very disparate contexts: animal studies and psychoanalytic writings (Lazarus & Folkman, 1984; Parker & Endler, 1996; Suls, David & Harvey, 1996). Early studies investigated how animals reacted to and tried to control environmental conditions (Lazarus & Folkman, 1984). For example, infant mice or rats given mild electric shocks developed more rapidly than their counterparts with no shocks (Aldwin & Sutton, 1998). Animal studies, however, lack the multidimensionality of the study of coping in humans.

Early psychoanalytic theory viewed coping as defence mechanisms, for example, dissociation or repression, which served to "reduce distress and minimise the changes in the internal and external environments" (Suls, David & Harvey, 1996, p.712). The evolution of coping theory differentiated between coping and defence by creating a hierarchy of mechanisms to deal with stress: coping was considered more beneficial than defence and the least helpful response was ego-failure (Aldwin, 1994; Lazarus & Folkman, 1984; Suls, David & Harvey, 1996). The psychoanalytic theory of coping and defence includes the notion that individuals have a limited number of responses available to them according to their personality style. This conception includes the understanding that coping responses do not vary situationally, no matter what the stressor, but are only influenced by the personality of the individual under stress.

The second generation of coping research began in the 1960s with the transactional approach. A transactional approach considers that the personality, the stressor and the coping all affect one another reciprocally (Aldwin, 1994). In the cognitive approach elaborated by Lazarus and Folkman (1984), the stressful event is assumed to be an event appraised as important to the individual and to be taxing or exceeding the person's resources. Coping thoughts and behaviours arise from the individual's appraisal of the stressor as threatening or challenging. In this manner, appraisal and coping strategies are a result of the transaction between the individual's personal resources and environment. Emotion-focused coping is thought to manage distress, while problem-focused coping concentrates on changing the situation that is causing the distress. Cognitive coping allows the individual to alter their beliefs about a stressful condition that cannot be changed (Pearlin, 1991).

Stress and Traumatic Stress

Life presents human beings with many circumstances: some pleasant, some neutral and some negative. There are many ways to describe negative life events. Stress is one word used to describe what people experience in the face of negative incidents. Originally a mechanical term, the application of the term to humans arises from the notion that some events are taxing to the system. At times, stress levels related to a specific life event reach a point at which an individual can no longer manage. Traumatic stress occurs as the result of exposure to events that are life-threatening. Post-Traumatic Stress Disorder (PTSD) is a condition that can result from exposure to extreme stressors (American Psychiatric Association, 1994) such as war (Keane, 1993; Solomon, Laror & McFarlane, 1996) or sexual assault (Brillon & Marchand, 1997; Regehr & Marziali, 1999). Symptoms of PTSD include intrusive thoughts and/or dreams of the traumatic event and efforts to avoid or numb oneself to memories related to it (American Psychiatric Association, 1994).

PTSD, as a diagnosable disorder, was first included in the Diagnostic and Statistical Manual (DSM-III) in 1980 (Yehuda & McFarlane, 1995). Originally it was conceived as a normative response to extreme stress. However studies since have cast doubt on the normative notion as it has been noted that many survivors of traumatic events have not developed PTSD (Yehuda, 1999). Consequently, theorists and researchers have begun investigating other possible risk factors such as age at time of trauma (van der Kolk, Hostetler, Herron & Fisler, 1994), personality (Regehr, Cadell & Jansen, 1999), intensity of the traumatic exposure (Green, 1994), and biological factors (Yehuda, 1999). In addition, PTSD has often been found to co-exist with other psychological conditions such as depression (Green, 1994; Keane & Wolfe, 1990).

Recent trauma literature has concentrated on recovery after trauma. Regehr and Marziali (1999) investigated pre-existing strengths and vulnerabilities and their impact on recovery. Harvey (1996) proposes an ecological model of trauma that takes into account community resources. The possible outcomes she proposes are recovery or non-recovery with intervention and recovery or non-recovery without intervention. Jaffe (1985) presents a model of self-renewal that includes active struggle, meaningful transformation and shared experience. He maintains that self-renewal is not possible if individuals remain silent about their experience, but must somehow share it by reaching out to others, both for gaining the support they need as well as providing it to others.

Meaning-Making

Meaning-making is a central tenet of coping with stress (Gottlieb, 1997; Moos & Schaefer, 1986; Park, Cohen & Murch, 1996). Although empirical evidence has been somewhat contradictory (Calhoun, Cann, Tedeschi & McMillan, 1998; Overcash, Calhoun, Cann & Tedeschi, 1996), the re-construction of meaning is necessary because trauma works by threatening or dismantling the individual's view of the self and of the world. (Epstein, 1991; Gluhoski & Wortman, 1996; Janoff-Bulman & Schwartzberg, 1991; McCann & Pearlman, 1990; Schwartzberg & Janoff-Bulman, 1991). The schemas of self and the world must either stretch to accommodate the traumatic material or be changed in order to explicate the trauma. This process is anchored in the meaning that one attributes to the traumatic incident, as well as how one views oneself and the world (McCann & Pearlman, 1990).

The popular connotation of coping is to be doing well in a stressful situation. The psychological definition, however, includes coping mechanisms that could be detrimental as well. For instance, it is possible to create negative meaning in a situation such as occurs when an individual believes that she or he is experiencing a difficult situation because it is God's punishment. An interpretation of negative significance like this may produce destructive outcomes.

Meaning-making is comprised of two processes: the appraisal of meaning and meaning-making coping (Park & Folkman, 1997a). The initial process is appraisal (Lazarus & Folkman, 1984; Park & Folkman, 1997a). Appraisal of a stressful event determines how an individual reacts to the situation, depending on whether it is deemed to be harmful, challenging or benign. Primary appraisal involves the assessment of the personal significance of the situation. Secondary appraisal involves determining what can be done.

Meaning-making coping refers to the significance which the individual ascribes to the stress or trauma (Park & Folkman, 1997a). Stressful events challenge how individuals view themselves, the world and themselves in relation to the world (Janoff-Bulman, 1992). In order to cope with and recover from trauma, individuals must reconcile the event with their beliefs, by altering how they view the event, themselves and/or the world (Horowitz, 1991, 1998; Janoff-Bulman, 1992).

Meaning-making involves the creation or re-creation of significance attached to an event or a life experience. The search for meaning provides the basis for Frankl's (1962, 1997) life work. His book *Man's Search for Meaning* (1962) recounts his experience in a Nazi concentration camp during the Second World War and how he came to understand the world and his experience. Frankl, a psychologist, is the founder of logotherapy, a form of psychotherapy based on his view that human beings are always searching for significance in their lives.

Antonovsky's (1979, 1987) salutogenic as opposed to pathogenic orientation has made important contributions to theories of meaning. He proposes a general life orientation that he calls a sense of coherence. Comprehensibility, manageability and meaningfulness are the three elements of the sense of coherence (Antonovsky, 1987). He considers meaningfulness to be the element that provides motivation to individuals.

In a classic study on meaning, Silver, Boon and Stones (1983) investigated how seventy-seven female survivors of incest made sense of their experience. Among many questions, they were asked how often they pondered the question "Why me?" and sought to understand what had happened. More than 80 per cent of the participants were still trying to understand their experience. Only a few related that they were not searching for meaning at that time. Of those women who had made some sense of their incest, more than 90 per cent of them reported some satisfaction with the resolution. Despite this, almost all of them continued to search for meaning. Silver, Boon and Stones concluded that the ruminations associated with the search for meaning helped these women to adapt to their situation but did not end with finding an answer.

Social comparisons are one way of making sense of a stressful situation (Gottlieb, 1997). These are cognitive exercises that involve comparing oneself to those who are believed to be worse off. This can include comparing one's own situation to another real situation or creating a hypothetically worse situation to which one compares oneself. In addition, social comparison can work on a specific dimension. In the study by Taylor, Wood and Lichtman (1983), women who had breast cancer compared themselves to others in different situations: women with lumpectomies compared themselves to those who had mastectomies and older women compared themselves to younger women, all imagining that those in the other category must be worse off. Another dimension of selective evaluation involves constructing normative standards to which one compares oneself in order to have the appearance of doing well under the circumstances (Taylor, Wood & Lichtman, 1983).

Tebb (1994) conducted focus groups with caregivers in order to explore the creation of meaning in caregiving. Three different groups of caregivers were used: those caring for someone who had had a stroke, female caregivers of people with dementia and paid caregivers. The total number of people participating was twenty-three. They were asked about the meaning in their caregiving experiences through semi-structured interviews in the groups and through a questionnaire. For the unpaid caregivers, a combination of guilt ("No one else could do it") and values ("Helping someone provides purpose in life") assisted them in deciding to give care. This association of guilt and values produced feelings of being needed and useful and gave meaning to their lives as caregivers that allowed them, along with social support, to tolerate their difficult circumstances.

Kessler (1987) conducted qualitative interviews with bereaved individuals and analyzed them from the growth perspective of existential psychology. Many themes emerged including an increased awareness of the fragility of life, the bittersweet experience of losing a loved one before realizing the importance of that person, caring about connections with others and faith/spiritual meanings. Many of the 31 people interviewed found new personal strength through their experience.

Thompson (1985) interviewed people after fire had destroyed or damaged their homes. Finding positive meaning out of this stressful experience included finding side benefits, making social comparisons, imagining worse situations, forgetting the negative and redefining. It was hypothesized that those who focused on the positive and who positively re-evaluated the situation would cope better immediately after the fire and one year later. Support was found for the hypothesis.

Dunn (1994) focused on positive meaning in disability. He makes a cautionary distinction between insiders and outsiders on the issue of disability. An insider is a person with disabilities, an outsider is a non-disabled person. While Dunn acknowledges that outsiders might think that people with disabilities are to be placed on pedestals and treated differently, and that a notion of positive meaning and of positive illusions (Taylor, 1989; Taylor & Armor, 1996; Taylor & Brown, 1994) in disability might add to that, he makes the distinction in order to warn against such views. Dunn (1994) posits that finding positive meaning is a process that can lead to changing the values and attitudes of the person involved and can make for better adjustment to disability.

Schwartzberg (1993) examined how gay men made sense of their HIV seropositivity. He found that many of the 19 participants viewed their diagnosis as an opportunity for spiritual or personal growth and it increased their sense of belonging to their community. Among other themes found, HIV was also seen as an irreparable loss, an isolating factor and as punishment in some cases. Many of these constructions existed simultaneously for HIV-positive individuals. Regardless of the particular interpretations each made, all the gay men Schwartzberg interviewed struggled to find meaning in being HIV-positive. Similar searches for personal meaning were found in the 15 seropositive men interviewed by Borden (1991).

Powell-Cope (1995) used in-depth interviews to determine how AIDS affected gay couples when at least one was HIV-positive. For the couples interviewed, accepting and living with HIV infection as a couple meant accepting a new worldview. This new world included expected loss and a new meaning of death. For some participants living with AIDS meant accepting that the disease is fatal; for others it meant believing that death was not inevitable. Each couple created new meaning for themselves in the process of learning to live with AIDS.

However disparate these approaches to meaning, there is one common element: stressful events alter one's view of oneself, the world and the relationship of the self to the world. Park and Folkman (1997a) differentiate between global meaning and situational meaning. Global meaning is one's view of the world and "encompasses a person's enduring beliefs and valued goals" (Park & Folkman, 1997a, p.116). Beliefs about how the world functions have been referred to as schemas (Thompson & Janigian, 1988) and the assumptive world (Janoff-Bulman, 1992; Janoff-Bulman & Frieze, 1983). Situational meaning is "formed in the interaction between a person's global meaning and the circumstances of a particular person-environment transaction" (Park & Folkman, 1997a, p.116). Situational meaning corresponds to Frankl's (1962) early work on meaning. Global meaning was more articulated in his book *Man's Search for Ultimate Meaning* (Frankl, 1997), which he wrote in the years before he died. His later work focused on people's attempts to explain the mysteries of life by religious and spiritual means. The various methods of social comparison (Taylor, Wood & Lichtman, 1983; Thompson, 1985) would fall into the category of situational meaning. The caregivers in Tebb's (1994) focus groups were reconciling their feelings with long-held values of helping others in order to adjust to their situation.

Meaning-making coping, when individuals find positive meaning in their experiences, is an important moderator of stressful experiences. The creation of meaning is central to the process of coping and has an important role to play in the models of positive outcomes that are described below.

Positive Outcomes of Stress

Stress and coping research has dealt little with positive outcomes. The psychological study of adaptation to stress arose out of an interest in bravery and strength but shifted to a narrow focus on negative outcomes (Aldwin, 1994). Such an emphasis is likely due to a pathogenic approach rather than a salutogenic or health-oriented one (Antonovsky, 1979, 1987). The questions have concentrated on identifying stressors that are associated with negative outcomes in order to prevent large numbers of individuals from becoming ill. Possible benefits or positive events in stressful situations have been overlooked but are now receiving attention in the coping literature.

A similar shift occurred in the study of resilient children. Research concerning resilience grew out of the study of developmental psychopathology and the concern with identifying risk factors in the lives of children associated with psychiatric disorders in adulthood (Garmezy, 1971). Such research is based on the assumption that understanding how individuals overcome adversity will provide guidance for intervention with other high-risk individuals (Masten, 1994). Early studies focused on children who experienced a single risk factor and evolved into the study of multiple stressors (Werner, 1990). The concept of resilience arose with the finding that across all risk factors there were always some children who became competent adults despite the life stressors they faced. The study of resilience instead of the identification of risk factors concentrated on stress-resistant (Garmezy, 1987), invulnerable (Anthony & Cohler, 1984; Garmezy, 1971), invincible (Werner & Smith, 1982) or resilient children (Werner, 1989).

In the stress and coping literature, some studies have demonstrated benefits of coping with stressful events and trauma. Moos and Schaefer (1986) were among the first to integrate anecdotal evidence of stress-related growth and research findings in order to propose a framework of positive adaptation. Positive outcomes of life crises include enhanced social and personal resources and the development of new coping skills (Schaefer & Moos, 1992).

One study examined narratives of successful and failed attempts to change (Heatherton & Nichols, 1994). One hundred and twenty-six students in the U.S. were asked to write about their experiences of change. The researchers imposed the choice of change or non-change stories. However, it might have been more significant to ask people to write about whichever situation had the most importance for them. Nevertheless, the researchers found that those who wrote about successfully making changes in their lives gave significantly more importance to issues of meaning than those who wrote about unsuccessful attempts. Increased self-knowledge and understanding was the component of meaning that was most often used.

Burt and Katz (1987) examined how 113 women recovered from rape. While fewer than 15% felt that they had changed for the worse, over half of the women reported having changed in a positive direction as a result of having coped with rape. Similarly, Calhoun and Tedeschi (1990) interviewed adults who had lost a spouse or parent about benefits arising from their bereavement. The majority of them reported an increased appreciation of the social support available to them, feeling more independent and able to accept their own mortality, experiencing greater self-efficacy and strength, a strengthening of their religious commitment and feeling more able to express their emotions.

War veterans are exposed to many stressful experiences and yet show some positive outcomes (Aldwin, Levenson & Spiro, 1994; Elder & Clipp, 1989). Aldwin et al. (1994) studied 1,287 American war veterans and observed some negative consequences of combat exposure that were lifelong. However, they also found that those veterans who perceived more positive benefits from their military experience were less likely to experience high levels of post-traumatic stress disorder than those who did not perceive benefits.

Within the framework of transactional coping, there has occurred a shift from a concentration of negative outcomes to consideration of positive ones. Folkman (1997b) has reworked the transactional model of coping to include positive psychological outcomes.

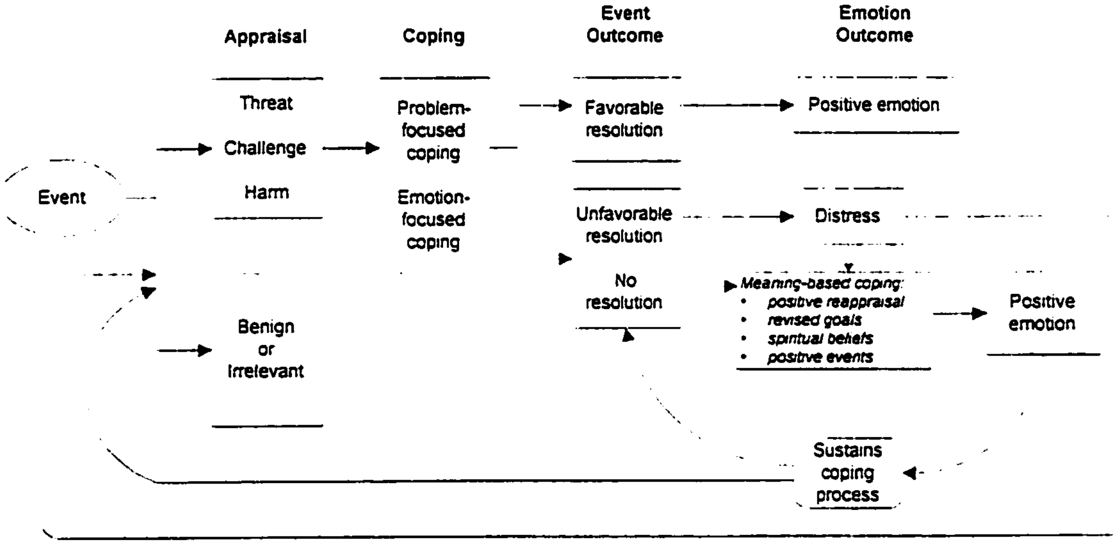
Positive Psychological Outcomes of Coping

Folkman (1997b) provides a transactional model of stress and coping that includes positive psychological states, the model for which is shown in Figure 2.1. The original model that Lazarus and Folkman (1984) proposed included positive emotion as a possible outcome only when there was a favourable resolution to a threatening event. The revised model includes the possibility of experiencing positive emotion when there is not a favourable resolution or no resolution at all (Folkman, 1997b).

Folkman's (1997b) model is designed to indicate the co-occurrence of positive and negative psychological states. It was originally assumed that positive and negative emotions would have an inverse relationship in that negative states would decrease as positive ones increased and vice versa (Aldwin, 1994). It was discovered, however, that the relationship between these emotional states is orthogonal or independent. Some theorists propose that stressful events can have either negative or positive outcomes for different people. However, most theories assume that positive and negative states co-exist in individuals and that outcomes, both positive and negative, are dependent on the context and the meaning of the situation. This relationship is illustrated by the pathway that leads from distress into meaning-based coping and then into positive emotion (Folkman, 1997b).

Folkman concludes that distress may actually motivate individuals to create significance in their negative experiences.

Figure 2.1: Positive Outcomes of Coping (Folkman, 1997b, p.1217)



Two additional pathways integrate positive psychological states into the revised model (Folkman, 1997b). The first connects unfavourable or no resolution directly to meaning-making that then produces positive emotion. Meaning-making in this model involves positive reappraisal, problem-focused coping and the revision of goals, spiritual beliefs, and finding ordinary events positive. Each of these types of coping is an example of either global meaning or activities of reconciling global meaning and situational meaning (Park & Folkman, 1997a).

The second pathway links positive emotion back into coping and appraisal (Folkman, 1997b). This indicates that positive psychological states help sustain motivation. Individuals may reappraise a situation after experiencing a positive emotion or may be motivated to try new coping responses.

Folkman (1997b) considers positive psychological states as part of the process of coping as well as an outcome. The positive psychological states may aid in the development of coping resources that can in turn lead to growth (Aldwin, Sutton & Lachman, 1996). As depicted in Folkman's (1997b) model, positive emotions function as part of the process by providing respite and aiding in the renewal of psychosocial resources such as social support. Folkman's model however, does not depict psychosocial resources or personality factors and their relationships to the coping process.

Post-Traumatic Growth

In a continuing trend of examining healthy outcomes of stress, recent literature has examined how individuals are transformed by trauma and even how they thrive after a stressful experience. Post-traumatic growth (Tedeschi & Calhoun, 1995; Tedeschi, Park & Calhoun, 1998) is a recent area of psychological research that has been gaining attention. Thriving after stress includes the notion of going beyond a return to the pre-trauma state, to grow and achieve more well-being (Ickovics & Park, 1998). Thriving has been gaining attention in the literature as well (Carver, 1998; Cohen, Cimbolic, Armeli & Hettler, 1998; Saakvitne, Tennen & Affleck, 1998; Snodgrass, 1998). Both of these concepts fall within the theory of coping with stress that transforms the individual.

Transformational coping is a way of adapting to stress that benefits and changes a person (Aldwin, 1994; Tedeschi & Calhoun, 1995). It is most often associated with coping with trauma. Indeed some suggest that trauma is a necessary precursor to change (Heatherton & Nichols, 1994). Generally stress and trauma are conceived as having negative consequences and not positive outcomes. However the idea that even a dangerous situation can be an opportunity is evidenced by the Chinese symbol for crisis, which combines the characters for 'danger' and 'opportunity'. This example emphasizes the notion that stress-related growth is possible.

Tedeschi (1999) theorizes about the process of growth for individuals and societies. He examines situations where the traumatic experience was violent, a potentially more traumatic situation than non-violent circumstances. He reflects on the necessity of change from victim to survivor in order for individuals to change and explores how, paradoxically, traumatized individuals may be more aware of their mortality as a result of their experiences and yet appreciate life more than before the trauma.

Calhoun and Tedeschi (1998) offer a model of transformation dealing with trauma. (See Figure 2.2.) This model, like the one above, is developed from an earlier version but based on new theory. The first panel, labelled 'person pretrauma', represents the personality characteristics and mental health of the person before the trauma occurred. This notion of the pre-existing characteristics determining to some extent the outcomes is echoed in the trauma literature (Green, 1994; Regehr, Cadell & Jansen, 1999; van der Kolk et al., 1994; Yehuda, 1999).

The subsequent panels represent the traumatic incident and the challenges that it represents to the individual (Calhoun & Tedeschi, 1998). The event is characterized as 'seismic' because of the shock that trauma sends through the system. Challenges to the individual's higher-order goals, higher-order beliefs and to the ability to manage emotional stress result from the impact of trauma to the system.

In the face of these challenges, individuals ruminate, which is a process described as "frequently returning to thoughts of the trauma and related issues, characterized by a sense of intrusion of these thoughts during daily activities" (Calhoun & Tedeschi, 1998, p.227). The model includes two stages of rumination with the first defined as more automatic processing and the second as more deliberate. Calhoun and Tedeschi consider that the shift between these two stages occurs with coping success: the ability to disengage from goals and beliefs that were rendered unattainable by the trauma.

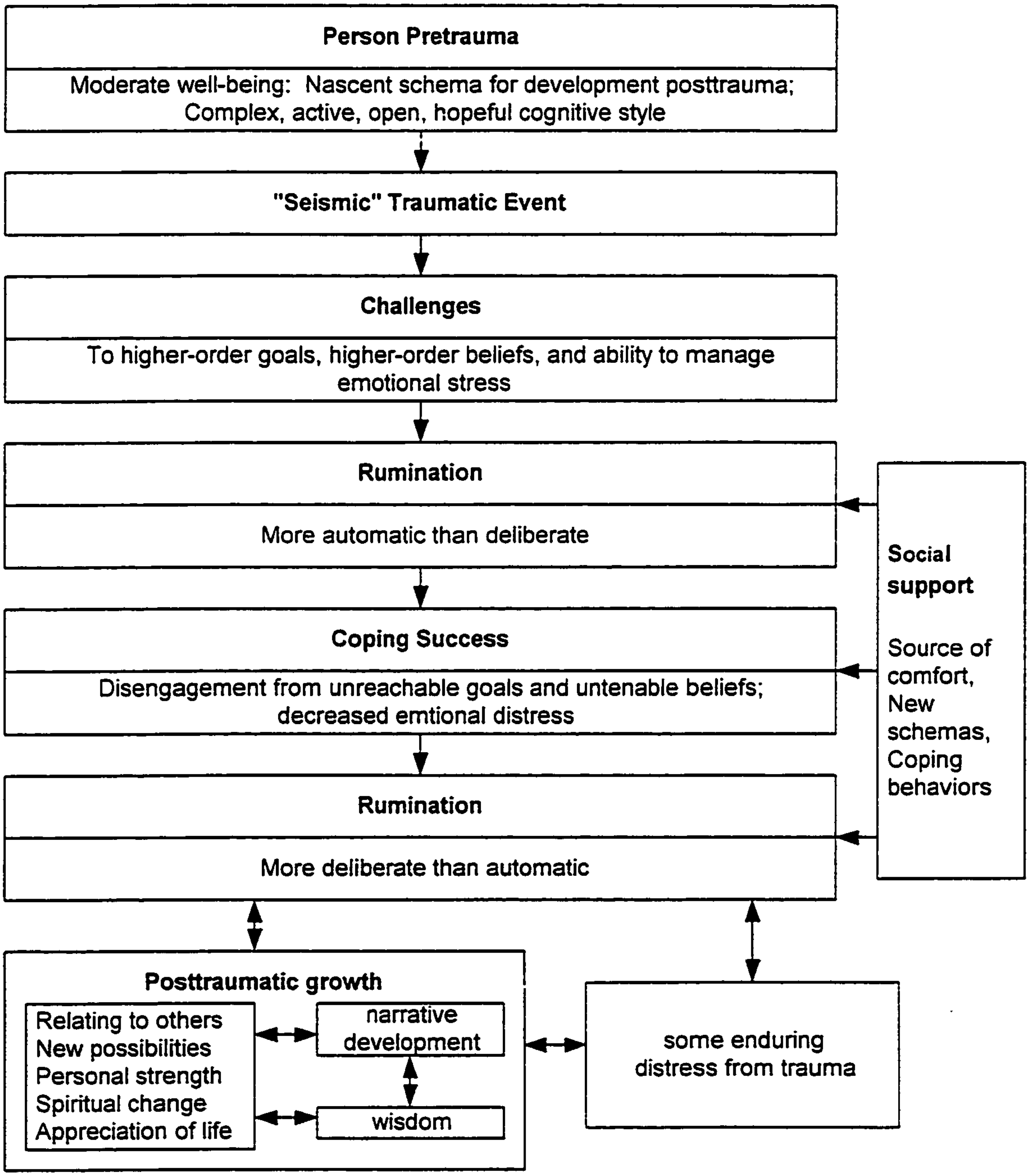
This cognitive process proposed by Calhoun and Tedeschi (1998) parallels the theory of stress reduction proposed by Horowitz (1991). In Horowitz's theory, cognitive reappraisal occurs through a series of comparisons between the trauma and the schemata, or notions that individuals hold of the self in relation to others. Recurring intrusive images occur as the result of trauma; healthy adaptation entails controlling the automatic images and thoughts in order to deal with them. This process is referred to as 'dosing' (Greenberg, 1995).

Calhoun and Tedeschi's (1998) model of post-traumatic growth, shown in Figure 2.2, includes more than the cognitive processes. The existence of supportive others plays a role in both levels of rumination as well as in coping success by providing comfort and examples of new goals and beliefs which can be translated into revised schemata and new behaviours.

The three panels before the outcome represent the process of meaning-making in the model. The ruminations and the coping success are similar to Folkman's (1997b) representation of meaning-based coping that entails positive reappraisal, revised goals, spiritual beliefs and positive events. In the model of post-traumatic growth (Calhoun & Tedeschi, 1998), the presence of double-headed arrows between the second panel of rumination and the outcomes indicates that the process of meaning-making is ongoing even while growth is occurring. Folkman (1997b) represents a similar process of feedback in her model.

Within the outcome of post-traumatic growth, Calhoun and Tedeschi (1998) have included narrative development. This indicates that the reworking of one's life narrative is often a part of transformation. This includes the reconstruction of schemas to include the trauma and usually

Figure 2.2: Post-Traumatic Growth (Calhoun & Tedeschi, 1998, p.221)



entails a notion for individuals that the incident was the beginning of a better turn in life. Often people experiencing post-traumatic growth believe that the trauma served to better acquaint them with their true selves. Each of these depends upon the construction or reconstruction of meaning and underlines the importance of the meaning-making process in growth.

Narrative development interacts with wisdom, which is characterized by the ability to comprehend the contradictions in life. In an earlier version of the model (Tedeschi & Calhoun, 1995), wisdom was depicted as a second stage outcome after initial growth was experienced. The contradictions in life or:

> Paradoxes are appreciated among persons who have developed [post-traumatic growth]: in loss there is gain; to manage one must wait for healing and pursue healing; the trauma must be left in the past, and made meaningful by the use of it to shed light on the future; one must recognize the need to receive help, but that the healing ultimately occurs within; both peace and distress can co-exist. Only an integrative perspective taken by the wise can encompass these paradoxes of trauma and growth. (Calhoun & Tedeschi, 1998, p.233)

Narrative development, wisdom and the five factors of growth as represented in the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) form a feedback loop, which together delineate post-traumatic growth. Individuals may experience growth in one or more of these five dimensions without change in all as they each represent "a somewhat different domain of change" (Calhoun & Tedeschi, 1998, p.222). Relating to Others requires modification of interpersonal behaviour, New Possibilities represents an alteration in goals, identity change is involved in Personal Strength and the remaining two entail revisions of the belief system.

In this model of transformational coping, Calhoun and Tedeschi (1998) have included 'some enduring distress from trauma' as an outcome that influences both the second stage of rumination and the outcome of post-traumatic growth. Indeed these three panels have bi-directional arrows and so constitute an additional feedback loop. Including distress as co-existing with growth echoes Folkman's (1997b) model in relation to the co-existence of positive and negative emotional states. It is also an important testament to the notion that growth does not alleviate the pain and suffering of the trauma but exists alongside and the distress continues to influence the individual.

The situating of post-traumatic growth in the transactional framework of stress and coping could be threatened by the inclusion of pre-existing personality characteristics in the model. However, an important aspect of the transactional model is the appraisal of the stressful event (Lazarus & Folkman, 1984). In the model of transformation after trauma the personality factors that precede the trauma influence how the trauma is perceived. This notion of the influence of personality fits within the transactional framework.

The theoretical framework of this research is the transactional approach to stress and coping. As part of the paradigm shift from a study of negative outcomes to positive ones, this study builds upon the recent theorizing about positive outcomes of stress and about post-traumatic growth. In order to establish the model to be tested and to specify hypotheses, a thorough examination of the issues related to AIDS caregiving and bereavement is necessary.

CHAPTER THREE

Coping in the Context of AIDS

Introduction

In order to understand the unique challenges of caring in the context of HIV disease, a brief overview of the issues arising from caring for people with other diseases is presented in this chapter. The nature of caregiving in the context of AIDS is then presented together with its attendant stresses. Following this, the research that has investigated how HIV carers have coped is presented along with the positive outcomes that have been found.

Carers

The research literature on the carers of people with AIDS is not extensive. However, the stresses and benefits of providing care to individuals with diseases other than AIDS are well documented. An overview of the literature concerning caregivers in general will be useful in illustrating the context of caregiving and will provide a contrast to the situation of AIDS carers.

Adult caregivers responsible for other adults are most often older or elderly. In two reviews of research concerning informal caregivers, Schulz and his colleagues (Schulz, Visintainer & Williamson, 1990; Schulz, O'Brien, Bookwala & Fleissner, 1995) refer to 75 empirical studies of the consequences of the stresses of caregiving. Forty-one of these studies pertain to dementia (Schulz et al., 1995) and the remainder to a variety of diagnoses of the care recipients (Schulz et al., 1990). Of those studies in which a mean age of caregivers is reported, the lowest is 47.6 years of age and the highest, 78. The mean age of 47.6 occurs in a study that only concerns the children of elderly care recipients (Schulz et al., 1990). Schulz et al. (1995) provide characteristics of the sample where possible. The largest category of caregivers is spouses, followed by adult children. The percentage of female caregivers ranges, where reported, from forty-eight to eighty-seven. The typical picture of a caregiver is an older person, most often a woman, either a spouse or an adult child of the care recipient. This is consistent with research by Fengler and Goodrich (1979) and by McCallion, Toseland and Diehl (1994).

Caregivers perform many tasks. When a care recipient falls ill or becomes dependent, the caregiver may take on many household roles previously carried out by the other person (Tebb, 1994). Caregivers may be required to care for the ill person twenty-four hours a day (Fengler & Goodrich, 1979; Motenko, 1989). They may be expected to take on daily living activities, such as finances, with which they have not dealt previously (Fengler & Goodrich, 1979). Caregivers may have to give up their independence or outside activities and can feel deprived of aspects of their relationship with the care recipients (Gottlieb & Gignac, 1996; Tebb, 1994). Caregivers of a person with dementia often have to cope with difficult or offensive behaviour on the part of the care recipient (Gignac & Gottlieb, 1997). All of these tasks may create stress for the caregivers. The stressful aspect of caregiving has been well-established (Zarit, 1989).

Caregiving and Bereavement

Methodologically it is difficult to distinguish between the stress of caregiving and the stress of bereavement when the care recipient dies (Gilhooly, 1984). Indeed, the process of grieving may begin well before death actually occurs (Rando, 1986). Caregivers may be able to prepare themselves for bereavement or they may be depleted by caregiving activities and be subject to complicated grief (Mullan, 1992). Bass and Bowman (1990) tested two hypotheses. The first was that those who experienced the most caregiver burden would experience relief at the death of the care recipient and would fare well with bereavement. The second, for which they found support in their data, was that those who struggled the most with caregiving also had the most difficulty adjusting to bereavement.

The stressors of caregiving and bereavement can have serious consequences. After the death of a spouse, increased physical illness (Parkes & Weiss, 1983) and mortality rate (Parkes, Benjamin & Fitzgerald, 1969) have been found. Caregiving and bereavement can also have a negative impact on mental health (Caserta & Lund, 1992; Deimling & Bass, 1986; Fengler & Goodrich, 1979; Gallagher, Rose, Rivera, Lovett & Thompson, 1989; George & Gwyther, 1986; Horowitz & Shindelman, 1983; Rabins, Fitting, Eastham & Fetting, 1990; Stroebe & Stroebe, 1983; Zautra, Reich & Guarnaccia, 1990).

Considerable attention in the literature has been paid to the factors that contribute to burden, or the distress experienced by caregivers, in order to discover who is most vulnerable. While it might be assumed that caregivers would experience less distress when the care recipient is hospitalized, caregivers continue to have heightened responsibilities such as assisting with walking or laundry and making the trip to the institution (Stephens, Ogrocki & Kinney, 1991). Indeed one study found that caregivers experience more stress when the care recipient is institutionalized than when at home (Stephens, Kinney & Ogrocki, 1991). Other results are sometimes contradictory. While some researchers have found that the severity of care recipients' symptoms can affect the caregiver (Pearson, Verma & Nellett, 1988; Pruchno & Resch, 1989; Vitaliano, Russo, Young, Teri & Maiuro, 1991), others have found no relationship (Hooker, Monahan, Shifren & Hutchinson, 1992; Gilhooly, 1984; Zarit, Reever & Bach-Peterson, 1980).

AIDS Carers

The carers of people with AIDS experience the same or similar stressors as the caregivers of people with other illnesses. However, there are differences due to the nature of the illness and the stigma involved.

Bereavement may be complicated by the magnitude of the losses involved. Some of the additional stressors of AIDS caregiving arise specifically for the gay and lesbian community due to homophobia. The consequence of these stresses is the potential of negative outcomes for those who care for someone with HIV.

The Nature of HIV Disease

Many differences between general and AIDS carers stem from the nature of HIV disease. The virus is transmitted through contact with bodily products such as blood and feces. The most common means of transmission are through sexual contact and intravenous drug use. The progression of the disease is unpredictable and is often described as a roller coaster (AIDS Ministry Program, 1991; Siegl & Morse, 1994; Weiser, 1996). An individual can be HIV-positive for years before developing any AIDS-related illnesses (Shernoff, 1995). Once people have had opportunistic infections, they can still survive and thrive for many years (Callen, 1990). Conversely, individuals can be exposed to HIV and become ill and die within a relatively short period of time. To date, there is no cure for HIV disease. Great advances have been made in managing HIV, producing increased life expectancy and improved quality of life. Medically, the disease in now viewed as a chronic illness. However, HIV and AIDS remain unrelentingly fatal.

As discussed above, the profile of a general caregiver is that of an older female, usually the spouse or daughter of the care recipient. In HIV caregiving, the percentage of male carers is much higher. In an American study, Turner and Catania (1997) found that the percentage of males caring for someone with AIDS was approximately equal to that of females, with men being higher in cities and slightly lower in national averages. A study in England found that seventy-seven per cent of those who cared for a person with AIDS were male (McCann & Wadsworth, 1992). Of 16 AIDS carers in an Australian study, 11 of them were male (Richmond & Ross, 1994). Based on probability samples, one study estimated the percentage of Americans who had been informal caregivers to someone with AIDS was 3.2% (Turner, Catania & Gagnon, 1994). One study found that friends were more likely than family members to be providing care to a person with AIDS (Turner & Catania, 1997).

In Canada, AIDS is the third leading cause of death among men between the ages of 20 and 44 (Statistics Canada, 1996). In the U.S., AIDS is the leading cause of death among men between the ages of 25 and 44; for American women it is the third cause of death (Wrubel & Folkman, 1997). Since AIDS is a disease that most often infects young people, the caregivers are younger (Nord, 1996b). Of those who had cared for someone with AIDS in the national U.S. sample, the highest prevalence of carers was in the group ranging between 18 and 39 of age (Turner, Catania & Gagnon, 1994). In the cities, the most common age range was 30 to 49. In the British sample, 62 per cent of the carers were between 30 and 45 years of age with the remainder split evenly between the higher and lower age categories (McCann

& Wadsworth, 1992). The young age of HIV carers makes it more likely that caregiving activities interrupt or interfere with professional activities, which may lead to the added stress of financial hardship (Pearlin, Semple & Turner, 1988).

While the predominance of younger carers does not indicate a stressor in and of itself, the nature of caregiving and bereavement may create stress. Since people with HIV and AIDS are generally young, the necessity to provide care is considered premature (Park & Folkman, 1997b) and the death of a young person is especially untimely (Nord, 1996b; Worden, 1991). The untimely nature of HIV disease and AIDS-related deaths may provide additional stressors for caregivers who do not anticipate giving care at this stage in their lives. Brown and Stetz (1999) found that there were four phases in the "labor of caregiving" for those providing care to people with AIDS as well as to those with advanced cancer. The first stage, that of becoming a caregiver, was sometimes complicated because caregivers were learning of the diagnosis and dealing with a seriously ill care recipient at the same time.

The tasks of caregiving and bereavement may be especially stressful for parents who do not expect to see their children die before them (Siegl and Morse, 1994). In another reversal of the natural order, grandparents may find themselves parenting grandchildren at a time when they were expecting support from their own children (Bor, Miller & Goldman, 1993). All of this may complicate grieving. It has been suggested that the elderly parents who provide care to their son or daughter with AIDS have been neglected as a population in need of support (Brabant, 1994).

The populations in which there have been the highest incidence of HIV infection have been among intravenous drug users and men who have sex with men (Bor, Miller & Goldman, 1993). Biological family members of those infected often experience a double impact of learning of the HIV infection at the same time as learning about the person's intravenous drug use, homosexuality or infidelity (Brabant, 1994; Hedge, 1996; Kadushin, 1996; Pequegnat & Bray, 1997; Siegl & Morse, 1994). The impact of such news can cause crises (Lovejoy, 1990). Some families reject the HIV-infected person (Kadushin, 1996; Rowe, Plum & Crossman, 1988). Some may not reject the individual but may experience great distress in feeling that they cannot express emotions such as anger to someone who they perceive to be dying (Frierson, Lippman & Johnson, 1987).

Caregiving in the context of HIV and AIDS may be complicated by the stigma associated with the disease (Herek & Glunt, 1988). The initial discovery of AIDS was made in gay men; the first names for the disease were 'the gay plague' and Gay Related Immune Disease (or GRID) (Shilts, 1987). The transmission of HIV occurs primarily through sexual contact and intravenous drug use, both highly stigmatized activities in this society. Those infected with the disease have often been blamed or told that it was what they deserved (Amelio, 1993; Cadwell, 1994). Some have experienced the isolation as being part of a blitz that is not experienced or even recognized by the rest of society and, worse yet, is a cause for ridicule and derision from others (Caruth & Keenan, 1995).

Carers have not been immune to this stigma. Many have been hesitant to talk about their caregiving activities for fear of disclosing the disease of the care recipient (Powell-Cope & Brown, 1992). Some carers avoid discussing the illness or fabricate by telling people that the care recipient has a less stigmatized disease such as cancer (Frierson, Lippman & Johnson, 1987; Graham, Brownlee & Ritchie, 1996). Fear of reprisals may increase isolation and reduce social support at a time when it is most needed (Demi, Bakeman, Moneyham, Sowell & Seals, 1997; Jankowski, Videka-Sherman & Laquidara-Dickinson, 1996). Support that may be available to caregivers generally through family, community and religious affiliation may not be as readily available to the carers of people with HIV disease (Goodkin, Blaney, Tuttle, Nelson et al., 1996). Those who have disclosed the HIV status of the care recipient may have experienced a great deal of stress before making this decision (Powell-Cope & Brown, 1992).

The nature of HIV disease and its transmission means that caregiving entails a risk of infection. Caregiving often entails the provision of physical care as the care recipient's health is deteriorating. This could include household chores as well as more personal tasks such as toileting and bathing (McCann & Wadsworth, 1992). Caregivers of people with AIDS are sometimes called upon to take on nursing activities for which they have little or no training (Wrubel & Folkman, 1997). An example of this is administering needles or dealing with intravenous catheters. Along with the demands that such activities entail, caregivers are often fearful about causing the care recipient pain. Since HIV is transmitted through blood and bodily products, any of these activities pose some risk of infection if proper precautions are not taken. Precautions need to be taken in all cases of caregiving in order to protect the health of both the carers and the care recipients. In other kinds of caregiving, the risk of becoming infected with the same disease through activities of caregiving is negligible. Cancer and dementia, for instance, are not transmitted through contact with the care recipient. This risk of infection in HIV caregiving provides a potential stressor in the lives of carers. Caregivers have acknowledged that this risk concerns them (Bonuck, 1993; Frierson, Lippman & Johnson, 1987; McCann & Wadsworth, 1992). In one study of AIDS caregivers, 42 per cent considered themselves to be at high risk of HIV infection (Clipp et al., 1995).

Caregiving in the context of AIDS is atypical of caregiving generally because carers are often HIV-positive themselves. In general caregiving, it is rare for the caregiver and the care recipient to have the same disease. It is relatively common, however, for an AIDS caregiver to be HIV-positive. In two studies, the percentage of HIV-infected carers ranged from ten per cent (McCann & Wadsworth, 1992) to thirty-three per cent (Folkman et al., 1996; Wrubel & Folkman, 1997).

Carers who are themselves HIV-positive face additional stressors. Because HIV works by depleting the immune system, there are risks involved in being exposed to noxious diseases. Carers may be more at risk of becoming ill themselves through exposure to the secondary infections of the care recipient. As well, the demands of caregiving may compromise the health of the caregiver (Land, 1992). Caring for someone who is deteriorating is never an easy task, but it takes on special significance when the caregiver may be wondering if he, too, may succumb to the disease (Turner, Catania & Gagnon, 1994) and may be wondering who will be there to care for him.

Bereavement and AIDS-Related Multiple Losses

Grief is an inseparable part of caring for someone with HIV disease; it has been referred to as the secondary epidemic of AIDS (Wardlaw, 1994). The grief may be anticipatory (Walker, Pomeroy, McNeil & Franklin, 1996) or may occur after the death of the care recipient. Since the nature of the illness is unpredictable, there may be complicated periods of anticipatory grief.

Bereavement overload, one term often used in the context of AIDS, has been borrowed from gerontology (Carmack, 1992). Bereavement overload refers to the experience of loss within the context of past losses and the fear of future losses. There is not sufficient time between losses to grieve each one. More recently, the terms 'AIDS-related multiple losses' and 'multiple loss syndrome' have arisen and the corresponding literature has been expanding.

Multiple AIDS-related loss applies to more than the number of people who have died. There has been a "loss of social support, loss of community leaders, loss of role models, loss of sexual spontaneity, loss of potential and loss of future plans" (Nord, 1996a, p.2). Klein (1998) lists the losses that are experienced when someone is diagnosed as HIV-positive:

- Loss of validation from society, often including the loss of family due to rejection and fear,
- Loss of health,
- Loss of physical and emotional well-being,
- Loss of sense of community,
- Loss of sexual freedom,
- Loss of employment stability due to the stigma attached to HIV/AIDS,
- Loss of (discretionary) income due to illness-related expenses,
- Loss of free time due to constraints of caregiving,
- Loss of privacy and personal power resulting from the outing of sexual orientation when HIV status becomes known,
- Loss of caregiver role when the PLWA dies,
- Loss of persons still alive due to personality changes caused by the infection and the disease,
- Loss of one's history,
- Loss of a sense of world order,
- Loss of role models and leaders who became activists in the cause,
- Loss of dreams of growing old together, and,
- Loss of hope for the future. (Klein, 1998, p.49)

The unrelenting losses associated with HIV disease cause trauma (Nord, 1996a, 1996c, 1997, 1998; Shernoff, 1997a). Individuals who experience multiple losses show evidence of traumatic stress (Bigelow & Hollinger, 1996; Gluhoski, Fishman & Perry, 1997a, 1997b; Goodkin et al., 1996; Houseman & Pheifer, 1988; Martin & Dean, 1993; Sikkema, Kalichman, Kelly & Koob, 1995). Some may exhibit signs of what would traditionally be considered pathological grief but the paradigms of grief work have been challenged by AIDS and the multiple losses involved (Nord 1996a, 1996c, 1997, 1998; Ryan, Hamel & Cho, 1998; Schwartzberg, 1992). Many of the traumatic stress reactions are quite normal in the circumstances (Nord, 1996a, 1996c, 1997, 1998; Perreault, 1995).

In North America the losses due to HIV/AIDS within the gay and lesbian community have been enormous. It is not unusual for gay men to have lost dozens of friends and acquaintances (Shernoff, 1995, 1997b); numbers of deaths in studies have ranged from an average of eight to sixteen up to a mean of 67.7 (Nord, 1996a). The magnitude of AIDS-related losses has led to the suggestion that death has become normative in the gay and lesbian community (Goodkin et al., 1996; Neugebauer, Rabkin, Williams, Remien, Goetz & Gorman, 1992).

The Gay and Lesbian Community

The enormity of these deaths and losses creates extra stressors in the gay and lesbian community. Carers are often members of families of choice of the HIV-infected individual bound by shared commitments and values rather than by blood or marriage (Nord, 1996b; Nord, 1997). Some biological families reject or distance themselves from a gay family member (Rowe, Plum & Crossman, 1988; Wardlaw, 1994), which can make a family of choice a necessity. In other cases, biological family members do not share the same values and families of choice arise out of the bonds that are formed with others who do (Nord, 1997).

Gay men and lesbians cannot avoid heterosexism and homophobia in a society that considers heterosexuality as the norm. *The Gay Almanac* (Lesbian and Gay Community Services Center, 1996) defines homophobia as "the fear of homosexuals and homosexuality" (pp.88-89) and heterosexism as "a bias toward heterosexuality to the exclusion of homosexuality" (p.88). Heterosexism and homophobia provide a possibility of a double impact of stigma for gay men with HIV disease (Cadwell, 1994; Herek & Glunt, 1988; Weitz, 1990). Telling others of their illness may also entail disclosing their sexual orientation for the first time (Brabant, 1994; Hedge, 1996; Pequegnat & Bray, 1997; Siegl & Morse, 1994).

Heterosexism and homophobia can have a great impact on the relationship of gay men and lesbians to their families of origin. Homophobia may be internalized to the extent that men and women may accept the notion that being gay is bad and thereby will hurt their families if they are told (Lesbian and Gay Community Services Center, 1996). Some families deal with the knowledge of their family member's homosexuality by not talking about it (Britton, Zarski & Hobfoll, 1993). Some gay men and lesbians are rejected by their family of origin, others are simply distanced from them (Wardlaw, 1994).

The lack of recognition of gay relationships, including those in families of choice, can cause numerous stresses for carers of those living with HIV. Gay relationships may not be recognized within the medical system (Rowe, Plum & Crossman, 1988) and tensions may arise with biological family members who exclude those they do not consider to be relatives (Worden, 1991). Caregiving and bereavement may interfere with the work responsibilities of those affected by AIDS (Pearlin, Semple & Turner, 1988). Conversely, unsupportive workplaces can disrupt grieving. Time off for bereavement may be readily available to someone in a heterosexual marriage or biological family. This may not be true for a member of a family of choice. If a gay caregiver's biological family deals with homosexuality by not talking about it, caregiving and bereavement may cause tension because there is no established way of processing feelings (Britton, Zarski & Hobfoll, 1993). For both those who are HIV-positive and their carers, heterosexism and homophobia may cause a double stigma as well as the potential for adding much stress to their lives.

An additional negative impact of AIDS on gay men has been the appearance of what has been termed survivor guilt (Hardy, 1998; Odets, 1994). The guilt has been experienced by gay men who are HIV-negative and who feel that they do not deserve to be healthy when so many others have fallen ill.

Negative Consequences

Not surprisingly, research has shown that the stresses of HIV caregiving and the related losses have taken a heavy toll on those affected by AIDS. Many studies have found high levels of depression. In a San Francisco based study of HIV-negative as well as HIV-positive gay men, both groups had significantly more depressive symptoms than the norm (Folkman, Chesney, Pollack & Coates, 1993). A study of AIDS caregivers in San Francisco and Los Angeles found that they had high levels of depression and were more frequent users of psychotherapy than the general population (LeBlanc, Aneshensel & Wight, 1995). The caregiving partners of men with AIDS demonstrated high levels of depression (Folkman, 1997b). Typically, the depressive levels of these caregivers were more than one standard deviation higher than the norm for the general population. When a care recipient died, the caregiving partners demonstrated depressive levels similar to those of bereaved spouses for seven months following the death. After that the levels remained one standard deviation higher than the norm.

Distress has also been demonstrated to be an outcome of AIDS caregiving and bereavement. In a study of gay men in New York City, the participants demonstrated less depression than hypothesized, but their symptoms of Post Traumatic Stress Disorder increased over a two-year period (Martin, Dean, Garcia & Hall, 1989). Gluhoski, Fishman and Perry (1997a, 1997b) studied gay men in a longitudinal study that assessed the impact of AIDS on numerous psychosocial factors. Men who had lost three or more friends or family members in the previous year exhibited more symptoms of distress than those men who had experienced fewer deaths (Gluhoski, Fishman & Perry, 1997a). The gay men with more losses had significantly higher rates of distress as measured with five separate instruments of anxiety, depression and overall distress (Gluhoski, Fishman & Perry, 1997b).

The impact of multiple AIDS deaths was the focus of an Australian study (Viney, Henry, Walker & Crooks, 1992). Two hundred and fifteen gay men participated in open-ended interviews. Roughly two-thirds came from the gay community in Sydney and were compared to participants who came from Melbourne. In contrast to Sydney, the gay community in Melbourne was considered to be less devastated by AIDS as there had been fewer deaths. As the researchers had predicted, the participants from the more bereaved community demonstrated more anxiety and anger; however, contrary to their other hypotheses, there was more depression and guilt among the members of the less bereaved community.

Lennon, Martin and Dean (1990) studied 180 gay men in New York City who had lost a lover or good friend. Men who had provided care to the person with AIDS were more likely than non-caregivers to experience a strong grief reaction which would put them at risk for pathological grief. In San Francisco, a study of AIDS caregivers concluded that there were many unmet needs and barriers to services which put carers at risk for psychological and physical consequences (Wight, LeBlanc & Aneshensel, 1995).

Research into Coping with AIDS Caregiving

Little research has been conducted to determine how AIDS carers cope. Of the few studies that exist, no broad consensus of adaptation emerges. Social support was found to be of importance for caregiving spouses of HIV-positive hemophiliac men (Klein, Forehand, Armistead & Wierson, 1994). A British investigation found that the carers' burden was more strongly associated with characteristics of the needs of the patient than with their own coping strategies (Pakenham, Dadds & Terry, 1995).

Three qualitative studies have contributed to understanding how those affected by, not infected with, HIV cope with the trauma involved. Gay men and lesbians participated in the first study which sought to understand how individuals cope with multiple losses (Carmack, 1992). Interviews with three lesbians and sixteen gay men provided data from which a theory of functional attachment was generated. Functional attachment is considered to be a balance between engagement and detachment without engaging in either to a dysfunctional degree. Those who considered themselves to be functionally engaged felt involved in supporting others and derived satisfaction from this caregiving.

A second study, a Canadian project, involved interviews with parents of HIV-positive sons at various stages of the disease from asymptomatic to deceased (Siegl & Morse, 1994). Eight mothers and five fathers participated; their sons were gay, bisexual or intravenous drug users. Six stages of acceptance were outlined from the data collected: suspecting, taking it in, going along with a changed reality, sweeping along with the symptoms, beating down the denial, and learning to live with HIV disease. For all of the parents, reappraising their circumstances and their relationship with their sons was an important part of keeping reality at a tolerable level.

In the third study, also Canadian, seven caregivers in British Columbia were interviewed in their own homes where they had cared for their family members (Stajduhar, 1997). It was found that carers in the palliative stage of caregiving went through three distinct processes in their coping. They needed to reconcile themselves to the coming death, make decisions about treatment and let go. Those caregivers who had built supportive networks for themselves as part of the process of coping were best able to find new meaning in life and recover from bereavement.

The UCSF Coping Project

The most significant body of research into coping with AIDS caregiving has come out of the University of California San Francisco (UCSF) Coping Project (Cooke, Gourlay, Collette, Boccellari, Chesney & Folkman, 1998; Folkman, Chesney & Christopher-Richards, 1994; Folkman et al., 1996; Folkman, Chesney, Cooke, Boccellari & Collette, 1994; Folkman, Moskowitz, Ozer & Park, 1997; Mayne, Acree, Chesney & Folkman, 1998; Moskowitz et al., 1996; Richards, Acree & Folkman, 1999; Richards & Folkman, 1997; Rosengard & Folkman, 1997). The project collected quantitative and qualitative data from 1990 to 1997 on 314 men. In order to participate, the men had to self-identify as gay or bisexual, be in a committed relationship, and be willing to be tested for HIV. The caregivers had to be living with the care recipient who had AIDS and who required help with at least two tasks of daily living. The carers were tested for HIV themselves and divided into two categories: HIV-positive caregivers and HIV-negative caregivers. There was also a comparison group of HIV-positive non-caregivers who were in a committed relationship with someone who did not require care. The participants were "90% Caucasian, 3% African-American, 4% Hispanic, and 3% other. The average age of the participants [was] 36.6 years, and most earn[ed] between $20,000 and $29,000 a year. The average length of the relationship between study participants and their partners [was] 6.2 years" (Folkman, Chesney & Christopher-Richards, 1994, p.40). Numerous investigations have used the data from the UCSF Coping Project.

The qualitative interview data were used in various ways. Many of the quantitative studies of the UCSF Coping Project were enhanced and enriched by passages taken from the qualitative data. Interviews were also analyzed in order to describe the stresses and coping responses of AIDS carers (Folkman Chesney & Christopher-Richards, 1994). Interviews conducted after the care recipient had died were also used to illustrate four different theoretical perspectives of predicting well-being after bereavement (Folkman, 1997a; Nolen-Hoeksema, McBride & Larson, 1997; Pennebaker, Mayne & Francis, 1997; Stein, Folkman, Trabasso & Richards, 1997; Weiss & Richards, 1997). The interviews were also analyzed to assess the likelihood of bereaved caregivers to engage in unprotected sex after the death of their partner (Mayne et al., 1998).

An investigation of the role of spirituality in coping with the death of a partner used the data from the same interviews (Richards & Folkman, 1997). A three to four year follow-up to this study was done (Richards, Acree & Folkman, 1999). It was found that spirituality remained important to the majority of carers but its role in their lives had changed.

In addition, qualitative data were used to investigate positive meaningful events in the lives of the caregivers (Folkman et al., 1997). The original research design of the Coping Project did not include asking about positive events. The carers pointed out that by only asking about stressful events, the researchers were missing important knowledge of the coping process. Consequently interviews included inquiries about events that were meaningful to the caregivers. It was found that the positive events served three purposes: to strengthen coping resources, to provide respite from the stressors and to maintain motivation.

One of the first studies published from the UCSF Coping Project investigated caregiver burden (Folkman et al., 1994). It compared the HIV-negative and HIV-positive caregiver groups and hypothesized that the HIV-positive group would experience more burden. The HIV-positive carers did report more burden than HIV-negative caregivers. In addition, the HIV-positive caregivers were found to be more religious or spiritual, had less income and used more positive reappraisal, cognitive escape-avoidance and social support as coping mechanisms than their HIV-negative counterparts. It was concluded, however, that most of these differences were more due to HIV seropositivity than to caregiving, because the HIV-positive non-caregiver group showed similar results.

A subsequent study sought to predict caregivers' depression after the care recipient died (Folkman et al., 1996). Of all the participants in the UCSF Coping Project at that time, 110 had been bereaved. A variety of psychological measures were taken over a ten-month period: three months before bereavement to seven months after. Thirty-seven HIV-positive and 72 HIV-negative caregivers had experienced the death of their partner since beginning participation in the project and had met all the necessary requirements for inclusion. These men were compared with 53 HIV-positive non-caregivers to determine the effects of HIV seropositivity. Both groups of bereaved carers showed significantly more depressive mood than the general population, even seven months after the death. While both HIV-negative and HIV-positive carers were found to be highly depressed at the time of bereavement, the levels of depressive mood diminished more quickly for those who were HIV-negative than for their HIV-positive counterparts. Most significantly, the results showed that the meaning found in caregiving was more predictive of depressive mood after the death of the care recipient than caregiver burden. The appraised meaning of caregiving had an important role in the caregivers' adjustment to being bereaved.

Another study from the UCSF Coping Project examined how coping affected mood during caregiving and bereavement (Moskowitz et al., 1996). This investigation is unusual in that it examines the less frequently considered positive outcomes, such as life satisfaction and positive mood, as well as negative outcomes of caregiving and bereavement. The 110 participants were examined for five months before the death of the care recipient, the caregiving period, and for five months after the person's death, the bereavement period. Various coping strategies were associated with negative and positive mood states during both periods. Problem-solving and escape-avoidance strategies were used more during caregiving than bereavement. Problem-solving was used to deal with the tasks of caregiving and escape-avoidance is thought to have been used in order to maintain hope for a cure while the partner is still alive. Positive reappraisal was consistently linked to positive mood during both caregiving and bereavement. Moskowitz et al. concluded that positive reappraisal is associated with stress-related growth.

A further study that arose out of the UCSF Coping Project addresses suicidal ideation (Rosengard & Folkman, 1997). In order to draw conclusions about suicidal ideation in relation to HIV and bereavement, four groups were used from the participants of the research: bereaved, non-bereaved, HIV-positive, and HIV-negative. There was no relationship found between HIV serostatus and suicidal ideation; more bereaved men were found to have higher scores on the measure of suicidal ideation than the non-bereaved group. Participants who reported never having considered suicide were found to be the most optimistic. Those who experienced the most burden in caregiving, felt the least amount of social support, and used escape-avoidance coping were most likely to have high levels of suicidal ideation.

A final quantitative study using the data from the UCSF Coping Project involves assisted suicide (Cooke et al., 1998). Three months after their partner had died, participants in the project were asked if they had increased their partner's medication before his death. Of those participants who had increased the medication, seventeen indicated that they had done so in order to hasten their partner's death. The researchers expected that more aided deaths would take place among those who were dying at home but found that the people with HIV disease whose medications were increased were just as likely to be in hospital or a hospice as at home with the caregiver. The caregivers who assisted the deaths of their partners had higher scores on the scale measuring positive meaning in caregiving, indicating that the caregiving was of great importance to them. This was reinforced with interview data and the lack of a statistical relationship between higher caregiver burden and the decision to hasten death.

Positive Outcomes for AIDS Carers

Some of the possible benefits of coping with a stressful situation are an increased personal strength, an acceptance and appreciation of vulnerability, improved relations with others and a stronger appreciation of life (Tedeschi &

Calhoun, 1995). These benefits are well illustrated by the case studies of voluntary and paid caregivers involved in the Shanti Project in San Francisco (Garfield, 1995). The Shanti Project began as a palliative care project for cancer patients before the advent of AIDS, and evolved to focus more on AIDS work as the epidemic surfaced. All of the individuals interviewed experienced numerous stressors as a result of their work. Their stories, however, contain eloquent examples of what they have gained from their experiences.

An Australian study investigated strengths and frailness in members of the gay community (Viney et al., 1991). The participants from the gay community, both HIV-positive and caregivers, demonstrated significantly more strengths and frailties than the well and ill men from outside the gay community. The strengths that were found included competence and positive feelings. For the caregivers in an American city, benefits of AIDS caregiving outweighed the stresses involved (Clipp et al., 1995). Many of them stated that they would be willing to be caregivers again if given the opportunity.

The gay men who provided care to their partners in the UCSF Coping Project experienced positive psychological states (Folkman, 1997b). For those who were bereaved, their positive states of mind were lower than a comparative community norm, but only by a small amount. Those whose partners did not die experienced positive feelings as frequently as they experienced negative feelings. Their positive affect did not differ significantly from the community sample.

The caregivers involved in the UCSF Coping Project also benefited from positive meaningful events (Folkman et al., 1997). While they demonstrated higher than average depressive mood scores, they were experiencing concurrent positive moods at a similar rate to national norms. The ordinary events that they infused with positive meaning allowed them respite from the stress, bolstered their coping resources, and helped them to maintain their determination to provide care for their partners.

The same cohort of participants demonstrated another possible positive outcome when coping with the stress of AIDS caregiving and bereavement (Moskowitz et al., 1996). One hundred and ten caregivers from the UCSF Coping Project were included in this study of coping and mood during the period five months before and five months after the partner's death. Measures of both negative and positive mood were used. Active problem-solving coping was associated with improved positive mood states throughout the stages of caregiving and bereavement.

As demonstrated above, caregiving and bereavement are stressful in all contexts. The nature of HIV disease and its transmission makes the tasks of the caring potentially more traumatic. In addition, AIDS-related multiple losses and the challenges facing the gay community have made the impact devastating. A small amount of research into coping with these stressors has demonstrated that there is potential for growth to be experienced by those who care for someone who has HIV disease.

CHAPTER FOUR

Methodology

Research Design

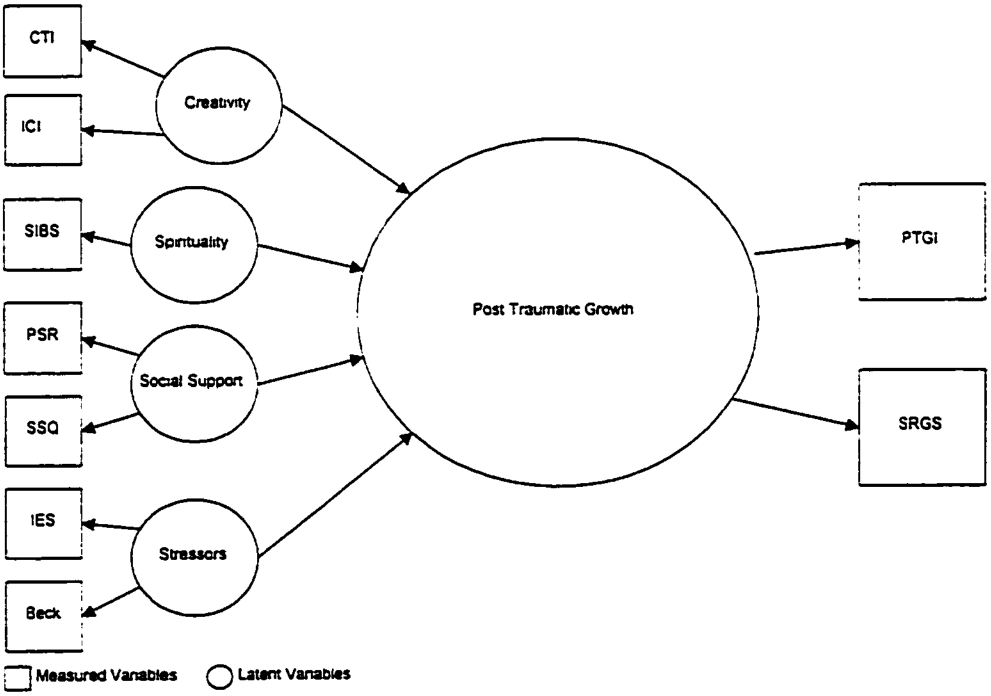
This research was designed to explore the factors that allow the bereaved caregivers of people with AIDS to survive and even grow in the face of their traumatic circumstances. An exploratory cross-sectional survey design was used; participants responded to a questionnaire comprised of various measures. Quantitative data was gathered in order to test the research model and the hypotheses.

Follow-up interviews were conducted in order to enrich the quantitative data. The interview questions were designed to explore the factors that were hypothesized to contribute to growth as conceptualized in the model as well as explore the post-traumatic growth experienced by the individual. The participants interviewed were chosen in part by their geographical location so that face-to-face interviews could be conducted. Principally, an effort was made to interview one individual with high scores and one with low scores on the measures of post-traumatic growth by each of the gender categories (male, female and transgender). One additional transgender participant with low growth scores was interviewed, providing a total of seven.

Development of the Research Model and Hypotheses

Given the realities of caregiving and bereavement in the context of AIDS, and based in the theoretical framework of the transactional approach to stress and coping, a research model was developed (see Figure 4.1). The model illustrates a hypothesized relationship of factors that allow for transformational coping. Post-traumatic growth (PTG) is used as the outcome or endogenous variable in a structural equation model (Goffin &

Figure 4.1: Model for Quantitative Analysis



CTI	Constructive Thinking Inventory		
ICI	Internal Control Index		
SIBS	Spiritual Involvement and Beliefs Scale	PTGI	Posttraumatic Growth Inventory
PSR	Provision of Social Relations	SRGS	Stress-Related Growth Scale
SSQ	Social Support Questionnaire		
IES	Impact of Events Scale		
BDI	Beck Depression Inventory		

MacLennan, 1997). Two standardized measures were available to capture this construct: the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) and the Stress-Related Growth Scale (SRGS; Park, Cohen & Murch, 1996). Both measures are discussed more fully later in this chapter.

Creativity

Much work has been done regarding personality and coping with stress (Tennen & Affleck, 1998). As the concept of PTG is relatively recent, little investigation has been done to examine the role of personality in its development. Based on the work of Tedeschi and Calhoun (1995; Tedeschi, Park & Calhoun, 1998), creativity emerges as the personality trait that is most important in PTG. Personality factors, and specifically creativity, seem to have a vital role in transformational coping. Folkman et al. (1996) suggest that the process of creating meaning in caregiving is affected only by the beliefs, values and goals of the individuals. Tedeschi and Calhoun (1995), however, give strong credence to the notion that aspects of personality influence meaning-making and transformational coping. They discuss many personality characteristics in relation to successful coping. The common thread that they find among the many personality factors is creativity. Creativity "involves inquisitiveness and imagination and may also demand a suspension of judgement and a 'letting go' of conventional ways of looking at the world" (Strickland, 1989, p.7).

The personality characteristic of creativity may be especially relevant to the gay community. Gay men and lesbians have mostly grown up in heterosexual families and few have had homosexual role models. In realizing and accepting their homosexual feelings, they have had to confront one of society's most strongly held taboos concerning sexuality. For many individuals the coming-out process has demanded of them much flexibility and a willingness to view the world in a different way. The aspects of flexibility and openness are central to the definition of creativity.

Creativity may be a necessary personality characteristic for caregivers. 'Being with' or sharing the inside world of the person that one cares for epitomizes caring (Mayeroff, 1971). 'Being with' is a state that fluctuates normally and allows periods of reflection when the caregiver is able to understand and respond to the person for whom one cares. However, when the care recipient is dependent because of illness, the rhythm of detachment may be interrupted. Creativity on the part of an AIDS caregiver may be a necessary aspect for dealing with the fluctuations of the activity of sharing the inside world of the care recipient.

Hennezel (1997) illustrates how the process of growth can take place even in the last stages of life. As a psychologist working with patients on a palliative care ward and in an AIDS hospice, she describes numerous cases in which individuals come to terms with all that they have done in their lives. Her case examples illustrate beautifully the possibility of human growth up to the very last moment. All of those who achieved such growth did so aided by the attentive care of at least one other person. Creativity is a necessary personality attribute for those who care for the dying (Garfield, 1995).

One necessary characteristic of a caregiver is that of allowing the other to grow in order to grow oneself (Mayeroff, 1971). Picano (1997) illustrates this point in a list he provided to a friend in order to help the friend to deal with the deterioration of his four-year-old son to leukemia:

> 1. His life is not your life. It's his life. His illness is not your illness. It's his illness. His death is not your death. It's his death. You may share in his illness and his death as you shared his life. You are not in control of his life; you have only limited responsibility for it. Keep this in mind at all times.
> 2. Don't panic. Once you panic you close yourself to opportunity. Keep yourself as calm as possible, especially when he is unable to do so. You will be depended upon to make rational logical choices when he cannot do so. Look into every possibility clearly. Not with hope, not with expectation, but with reality. Who knows, something might ease him, or help him.
> 3. Ignore people around you. Utilize others' help but rely only on yourself. Do whatever has to be done or whatever you two have agreed to do despite social convention, despite family wishes, despite what "people will say," despite what doctors would like to do "for the future benefit of mankind," despite how you think you'll feel about it later on. Make certain he is not in any pain. Be true to this and you won't regret it afterward. (Picano, 1997, p.*xxiv*)

Picano is urging his friend to be creative in dealing with the death of his son. He mentions staying open to opportunity and decision-making based on what the friend and his son want. He advises his friend to ignore other people. Creativity is a "highly individualistic activity" (Strickland, 1989, p.7) and requires flexibility on the part of the person (Tedeschi & Calhoun, 1995).

In order to assess the personality characteristic of creativity, since no specific measures were known, two constructs were selected. Constructive thinking is believed to be one aspect of creativity (Strickland, 1989; Tedeschi & Calhoun, 1995). Constructive thinking is defined as experiential intelligence that includes automatic thoughts which are either constructive or destructive (Epstein & Meier, 1989). This is measured by a subscale of the Constructive Thinking Inventory (CTI; Epstein & Meier, 1989). In addition, the Internal Control Index (Duttweiler, 1984) measures locus of control. Individuals with an internal locus of control believe that the reinforcement that they receive is due to their behaviour, while someone with an external locus of control perceives that reinforcement is due to chance, luck or other powerful forces outside themselves (Duttweiler, 1984). The ICI is an additional measure of creativity because creative individuals are believed to be mindful (Strickland, 1989). Mindful people make active choices in their own lives, regardless of outside forces such as powerful others and chance (Alexander, Langer, Newman, Chandler & Davies, 1989; Langer, 1997). In addition, Strickland (1989) linked creativity to internal locus of control based on social learning and self-regulation theories.

Spirituality

Spirituality and/or religiosity are an important part of meaning-making and transformational coping. For the participants in the UCSF Coping Project, spirituality aided in the construction of positive meaning in the early stages of bereavement (Richards & Folkman, 1997). One hundred and twenty-one caregivers were interviewed just after the death of the care recipient and 54 per cent of them spontaneously offered accounts of religious or spiritual beliefs and practices. These included the caregivers' assuming the role of spiritual guide during the final stages of the care recipient's life. Often the caregivers gave permission for their care partner to die and viewed this as easing the transition into death. The notion of easing the transition is supported by others (Hennezel, 1997; Levine, 1987).

The spirituality revealed by the caregivers also included that of a belief in a higher power and the observance and creation of rituals (Richards & Folkman, 1997). Spiritual and religious beliefs influence the meaning of death (Frankl, 1997; Spilka, Hood & Gorsuch, 1985). Some participants believed that their relationship with the care recipient continued after death in another form, while others believed that it was over (Richards & Folkman, 1997). It is of great comfort to believe that there is life after death (Spilka, Hood & Gorsuch, 1985; Richards & Folkman, 1997).

As many people in the gay and lesbian community have distanced themselves from traditional religious institutions that are not supportive of them (Hardy, 1998), it was extremely important to find a measure of spirituality that is inclusive. This necessitated finding one that used language that was not based in Christianity or even in theism.

The Spiritual Involvement and Beliefs Scale (SIBS; Hatch, Burg, Naberhaus & Hellmich, 1998) explores spiritual practices and refers to a higher power rather than God. The instrument is designed to measure spiritual principles that underlie various religious orientations, including atheism. The authors sought to surpass the narrow Judeo-Christian orientation in other measures of spirituality and to assess spiritual actions as well as beliefs. They acknowledge that by "including spiritual activities, the scale risks capturing what has been termed 'extrinsic' religious orientation, namely, self-serving, empty participation in religious activities and rituals" (Hatch et al., 1998, p.482). The questions addressing activities tend to focus on the effect on the individual rather than only assessing frequency.

Social Support

The support of others is crucial in a time of stress and trauma (Tedeschi & Calhoun, 1995). Family, friends, others in a similar situation and/or professionals may provide support (Garfield, 1995; Tedeschi & Calhoun, 1995). Supportive others provide opportunities to model, test and develop new coping behaviours as well as new schemata (Calhoun & Tedeschi, 1998). Two measures of social support were selected for this variable: the Social Support Questionnaire, which was used in the UCSF Coping Project (O'Brien, Wortman, Kessler & Joseph, 1993), and the Provision of Social Relations (PSR; Turner, Frankel & Levin, 1983).

Stressors

The role of stress in traumatic growth is pivotal in that there is, by definition, no growth without initial trauma. Stress may continue to be a factor in people's lives even as they are growing; this is illustrated in the model of PTG with the inclusion of some enduring distress as part of the outcome loop (Calhoun & Tedeschi, 1998). Consequently, while Post Traumatic Stress Disorder (PTSD) and depression may be traditionally measured as outcomes, here they are hypothesized to exogenous variables which exert an influence on Post-Traumatic Growth. The latent variable of stress was measured with the Impact of Events Scale (IES; Horowitz, Wilner & Alvarez, 1979) and the Beck Depression Inventory (Beck, 1967).

Hypotheses

Specifically the following hypotheses were tested:

1. Caregivers with high degrees of creativity will demonstrate more post-traumatic growth.
2. Caregivers who are more spiritual will demonstrate more post-traumatic growth.
3. Caregivers with more social support will demonstrate more post-traumatic growth.
4. Caregivers who demonstrate fewer signs of stress will have more post-traumatic growth.

Participant Selection

Participants were recruited by placing posters (see Appendices One and Two) in agencies dealing with AIDS caregivers, such as AIDS service organizations, hospices, residences for people with AIDS as well as some spiritual or religious locations. In addition, posters were distributed at two conferences of the Canadian AIDS Society. Participants were sought throughout Canada. Because of the bilingual makeup of the country, the questionnaire package was produced in both official languages, English and French (see Appendices Five and Six). Of the measures used, only two existed in both languages. The remainder was translated from English to French for the purposes of this research.

A toll-free number was established to enable participants Canada-wide to volunteer at no cost to themselves. Calls to the number went directly to voice mail; the message giving a brief explanation of the research had been recorded in both languages. Participants who saw the poster and were interested in the research contacted the toll-free number and left a message. They were contacted and the study was explained to them. If they agreed to participate a package was mailed to them which included a letter of informed consent (Appendices Three and Four), the questionnaire (Appendices Five and Six), a stamped addressed envelope for them to return the questionnaire, as well as a cheque for $20.

Two hundred and four people indicated an interest in the study; 202 questionnaires were mailed. One hundred and seventy-six questionnaires were returned, resulting in a return rate of 86.7%. Data was not kept on where or how individuals learned of the research.

Data Collection

Sociodemographic Questionnaire

No standardised measures existed to assess the sociodemographics and stressors of this population. Consequently, a questionnaire was created which included questions regarding sexual orientation, HIV serostatus, the number of losses to AIDS that participants had experienced, the length of time since they were bereaved and their relationship to the person who died. The development of this questionnaire is in accordance with other research (Cooke et al., 1998; Folkman, Chesney & Christopher-Richards, 1994; Folkman, et al., 1994, 1996, 1997; Moskowitz et al., 1996; Richards & Folkman, 1997; Rosengard & Folkman, 1997).

Creativity

1. A Subscale of the Constructive Thinking Inventory (CTI)

The CTI is a 108-item instrument designed to measure "automatic constructive and destructive thinking" (Epstein & Meier, 1989, p.333). Because 108 items would have lengthened the response time considerably, the subscale of global constructive thinking was used. This involves 29 statements such as "I tend to classify people as either for me or against me".

Participants choose among five potential responses: definitely false, mostly false, undecided or equally false and true, mostly true, definitely true.

The instrument has been reported to have a score of 0.90 for internal consistencies and 0.86 for test-retest reliability when administered to 1500 college students in the U.S. (Epstein, 1993). The alpha reliability was reported as 0.90 in a separate sample of 450 college students (Epstein & Katz, 1992). The internal consistency was reported as 0.89 with 158 older adults (Epstein, 1993). In a study of 221 pregnant women, the Chronbach's alpha reported for the global CTI scale was 0.92 (Park, Moore, Turner & Adler, 1997). Validity of the overall CTI instrument was established with numerous investigations of its relationship to other self-report measures (Epstein, 1993).

2. Internal Control Index (ICI)

The ICI was developed to assess locus of control where individuals seek and anticipate reinforcement (Duttweiler, 1984). The ICI is a 28-item scale with phrases such as "I ______ change my opinion when someone I admire disagrees with me". Respondents choose among five responses to fill in the blanks: Rarely, Occasionally, Sometimes, Frequently, Usually. The possible range of scores is from 28 to 140 where higher scores indicate more internal locus of control. The ICI demonstrates fair validity and good internal reliability (α = 0.84 and α = 0.85) (Corcoran & Fischer, 1987).

Spirituality

The Spiritual Involvement and Beliefs Scale (SIBS)

The SIBS is designed to assess the importance of spirituality across religious, spiritual and philosophical beliefs (Hatch et al., 1998). The 39 questions are answered using a seven-point Likert scale; 34 of these are based on agreement ranging from Strongly Agree to Strongly Disagree. In four questions the 7 points on the scale represent frequency ranging from Always to Never. The remaining question asks respondents how spiritual they consider themselves to be; seven represents the most spiritual.

The first version of this instrument was tested on 83 individuals: 50 patients of a family practice and 33 family practice educators. Reliability and validity were reported to be high with a Chronbach's alpha of 0.92 and test-retest reliability of 0.92 after nine months. Validity was established through high correlation with another measure of spirituality. The version used in this research was established after the SIBS was administered to 154 individuals of various spiritual backgrounds as well as tested in focus groups from five diverse churches or religious institutions. On a convenience sample of 50 people identified by various religious backgrounds, including none, the Chronbach's alpha was 0.96 (Hatch, 1999). The range of possible scores is from 39 to 273 with higher scores indicating more spirituality.

Social Support

1. Social Support Questionnaire (SSQ)

The Social Support Questionnaire is a 23-item instrument that assesses perceived social support as well as social integration (O'Brien, Wortman, Kessler & Joseph, 1993). Along with the overall score of social support, six other indices are generated: emotional support, material support, conflict, subjective social integration, social validation, and loved/respected. This is the measure of social support administered to the participants in the UCSF Coping Project: a longitudinal study of caregiving partners of men with AIDS (Folkman et al., 1994).

Responses are chosen from among five with questions such as: "Have you felt isolated from others?". In the first section answers are in relation to occurrences in the last month; the responses range from Never to All the Time. The second part deals with the availability of people to the respondent. Questions such as "Do the people in your personal life approve of the ways you do things?" have the possibility of answers that range from Definitely Not to Definitely. The reported alpha coefficient is 0.89 (Folkman et al., 1994).

2. Provision of Social Relations (PSR)

The PSR was designed to measure individuals' perceptions of the provision of support to them (Turner, Frankel & Levin, 1983). There are 15 items to which participants respond, using 5 choices ranging from Very Much

Like Me to Not at All Like Me. "I feel very close to some of my friends" is an example of one question. There are two dimensions of the PSR: family support and friend support. Higher scores indicate more social support.

The PSR was developed and tested on several populations in southwestern Ontario (Turner, Frankel & Levin, 1983). It demonstrated good reliability with 200 university students, 523 ex-psychiatric patients and 989 people with disabilities. Validity was established through correlations with other measures. Recently, the PSR was used with family caregivers of terminally ill people (Cheng, Schuckers, Hauser et al., 1994).

Stressors

1. *Impact of Events Scale (IES)*

The IES is a 15-item scale that measures the responses to stressful events (Horowitz, Wilner & Alvarez, 1979). There are two subscales: avoidance and intrusion. Responses range from 1 (Not at all) to 4 (Often), measuring how frequently a reaction to the stressful event occurred.

The IES has been tested on 35 outpatients and 37 adult volunteers who had experienced the death of a parent within the last two months (Corcoran & Fischer, 1987). Alpha reliability was reported at 0.86 for the intrusion subscale and 0.90 for the avoidance. Validity of the measure has been established.

2. *Beck Depression Inventory (BDI)*

The BDI was originally developed in 1961 to measure depression (Beck, 1967). The current version has 21 items. Each item is a group of statements from which respondents pick the most applicable to them, in terms of their experiences in the last week. The four choices range from 0 (no depression) to 3 (severe depression) (Beck & Beamesderfer, 1974). The total score range is from zero to 63 with higher scores indicating more severe depression.

The BDI is now one of the most widely used measures of depression (Corcoran & Fischer, 1987). After 25 years of use, Beck, Steer and Garbin (1988) assembled the data from the use of the BDI with psychiatric and non-psychiatric populations. Internal consistency alphas ranged from 0.73 to 0.95 and test-retest reliability estimates were good with a large variety of interval times. Validity was established with content, concurrent, discriminant, construct and factorial assessments. Some doubt has been raised about the scores of individuals changing over time but this has implications for the BDI as a diagnostic tool more than it does for research purposes (Kendall, Hollon, Beck, Hammen & Ingram, 1987). Indeed, Kendall et al. point out that the BDI was never intended to serve as a screening method.

Post-Traumatic Growth

1. Posttraumatic Growth Inventory (PTGI)

The PTGI has 21 items which are answered with a 6-point Likert scale ranging from 0 (I did not experience this change as a result of my crisis) to 5 (I experienced this change to a very great degree as a result of my crisis) (Tedeschi & Calhoun, 1996). It was developed to measure positive outcomes of trauma. There are five factors: New Possibilities, Relating to Others, Personal Strength, Appreciation of Life and Spiritual Change.

This relatively new scale was tested on 604 undergraduate students in the U.S. An alpha coefficient of 0.90 was reported with test-retest reliability at 0.71 over two months.

2. Stress-Related Growth Scale (SRGS)

The SRGS was designed to measure positive outcomes of stressful events (Park, Cohen & Murch, 1996). A 15-item version has been developed out of the original 50-item measure (Cohen, Hettler & Pane, 1998). Responses are made in relation to the stressful event and range from 0 (not at all) to 2 (a great deal).

The SRGS 50-item measure was tested on 922 students in the U.S. (Park, Cohen & Murch, 1996). The reported alpha was 0.94 and was found to be 0.96 on a sample of adult church members (Hettler & Cohen, 1996). Test-retest reliability for the college students over two weeks was 0.81 (Park, Cohen & Murch, 1996). Validity was established by having parents and friends provide the same information as the students. The resulting correlations were significant but low (r = 0.21 to 0.31).

Data Analysis

Quantitative data

As the design of this research is a cross-sectional survey, statistical analysis was limited to trying to understand the variability in the post-traumatic growth of bereaved caregivers. The measures were chosen to allow for an analysis using Structural Equation Modeling (SEM). In addition, bivariate tests and regressions were performed, notably a test of groups to make sure that males and females, anglophones and francophones and those who are either HIV-positive or HIV-negative can be analyzed together.

SEM analyzes multivariate relationships and builds on path analysis (Knoke & Bohrnstedt, 1994). The advantage of SEM over path analysis is its ability to link observed indicators with unmeasured variables. For example, in the above model, both the ICI and the subscale of the CTI are being used to represent the unmeasured concept of creativity. Analysis consists of building matrices based on the relationships in the model. LISREL 8.3 (Joreskog & Sorbom, 1996), the most commonly used statistical package for SEM, estimates parameters and tests the significance of the model.

Interview data

In order to conduct follow-up interviews, the quantitative data was analyzed to determine if there were significant differences in the means of the growth scales (the SRGS and the PTGI) in terms of any of the sociodemographic variables. A one-way ANOVA on the first one hundred cases entered demonstrated significant differences between the three groups of gender on both measures of post-traumatic growth (F[2,97] = 4.820, p = 0.010 for SRGS and F[2,97] = 3.020, p = 0.053 for PTGI). Because gender was the only variable that demonstrated significantly different means within the first one hundred participants on both measures of post-traumatic growth, interviews were conducted with 2 female, 2 male and 3 transgender participants. The individuals were chosen by their high or low post-traumatic growth scores and by their geographical location so that face-to-face, rather than telephone, interviews could be conducted.

Participants were interviewed using a semi-structured format (see Appendix Seven). The open-ended questions attempted to reflect the variables used in the quantitative measures. With the participants' permission (see Appendix Eight), the interviews were audio tape-recorded, transcribed verbatim and verified for accuracy. The transcriptions of the interviews were subjected to thematic analysis.

CHAPTER FIVE

Quantitative Results

Summary of Results

The results of this study support two of the hypotheses: as spirituality and social support increase, there is greater growth after trauma. There was no support for the predicted relationship between creativity and stress-related growth. The results demonstrated the opposite of the hypothesis concerning stress and post-traumatic growth: high stress was associated with greater growth. Overall, the role of spirituality in traumatic recovery was underlined in all the analyses.

Quantitative Results: Descriptives

Questionnaire

One hundred and seventy-six people responded to the questionnaire. As is shown in Table 5.2, 51.7% of these individuals were male, 46% were female and 2.3% were transgender. Seventy-nine per cent responded to the questions in English; 21% completed French questionnaires. Participants came from all provinces except Newfoundland. There were two people in Nunavut who answered questionnaires; no other territories were represented.

While 90.9% of the participants were born in Canada, responses to the question regarding ethnocultural background (see Appendices Five and Six) ranged enormously.

Table 5.1: Ethnocultural Background of Participants

Category	Number
Canadian	66
Aboriginal	6
Metis	6
African Canadian	3
Quebecois (Francophone)	17
French Canadian (Anglophone)	9
Catholic (practising and non-practising)	17
Christian and/or Protestant	7
Muslim	1
Jewish (non-practising)	1
Atheist	1
Spiritual	3

Note: Participants may have identified themselves in more than one category

The participants ranged in age from 19 to 79; the mean age was 40.6 years with a standard deviation of 11.4 (see Table 5.2). Fifty-four percent of the sample had completed college or university or CEGEP (in Quebec), 28% had completed high school and 18% had less than a high school diploma. Fifty-three percent of the participants were employed part- or full-time while 47% were unemployed. The employment status did not differentiate between those who were unemployed because of retirement, on disability pensions or other reasons. Given that 44% of the sample was HIV-positive, a large number of whom may have been on disability or pensions, the employment question should have reflected these differences.

Table 5.2: Sociodemographic Characteristics of Participants

Variable	N	Missing	Statistic	
Age in years	172	4	Mean	40.65
			Standard Deviation	11.38
Gender	176	0	Male	91 (51.7%)
			Female	81 (46.7%)
			Transgender	4 (2.3%)
Employment	174	2	Not employed	81 (46.6%)
			Part-time	35 (20.1%)
			Full-time	58 (33.3%)
Education	175	1	Less than grade 12	32 (18.3%)
			Grade 12 or 13 grad	49 (28.0%)
			College grad	33 (34.9%)
			University grad	61 (34.9%)
Sexual Orientation	175	1	Gay	70 (40.0%)
			Lesbian	11 (6.3%)
			Bisexual	9 (5.1%)
			Heterosexual	85 (48.6%)
HIV Status	175	1	HIV-positive	77 (44.0%)
			HIV-negative	86 (49.1%)
			Unknown	12 (6.9%)
Years Since Death	170	6	Mean	4.33
			Standard Deviation	3.15
Relationship to Deceased	176	0	Partner	38 (21.6%)
			Friend	71 (40.3%)
			Family of choice	17 (9.7%)
			Family of origin	27 (15.3%)
			Other	23 (13.1%)
How Many Deaths	174	2	Mean	13.88
			Standard Deviation	21.95
Language	176	0	English	139 (79%)
			French	37 (21%)

Of those who responded, 51% were gay, lesbian or bisexual and 49% were heterosexual (see Table 5.2). Forty percent identified that the person who had died of AIDS was a friend, 22% indicated partner, 10% selected family of choice and 15% of participants had lost a member of their family of origin. The relatively high category of other (13%) reflects the fact that many care recipients were associated with the participants through volunteer or work-related relationships and therefore did not fall within the category of family or friends. Similarly, three percent of people reported that they had experienced zero AIDS-related deaths of friends or family members. The range of deaths experienced was from 0 to 110. The mean was 13.8 and the standard deviation, 22. Many individuals answered this question by writing a plus sign after the number. This was recorded as the number that each identified. In addition, numerous people responded that they had stopped counting. Therefore, it is assumed that the number of deaths is under-reported. The time since death ranged from one month to eighteen years; the mean was 4.3 years with a standard deviation of 3.2.

The Subscale of the Constructive Thinking Inventory

The mean of the subscale of the Constructive Thinking Inventory (Epstein & Meier, 1989) was 107.12 (standard deviation 16.58). Epstein (1993) tested 1500 college students: their mean on the Global Constructive Thinking subscale was 98.51 with a standard deviation of 15.84. In a sample of 158 older adults, the mean was 107.76 (standard deviation = 14.69) (Epstein, 1993). This indicates that the sample of bereaved HIV carers demonstrate as much flexible thinking as the group of older adults and somewhat more than the college students.

Internal Control Index

The mean score on the Internal Control Index (Duttweiler, 1984) for the HIV carers in this study was 106.98 with a standard deviation of 12.66. This is comparable to the scores reported by Duttweiler (1984) on a sample of 508 college students (mean of 106.6, standard deviation of 12.6). This indicates that the people who participated in this study have a comparable sense of control in their own lives as the college students. There was a significant difference between the groups of participants who were HIV-positive and HIV-negative (see Table 5.3). Those who were HIV-positive had significantly lower scores on the ICI, indicating a greater sense that events occur outside of their control. This is perhaps not surprising given the fact that they have been diagnosed with an unpredictable and unrelentingly fatal disorder.

Table 5.3: Internal Control Index Means by HIV Serostatus

	N	Mean	Standard Deviation	t-test
HIV-positive	77	104.36	14.51	$t = -2.735$ $\alpha = 0.007$
HIV-negative	86	109.56	9.30	

Spiritual Involvement and Beliefs Scale

The mean score on the Spiritual Involvement and Beliefs Scale (Hatch et al., 1998) was 200.05 with a standard deviation of 36.31. In comparison, 150 Californian nursing students had a mean of 201.2 on the SIBS (Hatch, 2000). In addition, a sample of medical students and elderly people in Florida, totalling 304 participants, had a mean score on the SIBS of 203.2. This indicates that the sample of HIV carers was slightly less spiritual than the nursing and medical students and the elderly, although the difference is within one standard deviation.

Social Support Questionnaire

The SSQ (O'Brien et al., 1993) has five subscales and one measure of overall support. The means and standard deviations are reported in Table 5.4. The subscales reflect greater levels of support as scores increase, except on the conflict scale where high scores indicate that the person feels more social conflict. The overall support index includes only the subscales of emotional support, material support, subjective social integration, social validation, and loved/respected; the total does not include the conflict index. Comparison data are not available.

Table 5.4: The Social Support Questionnaire Subscale Means

	Overall Social Support	Emotional	Material	Conflict	Subjective Social Integration	Social Validation	Loved/ Respected
Mean	53.81	17.59	9.89	7.18	11.07	7.98	7.28
Standard Deviation	11.64	3.82	2.89	3.22	4.18	2.38	1.37

Provision of Social Relations

The mean score for the HIV carers on the PSR Family (Turner, Frankel & Levin, 1983) was 14.47 (standard deviation, 7.08) and on the PSR Friends was 17.05 (standard deviation, 5.72). The overall mean was 31.52 (standard deviation, 10.68). With a possible range of between 15 and 75 points, this indicates that this population experienced moderate social support. Norms are not available (Corcoran & Fischer, 1987), however Cheng, Schuckers, Hauser et al. (1994) administered the PSR to 28 elderly caregivers of terminally ill veterans. Their mean score on the PSR was 26.5 (standard deviation = 7.0). In comparison to these elderly caregivers, the HIV carers in this study demonstrated more social support. A t-test was not performed because of the small size of the elderly caregiver sample.

Impact of Events Scale

This population of HIV carers demonstrated a high amount of stress as measured by the IES (Horowitz, Wilner & Alvarez, 1979). Zilberg, Weiss and Horowitz (1982) measured stress in 72 individuals who had experienced the death of a parent. Of the total, 35 were patients who sought help at a clinic; the remaining participants were solicited from next of kin records on death certificates. The HIV caregivers who participated in this study demonstrated more stress overall than the bereaved adult children (IES Intrusion: mean = 18.81, standard deviation = 4.76; IES Avoidance: mean = 18.09, standard deviation = 5.57). However, the mean scores of the subsample who had referred themselves to an outpatient clinic in the Zilberg, Weiss and Horowitz (1982) study were higher than the HIV carer means on both subscales.

Horowitz, Wilner and Alvarez (1979) report means of two populations: one group of 110 medical students and 66 stress clinic patients. Although there were no significant differences between genders in the present study ($p > 0.05$ for intrusion and avoidance subscales and the total), the comparative data was divided by gender. However there was no data on transgender individuals. The HIV carers demonstrated much higher means than the medical students and comparable means to the stress clinic patients (see Table 5.5). All of the differences between the test populations and the HIV carers were significantly different ($p < 0.001$), with the exception of the difference between the total IES scores for the males in the stress clinic and the male HIV caregivers.

Table 5.5: Impact of Events Scale Means

		Males Mean (Standard Deviation)	Females Mean (Standard Deviation)
Stress Clinic	Intrusion	21.2 (12.5)	21.4 (8.6)
	Avoidance	14.1 (12.0)	20.6 (11.3)
	Total	35.3 (22.6)	42.1 (16.7)
Medical Students	Intrusion	2.5 (3.0)	6.1 (5.3)
	Avoidance	4.4 (5.3)	6.6 (7.0)
	Total	6.9 (6.8)	12.7 (10.8)
HIV Carers	Intrusion	18.69 (5.11)	18.89 (4.4)
	Avoidance	18.36 (5.88)	17.86 (5.30)
	Total	37.05 (9.55)	36.75 (8.74)

The mean of 36.9 (standard deviation = 9.06) is well above and significantly different from ($t[175] = 15.96$, $p < 0.001$) the score of 26 which is indicative of Post Traumatic Stress Disorder (McFarlane, 1988a). Of all the HIV carers in this study, 86.4% of them qualify for this diagnosis.

Beck Depression Inventory

The mean on the Beck Depression Inventory (Beck & Beamesderfer, 1974) was 11.95 with a standard deviation of 9.29. Beck, Steer and Garbin (1988) recommend using cut-off scores to delineate depression. According to their guidelines, 50.3% of the HIV carers demonstrated little or no depression (0 to 9 on the BDI), 24.6% scored mild to moderate (10 to 18), 20.0% had scores for moderate to severe depression (19 to 29) and 5.1% displayed severe depression with a BDI score of 30 or higher. Folkman et al. (1994) reported more depression in the HIV-positive caregivers than their HIV-negative counterparts; there was no significant difference found by HIV status in the current sample.

Stress-Related Growth Scale

The caregivers in this study had a mean score of 19.76 on the SRGS (Park, Cohen & Murch, 1996) with a standard deviation of 6.59. No comparative information was available, as no published studies have used the short form of the SRGS.

Posttraumatic Growth Inventory

The means and standard deviations within the current sample on the PTGI (Tedeschi & Calhoun, 1996) and its subscales are shown in Table 5.6. There were no significant differences between scores for men and women ($p > 0.05$). However, the transgender individuals had significantly different scores. No comparison data exists for the transgender population and the differences may be due more to the small sample size than any real distinction. Tedeschi and Calhoun (1996) administered the PTGI to 604 undergraduate psychology students and reported significantly different scores for women than men for all the subscales except New Possibilities as well as the total score. The overall means of the male and female HIV carers in this study were lower than the overall means in the student populations in the Tedeschi and Calhoun (1996) studies. This indicates that the HIV carers experienced less growth from their traumatic experiences than the students.

Table 5.6: Posttraumatic Growth Inventory Means by Gender

Gender	Statistic	Post-traumatic Growth Inventory	PTGI New Possibilities	PTGI Relating to Others	PTGI Personal Strength	PTGI Appreciation of Life	PTGI Spiritual Change
Male	Mean	61.46	14.12	19.95	12.80	9.95	5.02
	Std. Dev.	23.71	6.95	8.28	4.82	4.04	3.39
Female	Mean	64.78	14.86	21.33	12.42	10.70	5.46
	Std. Dev.	24.17	6.65	8.96	5.32	3.32	3.32
Transgender	Mean	31.50	6.50	11.25	6.00	4.50	3.25
	Std. Dev.	38.93	9.95	13.74	7.35	6.14	4.72
Total	Mean	62.31	14.29	20.39	12.47	10.17	5.18
	Std. Dev.	24.64	6.95	8.81	5.18	3.87	3.39

Quantitative Results: Correlations

Pearson correlation coefficients were calculated for all the ordinal level data. Because of the large number of correlations generated, there is a larger probability of finding significant relationships by chance. Therefore, only correlations with a p-value of 0.001 or less were considered significant.

Sociodemographic Variables

Of the correlations among the three sociodemographic variables (age, years since death of the care recipient and the number of friends or family lost to AIDS) to the outcomes variables, there were no relationships with statistical significance.

Individual Characteristics

There were no significant correlations between the subscale of the Constructive Thinking Inventory or between the Internal Control Index and either of the outcome variables, the SRGS and the PTGI.

The Spiritual Involvement and Beliefs Scale was significantly positively correlated with both outcome measures and one of the subscales of the PTGI (see Table 5.7). The association of the SIBS with the SRGS is positive (.305) but of low magnitude. Similarly the correlation between the SIBS and the overall PTGI is a weak positive one (.251). This indicates that the people with the highest levels of spirituality experienced the greatest stress-related growth.

The strongest association (.565) was between SIBS and the PTGI subscale called Spiritual Change: those individuals who were the most spiritual experienced the greatest spiritual change related to the death of the care recipient. However, the strength of this relationship must be interpreted cautiously as the Spiritual Change subscale contains only two items: "I have a stronger religious faith" and "I have a better understanding of spiritual matters".

Table 5.7: Correlations

	SRGS	PTGI New Possibilities	PTGI Relating to Others	PTGI Personal Strength	PTGI Appreciation of Life	PTGI Spiritual Change	PTGI
SIBS	.305**	.166	.162	.166	.200	.565**	.261**
PSR	-.150	-.154	-.263**	-.021	-.136	-.025	-.168
IES Avoidance	.146	.099	.125	.154	.059	.248**	.140
IES Total	.156	.078	.128	.162	.074	.254**	.141

**Correlation is significant at the 0.001 level (two-tailed)

Social Support Measures

There were no significant associations between the Social Support Questionnaire, any of its subscales and the PTGI or the SRGS. There was one significant correlation between the Provision of Social Relations and the outcome variables (see Table 5.7). The fairly weak negative relationship between the PSR total and PTGI Relating to Others indicates that the more social support an individual had, the less growth was experienced in the domain of relations with other people.

Measures of Distress

There was a positive weak association between two of the Impact of Events Scale measures (total distress and avoidance) and the PTGI spiritual subscale (0.254 and 0.248 respectively). These positive relationships indicate that the more distress a person has, the more spiritual growth they experience (see Table 5.7).

There was no significant correlation between the Beck Depression Inventory and either of the outcome variables, the SRGS and the PTGI.

Quantitative Results: Multiple Regression

In order to determine if all the participants could be treated as one group, t-tests and one-way ANOVAs were conducted with pertinent categorical and outcome variables. Some of the interesting results have been commented upon in the descriptive analyses above. The results of the tests are summarized in Table 5.8.

Post-hoc tests on gender indicated that the only significant difference appeared between transgender individuals and the other two genders on both the PTGI and the SRGS. However, the total sample size of 4 was too small to allow for a separate examination of transgender individuals. As a result, they were eliminated from the analysis.

Table 5.8: One-Way ANOVAs with Outcome Variables

	SRGS		PTGI	
	Statistic	Significance	Statistic	Significance
Gender	F (2,173) = 5.005	α = .008**	F (2,173) = 3.698	α = .027*
HIV Status	F (2,173) = .774	α = .463	F (2,172) = .275	α = .760
Language	t (174) = .770	α = .443	t (174) = .745	α = .457
Sexual Orientation	F (3,171) = 1.736	α = .161	F (3,171) = 1.081	α = .359

*Significant at the 0.05 level
**Significant at the 0.01 level

In order to be included in the stepwise regression, HIV status, sexual orientation and level of education were divided into variables with two categories. Those who reported that they were HIV-negative were collapsed into one category with participants whose status was unknown to create the first dichotomous variable with the HIV-positive individuals. In addition, the categories of gay, lesbian and bisexual were folded into one category. Along with the category of heterosexual, this created a second new variable that could be entered into the analysis. Level of education, which originally had four categories, was broken into those who had high school education or less and those who had more than high school.

Multiple Regression to Explain the Variance in the SRGS

The stepwise regression analysis demonstrated that the Spiritual Involvement and Beliefs Scale (Beta = 0.356, $t = 4.778$, $p < 0.001$) was the single best predictor of the dependent variable with 13% (R Square = 0.127) of the variance in SRGS explained. In subsequent steps, the SIBS (Beta = 0.375, $t = 5.198$, $p < 0.001$), the education variable (high school; Beta = -0.195, $t = -2.545$, $p = 0.012$), the Provision of Social Relations Friends subscale (Beta = -0.241, $t = -3.216$, $p = 0.002$) and HIV status (Beta = -0.157, $t = -2.016$, $p = 0.046$) combined to produce the best fitting model which explained 23% (R Square = 0.226) of the variance in the SRGS.

Multiple Regression to Explain the Variance in the PTGI

For the PTGI, the stepwise regression demonstrated that the Spiritual Involvement and Beliefs Scale (Beta = 0.263, $t = 3.419$, $p = 0.001$) was the single best predictor of the Posttraumatic Growth Inventory, with 7% (R Square = 0.069) of the variance in the dependent variable explained. The results further revealed that the SIBS (Beta = 0.250, $t = 3.352$, $p = 0.001$), the Beck Depression Inventory (Beta = -0.231, $t = -3.088$, $p = 0.002$), level of education (Beta = -0.220, $t = -2.869$, $p = 0.005$), PSR Friends (Beta = -0.289, t = -3.035, p = 0.003), and the SSQ Subjective Social Integration subscale (Beta = -0.190, t = -2.051, p = 0.042) combined to produce the best fitting model which explained 18% (R Square = 0.178) of the variance in PTGI.

Quantitative Results: Structural Equation Model

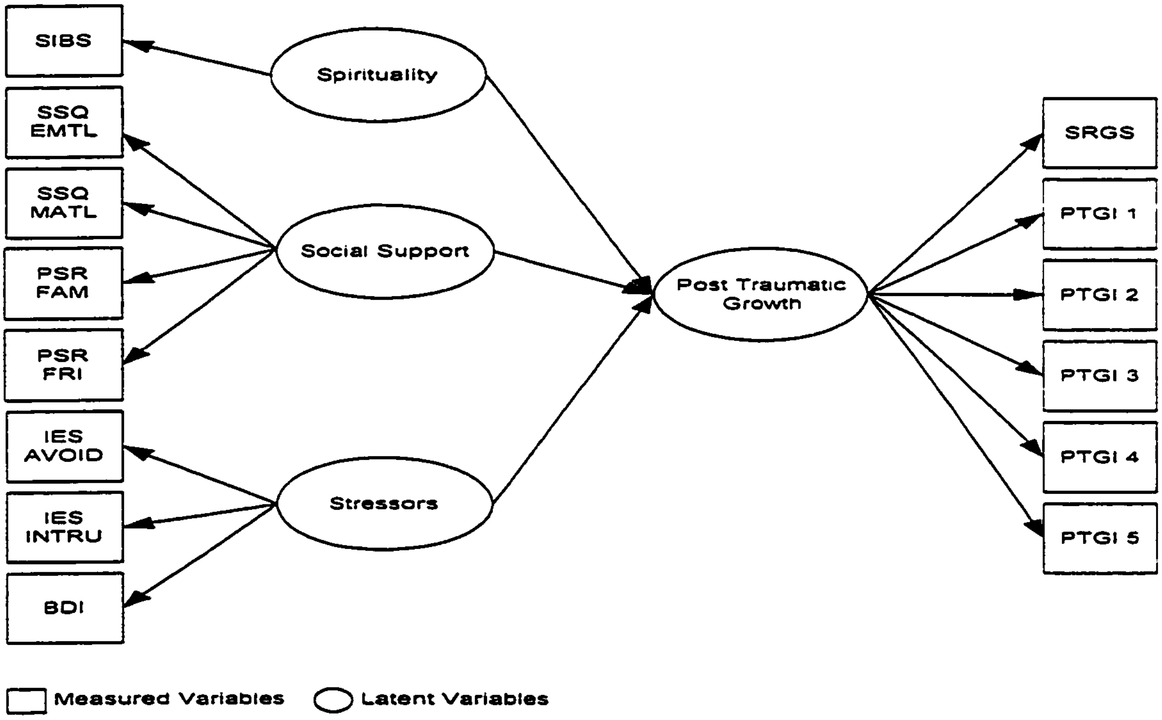
A structural equation model was created in order to test the following hypotheses:

1. Caregivers with high degrees of creativity will demonstrate more post-traumatic growth.
2. Caregivers who are more spiritual will demonstrate more post-traumatic growth.
3. Caregivers with more social support will demonstrate more post-traumatic growth.
4. Caregivers who demonstrate fewer signs of stress will have more post-traumatic growth.

Because two individuals did not complete their questionnaires, only 174 participants' data could be used in the structure equation analysis. LISREL 8.3 (Joreskog & Sorbom, 1996) was used to test the model. Pearson product moment variance-covariance and their associated asymptotic covariance matrices were analyzed using the maximum likelihood estimation procedure.

The first step in the analysis was to perform a Confirmatory Factor Analysis on each portion of the models that was identified, to confirm that the measurement variables loaded on the latent variables as modelled. Two of the possible subscales of the Social Support Questionnaire were selected for inclusion; Emotional and Material Support contained the most items and were deemed the most pertinent. The latent variables of stressors, social support

Figure 5.1: Revised Model



SIBS	Spiritual Involvement and Beliefs Scale
SSQ EMTL	Social Support Questionnaire Emotional Support
SSQ MATL	Social Support Questionnaire Material Support
PSR FAM	Provision of Social Relations Family
PSR FRI	Provision of Social Relations Friends
IES AVOID	Impact of Events Scale Avoidance
IES INTRU	Impact of Events Scale Intrusion
BDI	Beck Depression Inventory
SRGS	Stress-Related Growth Scale
	Posttraumatic Growth Inventory
PTGI 1	New Possibilities
PTGI 2	Relating to Others
PTGI 3	Personal Strength
PTGI 4	Appreciation of Life
PTGI 5	Spiritual Change

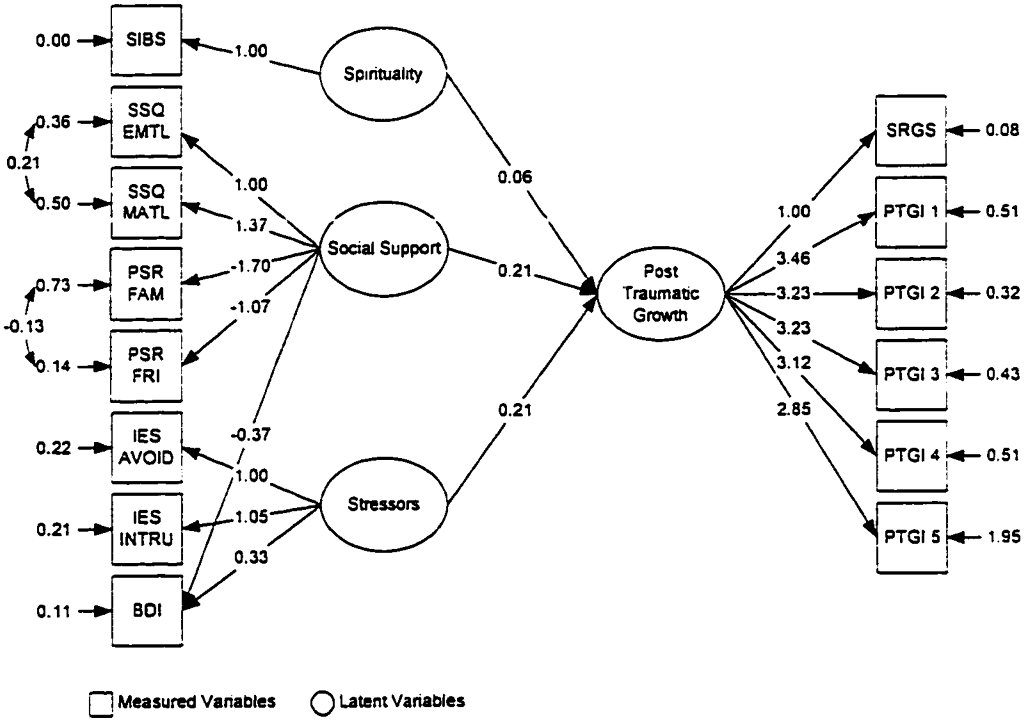
and post-traumatic growth were confirmed with p-values of the Satorra-Bentler Scaled Chi-Square greater than 0.05. This indicates that the data fit the proposed model. However, the latent variable of spirituality could not be identified separately as there was only one measurement variable.

The portion of the model with the latent variable of creativity using the subscale of the Constructive Thinking Inventory and the Internal Control Index as measurement variables was not confirmed. The p-value of the Satorra-Bentler Scaled Chi-Square was 0.007, which indicates that the data did not fit the proposed model. As a result, the latent variable of creativity was eliminated from further analysis. Consequently the first hypothesis concerning creativity cannot be tested.

The revised model for testing is shown in Figure 5.1. This model has only three latent constructs on the left, the exogenous variables, with the elimination of creativity. During the analysis, one modification was made in order to produce the final model shown in Figure 5.2. The modification is outlined below in the section on social support.

The overall fit of the model was satisfactory but not excellent (see Table 5.9). The Satorra-Bentler Scaled Chi-Square goodness-of-fit test was significant at a p-value of 0.00. This indicates that there was a discrepancy between the model and the data. However the argument has been made that testing a perfect fit is not appropriate for social sciences because of the complexity of the causal relationships; rather it would be better to assess the fit of the model to the data (Goffin & MacLennan, 1997). Steiger (1989,

Figure 5.2: Final Model for Structural Equation Modelling



SIBS	Spiritual Involvement and Beliefs Scale	SRGS	Stress-Related Growth Scale
SSQ EMTL	Social Support Questionnaire Emotional Support		Posttraumatic Growth Inventory
SSQ MATL	Social Support Questionnaire Material Support	PTGI 1	New Possibilities
PSR FAM	Provision of Social Relations Family	PTGI 2	Relating to Others
PSR FRI	Provision of Social Relations Friends	PTGI 3	Personal Strength
IES AVOID	Impact of Events Scale Avoidance	PTGI 4	Appreciation of Life
IES INTRU	Impact of Events Scale Intrusion	PTGI 5	Spiritual Change
BDI	Beck Depression Inventory		

Table 5.9: Fit Statistics for Structural Equation Model

χ^2	df	p	RMSEA	CFI	GFI	AGFI	NFI
144.86	69	0.000	0.080	0.91	0.88	0.82	0.86

1990) developed the Root Mean Square Error of Approximation (RMSEA) and proposed that values below 0.05 indicate an excellent fit and that values less than 0.10 indicate a reasonable fit. Thus this model's value of 0.08

indicates that the model fits reasonably well. Similarly the Goodness of Fit Index (GFI) is pleasing at 0.88 as it approximates the recommended 0.90. The model in its simple form fits the data satisfactorily. The fit indices might be improved upon by adding paths that would complicate the model and not necessarily be supported by theory.

Spirituality

As there was only one measurement variable for spirituality, the loading of the Spiritual Involvement and Beliefs Scale on the latent construct had to be set to one ($\lambda_{x1\text{-}1} = 1$). It was hypothesized that post-traumatic growth would increase as spirituality grew. Spirituality had a significant direct positive effect on Post-Traumatic Growth ($\gamma_{1\text{-}1} = 0.06$, $t = 1.90$, $p < 0.05$). Therefore there is support for the hypothesis: individuals who are more spiritual as measured by the SIBS experience more post-traumatic growth.

Social Support

In order to set the metric for the latent variable of social support, the loading of the first measurement variable, SSQ Emotional, was set to one ($\lambda_{x2\text{-}2} = 1$). The loadings of SSQ Material ($\lambda_{x3\text{-}2} = 1.37$, $t = 9.29$, $p < 0.05$), PSR Family ($\lambda_{x4\text{-}2} = -1.70$, $t = -4.54$, $p < 0.05$) and PSR Friends ($\lambda_{x5\text{-}2} = -1.07$, $t = -5.19$, $p < 0.05$) were all large and significant. In addition, a modification was made to load the measure of depression on the latent variable of social support. The relationship is significant ($\lambda_{x10-2} = -0.37$, $t = -3.35$, $p < 0.05$) and supported in the literature (Cohen & Wills, 1985; Holahan & Holahan, 1987; Van Hook, 1999). Social support had a significant positive direct effect on post-traumatic growth ($\gamma_{2-1} = 0.21$, $t = 3.17$, $p < 0.05$), giving support to the third hypothesis. This indicates that the more social support a person had, the more growth was experienced in the aftermath of trauma.

Stress

Similar to social support, the metric was set by fixing the loading of the first measurement variable, IES Intrusion, on the latent variable of stress as one ($\lambda_{x6-3} = 1$). The loadings of IES Avoidance ($\lambda_{x9-3} = 1.05$, $t = 6.97$, $p < 0.05$) and Beck Depression Inventory ($\lambda_{x10-3} = 0.33$, $t = 3.85$, $p < 0.05$) were both significant. Contrary to what was hypothesized, stress had a significant positive direct effect on post-traumatic growth. Thus, the more stress experienced by an individual, the more growth they evidenced.

Post-hoc Tests

Two post-hoc additions to the original model were explored. Gender was introduced as an additional latent variable. In order to do this, transgender individuals had to be eliminated from the analysis as the variable had to have only two categories. The sample size was then decreased to 170. However it was established that the addition of gender did not improve the fit of the model. In addition, the possibility of including the number of people who had died in the stressors variable was explored. However the loading estimate on stress was not significant ($p > 0.05$) and the error estimate was huge (481.85). It was decided not to introduce this measurement variable into the model.

CHAPTER SIX

Interview Results

Participants

Based on the first 100 questionnaires entered, one-way ANOVAs demonstrated a significant difference by gender on the two outcome measures, SRGS ($F[2,97] = 4.820$, $p = 0.010$) and PTGI ($F[2,97] = 3.020$, $p = 0.053$). Post-hoc tests indicated that significant differences occurred among all three genders. Accordingly, it was decided to interview two individuals of each of the three genders: one with high post-traumatic growth scores and one with low. Seven people were interviewed, as a third transgender individual was included. Those individuals and their bereavement and caregiving are described below. All identifying information has been removed.

High Growth Individuals

B is a 52 year old white female. She identified herself as HIV-negative and heterosexual. B is a college graduate and is employed full-time; she was just leaving an AIDS service organization for a related agency at the time of the interview. In part because of her job, B knows more than 100 people who have died of AIDS-related causes. Her brother died 11 years ago.

G is 64 years old and is Caucasian of Anglo Saxon Protestant descent. He is a gay man, a university graduate and works part-time in entertainment. He has participated in care teams as a volunteer and has known 53 individuals who have died. G is HIV-negative.

C is a white transgender individual who identified herself as French-Canadian. She has a less than grade 12/13 education, is no longer employed because of being HIV-positive and is a dedicated daily volunteer at an AIDS service organization. She identifies herself as gay. Five years ago she lost a friend to AIDS; she knows more than 20 people who have died.

Low Growth Individuals

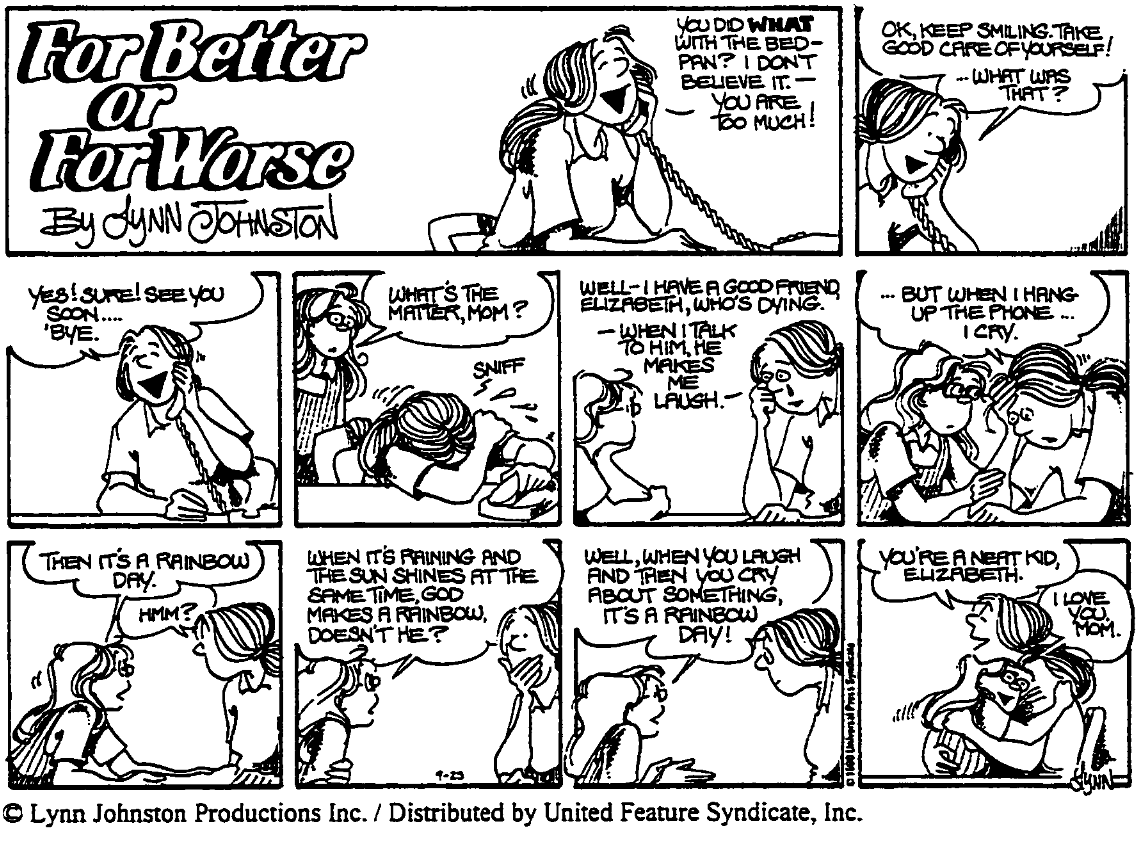
S is white, 44 years old and HIV-positive. She identifies herself as transsexual and heterosexual. Six years before the interview, her partner died of AIDS-related complications. S is a university graduate; she is not employed. She has lost 25 friends or family members to AIDS.

D is a white 26-year old woman who had been employed full-time in an AIDS service organization until a few months before the interview. She is currently employed in a different sector. She identifies herself as bisexual and HIV-negative. D has lost more than 20 friends to HIV disease; her friend for whom she cared a great deal died 4 years before. She recently completed her high school certificate.

At the age of 35, A is not employed as he is HIV-positive. He had worked previously as a bureaucrat and has a university degree in social work. A is Metis; he identifies himself as transgender and gay. He started caregiving when his foster daughter died of AIDS many years previously; his best friend died one year before the interview. He has lost a total of 70 friends and family members and continues to volunteer his time at the hospital for those who are ill now.

M is a 31 year old white gay man who is HIV-positive. He identified himself as a Canadian atheist. His partner died 4 years ago; M has lost 6 friends to AIDS. He is not employed and is a high school graduate.

Figure 6.1: Cartoon



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Interviews

All of the individuals interviewed were undergoing or had experienced a process of finding meaning in their bereavement and/or in HIV disease in general. The cartoon pictured above is a touching illustration of the meaning process. The mother's tears are evocative of the pain experienced by the HIV carers. Her laughter is echoed by the interviewees' use of humour. The support that Elizabeth offers her mother, Elly, is paralleled by the support that all the interview participants received from many sources. The spirituality expressed in Elizabeth's metaphor of the rainbow is a central and essential theme of the interviews. As is the case in this comic, support and spirituality are intertwined for some individuals. The metaphor that Elizabeth offers her mother makes the connection for Elly between her joy and her pain. It is through the spiritual connections that meaning is generated and benefits are understood and growth is realized.

The Tears

The seven people interviewed had all experienced the death of at least one person about whom they cared. For some this was a partner, for others it was a friend. Like the grief that Elly expresses in the comic strip, all of the interviewees experienced stress. A talked with great emotion about the day his foster daughter died:

> ...on my lunch hours I would use an hour of my vacation time and my hour for lunch and I would go up to the hospital. I was there, like I was up there 7 days a week and after work you know I'd go up and stay until 11, 12 o'clock at night... I just got back to work and they called me that I'd better get back up there and I said, could it not wait a few more hours? And they said no. So I went to my boss and got the rest of the time off, my family needs me. And I went up to the hospital and she wanted me. ... I got up there at 3:30 and I was laying beside her and I was just telling her how beautiful she is and not to be afraid that umm... there's a better place, that she's going to a better place and then it was about quarter to five she died in my arms. And I just continued holding her for about an hour after and er... I didn't know what to do because I went into a state of shock. I wouldn't accept that she was gone because I had taken care of her for 2 ½ years before she left me and like we were so close.

S's partner, J, suffered from dementia. Although she had become familiar with the effects of dementia earlier through her AIDS work, she found it difficult to accept in the person she loved. After J had convulsions at home they went to hospital by ambulance:

> ...we were in emerg for about six hours. When the doctor came out, J was starting to hallucinate. That people were trying to kill him and whenever I left his room, he was like, they'll kill me. ... But I felt uncomfortable because he was rude to the nurses, rude to the doctors, he didn't want to take the meds.

In addition to his behaviour, J's dementia reduced his ability to respond to any question that was not posed in a concrete manner. This caused pain to S:

> I said J do you love me? He went I don't know. I went oh. And then I walked away because it was emotional. And then I walked away and I was talking to one of the nurses and she's the one that said he doesn't know about that, he doesn't about love. And she helped me because you would say to him what do you want and he'd say I don't know. You couldn't give him

> a multiple choice, you could give him one or two but any more than that and he would say I don't know. And it took me a while to get over that. I realized very quickly that it wasn't him talking to me, it was the disease.

For those who work in AIDS service organizations, the stresses are both personal and professional. D talks about the impact on her of working with HIV, both the large issues:

> Even if you don't want to, you know, it's the fact that you notice the presence and the fact that you sit there and you think you know somebody that I know was here yesterday and they're not today and you go through a lot of feeling, you know.

and the small details:

> ...doing this kind of work, being with people that are positive and losing them and being close with them or not close with them or what have you, for me, and I cannot speak for the world, it affected every single facet of every little thing that I did. Right down to little things like not making sure I bought pasteurized honey. Pasteurized honey ... because you know what if I had somebody over that was HIV-positive - couldn't give them tea with honey.

C talks about the difficulty of dealing with the uncertainty:

> It's been hard. Especially at the office. We have a client now who is very, very ill and the person has cancer as well as AIDS and Hep C. It's like a triple one. And I don't even know when I go back to the office tomorrow if she's still going to be alive still.

B talks about the multiple deaths involved with working with people with AIDS:

> ...there's never enough time to move through the grieving process of one person before another person dies. Now it's ... certainly not to the extent now as it was a couple of years ago because of the new therapies but... Whereas before it was somebody died and moving into the practical aspect of funerals and supporting the family or the loved ones and the family maybe the loved ones as well, through the process and supporting the staff through the process and then somebody else died and so it was... there was never time to stop and allow myself to feel. To fully experience what that means to me.

B addresses the issue of the expression of grief. She notes that she is no longer afraid of expressing her grief but that there was a time when she thought that if she started crying she would never stop. Now, however, B has learned that many things are triggers:

> ...that bring memories and if it brings tears I have no embarrassment about that and if I'm in the middle of a supermarket and it starts to happen, I just let it happen. If people have a problem with it it's their problem because you know I have a right to all the tears I ever cried like this.

Overall G describes himself as a "happy puppy". He has made a conscious effort to seek support for and work through the grief and stress that he has experienced with his caregiving activities. However, toward the end of the interview, he stated:

> You know I've just... you've helped me realize something too: that I do have stuff that I have to get out. I've been so close to tears about 3 or 4 times and it's obviously there.

G has a strong belief that no one need die alone. He discusses his huge regret about one person with AIDS who was cared for by G and other members of a care team:

> … I spent the day with him and got ready... got him ready for bed and I just had a strange feeling and he said "I want you to go home". And I said, "I want to stay". "Well," he said, "it's not what you want, it's what I want". And it was said lovingly and I came and found him on the floor dead in the morning and I just thought why did I have that gut response and why didn't I stay?

M also expressed enormous regret. He assisted his partner B in dying. M has never felt closure around the death of his partner because a few months after B died new treatments were introduced. The new treatments have made the management of HIV disease more like a chronic disease than a fatal one and have prompted M to wonder what would have happened if he and B had waited. With great emotion throughout the interview, M describes his feelings:

> I was actually really confident the night he died that we'd said you know everything that had to be said to each other. We... we took the time specifically. But … periodic and sporadic times that I just think, holy what did I... how could I have missed you know saying that to him or... it's particularly bothersome it was in February of 1996, I think it was about 3 months after that, that... 3 or 4 months after that that they were starting making a lot of noise about... sort of the medical community and the news media started making a whole bunch of noise about this... I heard it on TV it was an AIDS cure, a generic cocktail that everyone talks about starting coming into the providence then and er... I think that's what keeps closure from happening; it's if we'd just waited. You know he'd been sick for 13 years... it really troubles me I guess….

> I have a friend whose situation mimicked our situation, B's and mine, in that M was healthy as I was and M's boyfriend, R, was spindly and shrinking and dying. ...R didn't take an active role in dying, he waited and now he's... he's thriving again, he's gained weight back and there is a deep resentment.

<u>The Laughter</u>

Many of the people interviewed used or spoke of humour. In the comic, Elly laughs on the phone with her dying friend telling a funny story about a bedpan. Even as she was recounting her partner's last hours, S laughed at a fond memory of holding a cigarette for J to smoke because it kept falling out of his mouth. M considers that he will be able to laugh when he is no longer depressed: humour symbolizes the end of grief and closure around B's death. G recounted how a transsexual individual that he cared for left his penis to G. Although this appalled some friends, G considers it the "ultimate compliment" and remarked: "...not a bad epitaph if you got to have one".

C laughed a lot during the interview. She talked about the relationship that she has with her mother:

> Yeah I would say we have a strange and wonderful relationship. She's strange and I'm wonderful.

She also used humour in a potentially threatening situation where two men on the street had been rude to her and then were making comments aloud wondering if she was a man or a woman. C was quite pleased with her reply:

> "I'm more of a woman than you could ever handle." And I said: "I'm more of a man than you could ever be".

Humour can restore dignity and provide support. Glen, a person that G was involved with was leaving hospital to die at home and was being transported by ambulance. The ambulance attendants knew Glen from previous trips and were joking with him when the doctor came over. G recounts that the physician:

> ...was very tight. And I said to myself in my head, I hope he's going to say: "Call me if you need me. I hope you have good journey. Are you all right?" But that wasn't going to happen. So being a talker I said, and I pulled a piece of paper out of my briefcase and I said, could you give us something that we could share with his family about what's going on and everything? And he started writing down all these Latin names and stuff and everything. He said: "First of all it's a virus". I said: "They know that doctor. But something else. What's challenging him at the moment?" So he finished writing this out and he handed it to me and said: "I suppose you'll tell me that his family have a degree in microbiology". And there was a pause and Glen said from the gurney: "You know, I'm not sure but I think my mother's degree is microbiology". And the ambulance driver said: "Doctor zero, Glen 10.

B considers humour a coping mechanism, especially working in an AIDS service organization:

> ...how do we get through it? It's having a black sense of humour. A macabre disgusting sense of humour. Somebody dying. For instance we have a student placement here, a social work student placement and... she had about 6 or 7 clients and 3 of them died like one right after the other and we were saying... we called her the Queen of Darkness. "Go to the Light, go to the Light. We're going to get you a flashlight and anyone we don't like we're going to give you the light and say go to the Light", you know. And with no guilt. With no guilt.

However, G cautions that humour must be used carefully:

> Tremendous sense of humour. I think that's a resource too. You know people say, what do you mean you go and you're part of a team and you make jokes. I said, no you don't but you try to look on the bright side of stuff. There's always, no matter how bad things are, there's a bright side and when it's really awful you shut up. There's nothing to be said. It's not appropriate to say, oh well it will be better tomorrow. It's not going to be better tomorrow. So you just simply shut your trap.

Support

Elizabeth's concern for her mother when she is crying is an expression of support. A child may be an unexpected source of social support. Nonetheless, Elly and Elizabeth share a hug at the end of the comic strip. Support is expressed from many sources in the interviews with the HIV carers. G shares an extraordinary story about hugs from an unexpected source:

> ...two of us were with C when he died and we waited the half-hour and we dialed 911 and the firemen came and the paramedics and everything and they sat me down, the police, and going through his medication and had I given him anything and they have my permission but it still emotionally churns you why are you doing this? ... We're in the middle of all of this; there are 30-some firemen, paramedics and police there when the Coroner of Ontario arrived... And she turned and she said: "Attention, attention! I don't think it takes a degree in medicine to see that this poor man has expired and that he probably expired of AIDS and I think that you've all probably been bullying these two guys and I think they're caregivers. Fine, come on, I'll take care of this, it's in my hands now. Thank you all very much. And as you leave I want you to hug

> these two people." … And then she raised her voice and said: "You know who I am: the Coroner of Ontario. You know what power my office has. You WILL hug these two men as you leave!"

Family provided a great deal of support for some of the HIV carers interviewed. B's family support was enormously appreciated by her: her mother, her daughter as well as her partner who had served in the war in Vietnam and:

> …was one of the very few of his regiment that went out that survived it and he did two terms or whatever they call it. And so he has tremendous understanding of multiple loss so has been a remarkable, remarkable support to me.

G credits his mother's example with teaching him to care for others as she was always taking people in and giving to others:

> I'd come home from school and there'd be this fabulous smell of a blueberry pie and I'd know it wasn't for us. Mother was taking it to somebody.

D is closer to her mother than anyone else:

> Well you know she's kind of the only person that's been there through no matter what crap I've put her through. Through the drugs and the drinking and the long black hair and the short black skirts and the leather jacket and the staying out all night and the not calling her and letting her know anything and you know. The pregnancy scares and the, you know, not using condoms when I should be and doing this and that and who's always been there? My mom, who I can still call at three o'clock in the morning even though she needs her sleep and I can phone her crying my eyes out and she would still be there for me because God knows I've done it enough times.

S's own family has not been supportive of her although she has been re-establishing contact with them lately after being estranged for many years. However, her partner's mother has been very supportive of her. J's mother "was like totally amazed by me and the way I would help her son". J's mother and S have remained in touch since J died. This relationship is highly valued by S even though J's mother lives far away.

A was raised in a foster family after being sexually and physically abused as a child. Although he and his sister were placed in different foster homes, they have remained close and she continues to be a support to A. The foster family in which A was raised provided both material and emotional support:

> Well before I started all this you know having an abusive childhood and never felt loved by neither one of my parents growing up as a kid and I thought I was going to be you know the big criminal and you know a high school drop-out and umm… And then as I started growing older and got into a foster home basically I was lucky because I got taken away when I was 6 ½ and I stayed in one foster home right through to umm.. and they even paid for me to go to university to get my Bachelor of Social Work… I guess when I was about 11 that I started to feel that I am a loving person you know. It took me 5 years to tell my foster parents that I loved them. Because I never wanted to hear that word. … And I asked them, my foster parents I said: "How come you don't, how come you don't beat me? How come you're not sexually molesting me, you know? …this is just a dream."

All of the interviewees had the support of friends. Unfortunately, many had lost numerous friends to AIDS and so their circles of support were reduced. A stated that he does not consider himself to have a large circle of friends and, although the relationships that he has are strong, he would like to have more. At the time that J was admitted, his partner S had a very good friend dying in the same hospital.

S credits a friend of hers with getting her into a group home when she was wasting away because she was no longer eating after J died. She says:

> I have many friends who, you know, all I've got to do is pick up the phone and say "I need you" and they're here.

After B died, friends of M's took him to Paris, France for a holiday. M states that his group of friends has been reduced because of his depression but that the ones that remain are very close. C characterizes the friends who are most helpful:

> People that listen. You know, people that are there for you, you are there for them.

Those who work in AIDS service organizations also turn to colleagues for support. C works through her feelings of loss by talking with the people in her office. G maintains a close bond with other members of the various care teams on which he has worked. These people are not constantly in touch but when they see each other there is "such a joy" because they have shared so intimately. B and the other staff in her organization worked as a team; for her it was "just fine for me to seek support from any of them at any point". D found that many of her friends did not understand her devotion to her volunteer and paid work with HIV, so she depended more on her coworkers:

> You only play with each other and I think it's because nobody else gets it and because you can't talk about what goes on with

> anybody else because everything is confidential so the only people you can talk about it with are the people you work with.

Support was also sought from professionals. Many of the people interviewed had been hospitalized on psychiatric wards at one time. A was hospitalized for five weeks after his foster daughter died. M was admitted to the psychiatric ward after several suicide attempts. G was admitted to hospital briefly after an incident where he had a knife but did not know what he was going to do with it.

Not all professional relationships were helpful: M had a psychiatrist who would doze off during sessions. M did, however, have some successes. He participated in a caregiver group at an AIDS service organization as well as an outpatient psychiatric group. He also credits another professional:

> Throughout this whole thing what was helpful was to have the same psychiatric nurse, Rita. She kind of kept me grounded.

B has received enormous support from the counsellors who work at the Grief and Bereavement Project of Ontario. She has also had individual counselling. G established a supportive connection with a coordinator at an AIDS service organization. Later he went for individual counselling. S has received crucial support from the personnel in the group home where she used to live and the residences in which she has an apartment now:

> I had to move into a group home and I lived there from April until almost two years. ... in that time I was able to get proper care, proper food and all that. And in November last year I was able to feed myself again and then the supervisor told me a group home isn't what you need anymore. So that way, they

> gave me this apartment. And it's my own apartment but there are staff that work here 24 hours a day. You call and say I need this or that and they come.

Spirituality

Overall, there was a strong sense of spirituality in the group of people interviewed. Many of the participants interviewed addressed issues of spirituality spontaneously. A identified that his caregiving has helped him connect with his Native culture:

> ...just with all the work and stuff that I'm doing and all the caregiving and stuff just knowing that I can feel better about myself and I can talk about it like when we go in sweat lodges and you know, we have native ceremonies, we burn sweet grass and... Yeah so it's brought me closer to my culture.

Without being asked, B identified that she is not religious but said:

> I think the work we do is very spiritual. It is, yeah... It's work of the soul. There is all kinds of administration and paper work... But what we're really doing is walking beside somebody on a journey that is umm... the last journey of their lives, which may take 5 years or 10 years or it may take a month you know?

Furthermore, B believes that the people who have died will repay her for her care by taking care of one another:

> My angels are different than other people's angels. My angels are all the people that have died of AIDS that I've loved. They're my angels. But they're not perfect by any stretch of the imagination but... I mean they're dead but they're human

> beings. The essence of everything they were when they were alive.

S identified that she feels that her partner is not very far away and talks about how she continues that connection with him:

> I went over and I held his picture and I went, "I'm not feeling very good". So what it is doing is having a conversation with him.

D talks about a rune she wears for strength that was given to her by a friend when D first started working for an AIDS organization. She also has a spell bottle that was given to her by a Wiccan friend. D uses it to prepare herself for difficult tasks the following day. D stated that she doesn't believe in God because relatives told her that "God needed your father more than you did" when her father died when she was twelve. Accordingly, D hesitates to label herself with any religion:

> I guess it all depends on what you define spirituality as… you should give back things that you take and I believe that you should take care of the people around you. I mean I'm sure that a lot of what I believe comes from this religion and that religion.

C did not wish to discuss spirituality as she found it too personal. She did however, identify that she believes that "there's something somewhere" and that this conviction has been a constant in her life before and throughout her process of change and growth with HIV disease.

M, who is an atheist, could make no distinction between religion and spirituality. Consequently, he could identify no spiritual connections for himself. Canda (1989, p.573) defines spirituality as "the basic human drive for meaning, purpose, and moral relatedness among people, with the universe, and with the ground of our being". In this sense, M' s search for purpose since his partner died is very spiritual:

> Well, when B was alive and dependent on me... there wasn't much that I didn't do to help out. I'm HIV-positive also so I'd taken time off work to spend more time coping with him and so when he died there was a huge, huge, huge void in my life. More than just that he was my partner but also that he was... I once said to him, he's a Franc... was a Francophone and I said to him in French: "Tu es ma raison d'être". You're my reason for being. And he got very upset and said, nobody should ever say that about any one else. And he's right because in terms of how things have changed since he died. I er... still miss him a lot and in some ways it's difficult to talk about because it's embarrassing to still be choked up 4 years later.

Spirituality was also expressed in the creation of rituals and memorials. A describes one way he likes to take care of himself and honour his dead friends:

> I travel all around the world to places that my friends would want to go. The ones that I've cared for. And I bring a picture of them and I let it float in the water: I let it go, you're here now...

B discussed the importance for her of making her office a positive space for herself. One of the aspects of the office that is important to her is the pictures on her wall of many of her friends and clients who have died. It is one way that she memorializes them:

> The pictures on the wall of dead people. People call it my dead people wall you know. But... not forgetting, remembering. Yeah. The remembering piece. I had a horrible time when it got so that there were names I couldn't remember. They weren't on the tip on my tongue. And it felt really bad. And now I can just remember the faces and if I can't remember the names immediately that's okay.

Because the people who participated were included by virtue of being bereaved carers, many were grappling with existential issues. Several discussed the importance to individuals of not being alone when they die. G's value of not leaving people alone at the time of death includes himself:

> I don't want to be alone. And I trust I'm not going to be when I'm 175 and pass away.

Several interviewees spontaneously talked about the changes in their feelings about death. B offered the fact that she was no longer afraid of death as part of the process of transformation that she has gone through. D, whose father died when she was young, is still terrified of dying and of being present when someone else is dying. However she has become more comfortable expressing herself about her fears and her losses. A spoke about being HIV-positive himself:

> Now I have no fear of death myself because I've seen so much of it. It's made me a stronger person...

Where Support and Spirituality Intertwine

Similar to the metaphor that Elizabeth offers her mothering the comic strip, spirituality and support overlapped for many of the HIV carers interviewed. A's spiritual connection allowed him the strength to forgive his parents for the abuse that he experienced, thereby creating anew a source of support for himself. He talked about his process of getting in touch after 11 years of no contact:

> ...I don't know, I just started saying prayers and I was going to the Centre of Positive Living which is... It's not a church basically you only hear the word God once I think once out of the whole hour that you're there. It just makes you feel better about yourself. And I thought, well, life is too short you know so last year I decided to make full truce with both my mom and dad. For Mother's Day I got my mother a beautiful mother's day card and inside it says you know I do love you for bringing [me] into this world and I says I am going to continue loving you; I forgive you. So I forgave both my parents for all the abuse and sexual abuse and umm... That made me even stronger too you know. I just had my birth mother out here. I flew her out 4 weeks ago, flew her out for a week. She has no money and I paid for it and we had... we had a wonderful time, wonderful time out here.

Many of the carers derived significance from the care that they were able to provide to the person who died of AIDS. This search for meaning is essentially a spiritual journey and certainly provides a source of support for those who experience it. B derived much significance out of her role as supporter, which in turn was a source of strength for her:

> I thought if I hadn't had all these connections to people who have died and abandoned me I wouldn't be who I am. And I believe that; I'm not religious but I believe and I'm absolutely convinced that this is something that I was meant to do. The

> work I've done for the last 15 years I was meant to do. I'm absolutely convinced of that and that the... and I had that feeling when, they asked me to apply for the job and I applied for it and I got it, I knew that it was absolutely the right thing to do and this is the way I feel, about where I'm going now. I think the work we do is very spiritual.

D also gained satisfaction from her role in an AIDS service organization:

> More than making an impact, I hope I helped somebody. Because that's what I really wanted to do is I wanted to make a difference for somebody. ... It means a lot to me I guess. I... I try and let the people that I care about know how much they mean to me...

A, an unpaid caregiver, also derived satisfaction from his role of carer in relation to his friend who lived upstairs and died one year before the interview:

> I got to the point that I was like I was even changing her diapers and that didn't bother me because you know inside I felt good knowing that I could do it. And I'd turn her over on her side and just keep rotating her so that she wouldn't get bedsores and put her in the wheelchair and take her for walks and sit and talk and...

S gained an increased sense of significance and strength from her ability to care for J:

> I am very proud that I was able to give him that kind of care. I may not have been able to do the nursing care but I was his primary caregiver. Right? And um, to go through that every day it really makes, you've got to be strong, you walk in there and don't know what you're going to get that day.

After B had died, M got a dog. Not only was the dog a source of support and affection for M, it also reinforced his ability to care for something. M observed:

> I can look at her sometimes and say, you know I've got a really healthy dog and I look after her well and I know that, so actually this just occurred to me that it is kind of funny the transfer that I was talking about of what a good caregiver I was for B and making the same comparison.

G even had a sense of his connections to those he has taken care of providing tangible support:

> ...we didn't get into this and I'm not sure I understand it but I've sometimes thought that my boys and girls are looking after me. As cornball as that is, I sometimes think that maybe they're looking after me right now. I did a whole 5 years of [a theatre production] without missing a performance. I was sick sometimes but you did it. And sometimes... and maybe it's not real but maybe I just need to know that. That somebody is looking after me.

G related another story of caring for someone through the night and then going to bet on the horse races even though he was exhausted. The person with AIDS had been a member of an equestrian team:

> I threw down $6, left the track, got a call from [an acquaintance] saying: "Do you realize you've won $1,400?" And nobody should make too much out of anything. There was also a message that [the person G had been caring for] had died. And I thought, equestrian team? I didn't make a huge thing out of it but my soul did. My soul did. My soul made a huge thing out of it.

Post-Traumatic Growth

All individuals interviewed had been changed by their experience of caring for someone who had died of AIDS. With the exception of M, all the reported changes were positive even in those who had low scores on the outcome measures. M entered into a depression after his partner died and is still struggling four years later:

> I used to be real vibrant and excited about life and very active.
> Now I've just become a... a recluse.

S had low scores on both outcome measures. She addresses the question of whether caring for her partner changed her:

> And what I got from J is I really like who I am.

A also had low scores on the PTGI and the SRGS. He talks about finding his best friend dead in his apartment when he went to turn him over in bed:

> ...and that made me stronger too. I find that as people pass on I'm a stronger person. Like even though I mourn but I mourn in a different way, not a whole lot in tears but I... I guess I mourn in trying to help another person you know. I guess I'm an ongoing caregiver.

For some, the benefits have come from the impact of HIV disease; AIDS cannot be separated from caring about those who are infected. B, who had high growth scores, talks about working in the AIDS movement:

> So yeah, I've learned a huge amount about how I should live life. I hate the word should but what the hell. About my capacity for pain and joy and er... sadness and grief and tenderness and love. Learning that I have tremendous depths and also learning how to live with sadness and joy and loss and all those things. So it makes, yeah it's... either I transformed or I would burn out. And so I chose to transform.

Notwithstanding her low scores on the growth measures, D, who also worked in an AIDS service organization, talks about the process of change she experienced when she started working in the field:

> It was quite funny I suppose just sort of to watch yourself grow, I guess which is such a cheesy way of saying it, but that's exactly what happened. I mean I started out being, you know, this person that was in it for one reason and one reason only and that was because I needed these volunteer hours and then it became this absolutely completely encompassing part of my life and anything and everything that I did had to do with it. And it was this crusade and I was going to save the world.

C had high scores on the measure of post-traumatic growth. She considers that the growth that has occurred is in part due to her seropositivity:

> It's going to sound crazy I guess but I think [being positive and having friends die has] enriched my life. I think I've lived with the disease for so long now that if they came tomorrow and said I didn't have this disease I was cured that you know, I think I'd be more devastated than when I got it.

For G, his experience of caring for friends has been intertwined with volunteering on care teams:

> And I think it's made me a better person, a brighter person, a more... learning to let things go.

In an eerie reference to the comic and to post-traumatic growth, of which she had no prior knowledge, B said:

> So I owe AIDS nothing. I owe AIDS nothing, but I sure owe a lot to the people who have contributed in very remarkable ways to my happiness. Not my sadness, my happiness. The sun always comes out after it rains. There's a thing I have, it was framed for me by a client, oh 7 or 8 years ago, that he got out of a book and it says: "Happiness too is inevitable". And I thought that's interesting and I wrote the name and it was Camus who wrote about the Black Plague. It was a quote.

B was very wise about HIV and the subsequent impact on her life. B would not hesitate to point out that the changes in her life were due to the people who had AIDS and not the disease itself. In light of her wisdom, it is fitting to use B's words in summary as she makes sense of grief and bereavement and the process of recovery:

> And they weren't lost, they died. I don't do the 'passed on', 'lost', you know. We know where to find them. Which grave or where they're scattered. I did that for years. And it isn't AIDS. AIDS is the catalyst. The courage of people doesn't come from AIDS, it comes from the individuals themselves and I think that's something to be celebrated. And wouldn't it be a sad commentary on the years and years of pain and grief if we couldn't celebrate people's lives and how much they've contributed to the world and mixed and mingled with the overwhelming sense of loss that their lives were cut too short. So it is the combination of umm... pride and celebration and joy and sadness and despair and apathy. And it is a mingling. It is not separate from. It's never separate from… one from the other. The emotions… you know Kubler Ross has like 5 stages and it's not 5 stages. It's a corkscrew that goes up and down with all kinds of other things coming into it. Emotions, you know all the other emotions.

CHAPTER SEVEN

Discussion and Conclusions

Overview

This exploratory study was undertaken in order to examine the factors that allow bereaved carers to experience positive changes in the aftermath of caring about someone who dies of AIDS. Caregiving and bereavement are stressful experiences no matter what the circumstances (Caserta & Lund, 1992; Deimling & Bass, 1986; Fengler & Goodrich, 1979; Gallagher et al., 1989; George & Gwyther, 1986; Horowitz & Shindelman, 1983; Rabins et al., 1990; Stroebe & Stroebe, 1983; Zautra, Reich & Guarnaccia, 1990). However, the realities of HIV disease create a potentially traumatic situation. Despite enormous progress, there is still stigma associated with AIDS that affects those who are HIV-positive as well as caregivers (Caruth & Keenan, 1995; Herek & Glunt, 1988; Powell-Cope & Brown, 1992). The nature of the disease and the possibility of transmission produce extra stress in caregiving (McCann & Wadsworth, 1992; Wrubel & Folkman, 1997). The reality of the magnitude of losses associated with AIDS, especially in the gay community, make the situation traumatic (Goodkin et al., 1996; Klein, 1998; Neugebauer et al., 1992; Nord, 1996a, 1997; Shernoff, 1995, 1997b).

The theoretical framework for this study is the transactional model of stress and coping (Lazarus & Folkman, 1984). The original model allowed only for negative outcomes if the stressful situation were not resolved in a beneficial manner for the individual. However, the model was reworked to include positive psychological states regardless of the outcome of the stressful event (Folkman, 1997b). In a further elaboration of coping theory, Calhoun and Tedeschi (1998) developed a model of post-traumatic growth which attempts to explain the process by which an individual experiences benefit in the aftermath of a traumatic experience. This study attempted to discover some of the factors that allow for such growth to take place in bereaved HIV carers.

Growth

Post-traumatic growth is a concept that has received increasing attention in the psychological literature (Tedeschi & Calhoun, 1995; Tedeschi, Park & Calhoun, 1998). People have been observed to benefit from experiences as diverse as natural disasters (Thompson, 1985), war (Aldwin, Levenson & Spiro, 1994; Elder & Clipp, 1989), disability (Dunn, 1994), rape (Burt & Katz, 1987), incest (Silver, Boon & Stones, 1983), and bereavement (Calhoun & Tedeschi, 1990; Frantz, Trolley & Farrell, 1998; Kessler, 1987; Lehman, Davis, Delongis, Wortman et al., 1993). To date, the phenomenon of post-traumatic growth has been explored within the context of HIV disease in only a limited fashion (Clipp et al., 1995; Folkman, 1997b; Folkman et al., 1997; Garfield, 1995; Moskowitz et al., 1996; Schwartzberg, 1993; Viney et al., 1991) and never using the instruments that have been developed to measure it.

In order to measure post-traumatic growth for the structural equation model, two instruments were used. The short form of the Stress-Related Growth Scale (Park, Cohen & Murch, 1996) was designed to measure positive outcomes of stressful events. In addition, the PTGI (Tedeschi & Calhoun, 1996) has five subscales. The New Possibilities subscale assesses how much individuals view life as holding potential after trauma, while the impact on relationships is gauged by the subscale Relating to Others. Personal Strength captures the self-reliance an individual may develop. Appreciation of Life assesses how much people value existence after a crisis, and Spiritual Change involves the impact on their spirituality. This group of 176 HIV carers demonstrated moderate post-traumatic growth as measured by the PTGI; in comparison, bereaved college students displayed higher growth (Tedeschi & Calhoun, 1996). Tedeschi and Calhoun also reported significant differences between the PTGI scores of men and women who had experienced trauma. No such difference was found by this study. However for the first time, growth was investigated with transgender individuals. As there were only four involved in this study, no statistical comparison could be made. More research in the area of post-traumatic growth and transgender people is required.

In addition to assessing the post-traumatic growth through pencil and paper measures, interviews were conducted with seven individuals. The interviewees were selected on the basis of gender and high or low scores on the SRGS and PTGI. The interview data revealed a fascinating result: many of the individuals with low scores on the growth scales related experiences of growth and transformation.

The measures of post-traumatic growth did not capture all the positive changes related by the participants in the interviews. All but one individual with the lowest scores had experienced some kind of positive change. The instructions with each questionnaire indicated that the participant should answer in relation to the death of the care recipient (see Appendices Five and Six). It is possible that this wording limited in some fashion the participants' evaluation of their own growth. It may be difficult for those who are experiencing multiple losses to distinguish the event of the death from the caring that went on before and the grief that comes after. In this sense, bereavement and HIV disease may be ongoing stressors for many individuals. Indeed, the notion that coping with chronic stress is different from coping with stress resulting from single events is supported in the literature (Gignac & Gottlieb, 1997). Further research is required to understand this phenomenon, both within the context of AIDS as well as to investigate whether the measures capture growth more comprehensively in other populations.

Creativity

Openness to experience and the ability to view the world creatively are considered to be necessary personality traits of people who experience post-traumatic growth (Tedeschi & Calhoun, 1996). For the purposes of the structural equation model, creativity was measured with the Internal Control Index (ICI; Duttweiler, 1984) and the global constructive thinking subscale of the Constructive Thinking Inventory (CTI; Epstein & Meier, 1989). Strickland (1989) proposes that people with an internal locus of control, those who are more likely to believe that their good fortune is due to themselves than to chance, are creative. Constructive thinking is defined as automatic thoughts that are constructive as opposed to being destructive (Epstein & Meier, 1989). Creative individuals are believed to think constructively (Strickland, 1989; Tedeschi & Calhoun, 1995).

It was hypothesized that creativity would be positively associated with post-traumatic growth, as measured by the SRGS and the PTGI. There was, however, no support found for this hypothesis as the latent variable of creativity was eliminated from the structural equation analysis because it was not contributing to the model fit. This may be due to the inability of the two measures, the ICI and the subscale of the CTI, to accurately represent creativity. Moreover, it may be indicative of the need for more personality traits to be included in the analysis in order to better explain the variance in the outcome measures of post-traumatic growth. Indeed, Tedeschi and Calhoun (1996) measured the relationship of six personality factors to the

PTGI: optimism, neuroticism, extraversion, openness to experience, agreeableness, and conscientiousness. They found significant correlations with everything but neuroticism. A more thorough exploration of the role of personality, including creativity, in growth after a crisis is warranted in future research.

Spirituality

> Spirituality is that attitude, that frame of mind which breaks the human person out of the isolating self. As it does that, it directs him or her to another in relationship to whom one's growth takes root and sustenance (Hardy, 1982, p.154)

Spirituality plays an important role in the creation of meaning in caregiving (Richards & Folkman, 1997). In order to measure spirituality/religiosity in the structural equation model, the Spiritual Involvement and Beliefs Scale (SIBS; Hatch et al., 1998) was used. The SIBS uses the language of higher power rather than theist terms and avoids any reference to any specific religion. This was believed to be important for this study as so many individuals from the gay, lesbian, bisexual and transgender community are estranged from religion (Hardy, 1998).

It was hypothesized that spirituality would have a positive relationship with post-traumatic growth as measured by the SRGS and the PTGI: the most spiritual individuals would experience the greatest positive changes after trauma. In the model, the hypothesis for spirituality was supported. Indeed, support for the role of spirituality was found in all the statistical tests as well as in the structural equation model. Spirituality was positively, although weakly, correlated with both outcome measures of post-traumatic growth. There was also a strong positive correlation between SIBS and the subscale of Spiritual Change in the PTGI. This indicates that the most spiritual individuals experience the most spiritual change in the aftermath of trauma. Furthermore, a multiple regression analysis was performed for each of the outcome variables, PTGI and SRGS. In each of the linear equations, the single best predictor of the variance in post-traumatic growth was spirituality.

The interview data further supported the role of spirituality in the process of growth. Each person interviewed had strong feelings about spirituality; several talked about the role that spirituality played in their lives before being asked. Even those who did not want to discuss their beliefs or did not consider themselves at all religious or spiritual had strong connections to the spirit as defined by Canda (1989, p.573): "the basic human drive for meaning, purpose, and moral relatedness among people, with the universe, and with the ground of our being". For some, spirituality was intertwined with the support that they received and the spiritual aspect of finding meaning in their caregiving was a crucial theme.

The instrument used in this research, the Spiritual Involvement and Beliefs Scale (SIBS), was designed to measure religiosity as well as spirituality (Hatch et al., 1998). The questions were based on many spiritual principles across diverse religions and early versions were tested on groups of self-identified atheists, Unitarians, Moslems, Christians and those of the

Baha'i faith (Hatch, 1999). Despite this intended connection in the SIBS (Hatch et al., 1998) and in other literature (Hardy, 1982; Schneiders, 1986), the HIV carers interviewed made a clear distinction between religion and spirituality. For them, the spiritual connections that they identified were removed from their religious experience.

Religion offers "an ultimate vision of what people should be striving for in their lives individually and collectively" (Pargament & Park, 1995, p.15). The spiritual quests and connections identified by the seven individuals interviewed demonstrated a strong sense of such a vision. However, religion "provides its adherents with a set of practical methods, a 'map' to keep them on the proper path toward the ultimate designation" (Pargament & Park, 1995, p.15). Many of the interviewees were emphatic about rejecting the map as prescribed in religion. This rejection may stem from the negative view of homosexuality in many religions. Helminiak (1995) describes the process by which gay men and lesbians may reject religion:

> The choice, as it often still remains, was pretty much between self and respectability, pure and simple. And the gay men and lesbians chose self. They chose to act honestly. They chose to trust things as they really are. They chose to live life without illusion. If in the process, for whatever complex reasons, that choice meant even rejection of God, they had the courage and the wisdom to opt for what is the more basic, a choice that even God must approve. (Helminiak, 1995, p. 308)

Pargament and Park (1997) suggest that religious coping provides an answer in the face of human insufficiency that non-religious coping does not. The HIV carers interviewed may have confronted the limitations of humans through spiritual coping rather than religious coping. The differentiation of spirituality and religion by the interviewees may be reflective of the connection between AIDS and the gay community. However, it is possible that the seven individuals interviewed were not highly religious and that another population of religiously affiliated HIV caregivers may have had different responses. Certainly, further research is warranted in this area.

The demonstration of the importance of spirituality in post-traumatic growth is paralleled by a re-emergence of interest in the role of spirituality in social work (Canda, 1988, 1989; Cascio, 1998, 1999; Jacobs, 1997; Tolliver, 1997), as well as in other disciplines. The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994) has included, for the first time, a category called Religious or Spiritual Problem (Cascio, 1999; Jacobs, 1997). Cascio (1998) emphasizes that it is important to note that the DSM-IV category does not imply pathology:

> This category can be used when the focus of clinical attention is a religious or spiritual problem. Examples include distressing experiences that involve loss or questioning of faith. problems associated with conversion to a new faith. or questioning of spiritual values that may not necessarily be related to an organized church or religious institution (American Psychiatric Association. 1994: p.685)

This interest is not a new one, however, as social work has its origins in religion; the first practitioners operated out of their own religious-based values of love and justice for all (Canda, 1988; Jacobs, 1997).

In an analysis of the qualitative data with the quantitative data from the UCSF Coping Project, Richards and Folkman (1997) discovered that those who reported more spirituality in their lives experienced significantly more distress than those who did not share stories of their spirituality. In the present study there was no relationship found between spirituality and distress, although the sample in general demonstrated high rates of distress. Further research into the role of spirituality in post-traumatic growth and the relationship to stress is warranted.

Social Support

Supportive others are an integral part of Calhoun and Tedeschi's (1998) model of post-traumatic growth. They serve as sources of comfort and offer new schema and coping possibilities that influence both stages of rumination as well as coping success. In order to measure social support for the structural equation model, four measures were used. The Provision of Social Relations (Turner, Frankel & Levin, 1983) was designed to measure individuals' perceptions of the provision of support to them. It has two subscales: the PSR Friends examines the perception of support from friends and the PSR Family, from family. The Social Support Questionnaire (O'Brien et al., 1993) has a total measure of support and six subscales: emotional support, material support, conflict, subjective social integration, social validation, and loved/respected. This is the measure of social support that was administered to the caregivers in the USCF Coping Project.

It was hypothesized that the carers with more social support would demonstrate higher post-traumatic growth. Support was found for this hypothesis in the structural equation model using the two subscales of the PSR and the Emotional and Material support subscales of the SSQ. However, in the analysis of bivariate relationships, a weak negative relationship between the PSR total and PTGI Relating to Others was significant. This association indicates that the more social support an individual had, the less growth was experienced in the domain of relations with other people. In addition, the PSR Friends and the PSR Family both loaded negatively onto the latent variable of social support in the structural equation model.

The inverse relationship between the subscales of the PSR and the latent variable of social support may be indicative of the lack of gay-positive and/or AIDS-related content. In contrast, the SSQ was designed for use with a gay male population and includes questions specific to HIV disease. A number of people responding to the questionnaire took the time to note on the page of the PSR that they assumed that the word 'family' meant biological family and not partner. Some even noted that their responses would be different if they had answered in relation to their family of choice and not biological family. Further investigation of the validity of the PSR within a predominantly gay population is warranted.

In addition to the quantitative data, the interviews underlined the importance of social support in the lives of HIV carers. All of the people interviewed had the support of friends, although many of their circles had been greatly reduced by AIDS. Interviewees also gained support from family and professionals; those who worked in AIDS service organizations also relied on colleagues.

An existing network of support can be enhanced through coping with trauma (Tedeschi & Calhoun, 1995). Family and friendship ties may be strengthened if a traumatized individual feels supported by them. Or, it may be that the changed situational and global meaning (Park & Folkman, 1997a) of the caregivers persuades them to appreciate the supportive others. Further exploration of the directionality of this relationship is necessary.

Stress

Stress is, by definition, part of post-traumatic growth: without a distressing challenge to the schemas or worldviews that one holds, there can be no post-trauma benefit. However, the role of stress in the process of growth has not been investigated. For the purposes of the structural equation model, the latent variable of stress was measured with two measures. The Beck Depression Inventory measures depression (Beck, 1967). The Impact of Events Scale gauges the responses to stressful events (Horowitz, Wilner & Alvarez, 1979). The two subscales, Avoidance and Intrusion assess how frequently a reaction to the stressful event occurs. High scores on the IES are considered indicative of Post-Traumatic Stress Disorder (McFarlane, 1988a).

The hypothesis concerning stress was that more growth would occur with less stress. The structural equation model did not support this association. In fact, the relationship indicated was a positive one: as more stress occurred, there was more post-traumatic growth. There is no known support for this result in the existing research. Further study is warranted in order to replicate and further understand the relationship between distress and post-traumatic growth.

The interview data provided rich examples of the stressors that people faced as well as the growth that they experienced. Unfortunately, the interviews did not explore the connection between stress and growth. It would be interesting to investigate this relationship with participants in future qualitative research.

Limitations

A critical limitation of this study is its design. The ideal design for this research would be a prospective long-term study. Ideally, it would begin by examining the psychosocial resources, stressors and growth of active carers and follow them throughout caregiving and over a length of time after bereavement in order to trace the benefits they experience over time. However, the scope of this research did not allow for such a design, as well as it being potentially intrusive for the participants involved.

The reality of multiple losses to AIDS causes an additional limitation of this study. Because it is unknown when the process of growth takes place

(Tedeschi, Park & Calhoun, 1998), this research only examined those who are bereaved. Caregivers in the active stages of caregiving may not have the time or the inclination to make meaning of their situation and may not grow or be able to assess their growth until after the care recipient has died. Participants were asked to identify how long it had been since the person with AIDS died (see Appendices Five and Six). Results did not demonstrate a relationship between the length of time since the death and post-traumatic growth. However more than 80% of the bereaved carers had experienced 2 or more deaths of family members or friends. The temporal aspect of the findings of this study in regards to post-traumatic growth must be interpreted with caution because of the participants' multiple bereavements.

Self-selection bias is an additional critical limitation of this study. As one interviewee pointed out: "...people that are in this war are very committed and very determined that their experience maybe helps". It is possible that the individuals who had experienced the most growth chose to respond to the recruitment posters, even though the flyers only specified that the study sought people who had lost someone to AIDS (see Appendices One and Two). However, the HIV carers in this study experienced less post-trauma growth than the comparative population of bereaved students (Tedeschi & Calhoun, 1996). In addition, this sample evidenced a great deal of distress: 86% of the HIV carers obtained a score of 26 or higher on the Impact of Events Scale (Horowitz, Wilner & Alvarez, 1979), which has been established as being the cut-off point which is indicative of a diagnosis of PTSD (McFarlane, 1988a).

It is of note, however that, like the firefighters who were exposed to a bushfire (McFarlane, 1988a; 1988b), this sample was not drawn from a population being treated for stress. Although there may be some selection bias in those who saw the poster at an AIDS service organization, data was not collected on whether the participants were involved in any help-seeking capacity with the agency, such as support groups. In addition, the IES (Horowitz, Wilner & Alvarez, 1979) was not conceived as a diagnostic measure. Thus, interpretations must be made cautiously about the existence of PTSD in the bereaved carers of people with HIV.

Implications for Social Work Practice

This study provides a portrait of bereaved HIV carers in Canada and the realities associated with that situation. The findings confirm the literature that suggests that, in contrast to carers of people with other diseases, HIV caregivers are younger, more often male, not necessarily a family member and are often HIV-positive themselves. The multiple losses associated with AIDS were illustrated in the large numbers of death each person had experienced. Not surprisingly, a large percentage of the bereaved carers demonstrated symptoms of Post-Traumatic Stress Disorder. And yet these individuals also experienced benefits in the aftermath of their suffering, even to the point of experiencing more growth in proportion to the trauma symptoms they were exhibiting. In addition, the results yield support to the hypotheses that growth would increase with higher levels of spirituality and social support.

This portrait and the relationship of spirituality, social support and trauma to growth have implications for social workers in all practice areas: clinical, community, social policy, as well as in social work education. The knowledge of factors that can play a role in post-traumatic growth can contribute to the work of social workers and others at any level of intervention. The notion that benefits can occur after a traumatic experience contributes to the paradigm shift from a pathogenic to a salutogenic or strengths-based approach (Antonovsky, 1979, 1987; Ickovics & Park, 1998). Post-traumatic growth is a concept that can be applied to any individual who or population that has experienced trauma. In addition, the significance of spirituality in the process of growth after a stressful experience supplements the increasing recognition of the importance of incorporating discussions of spirituality with clients (Canda, 1988, 1989; Cascio, 1998, 1999; Jacobs, 1997; Richards & Folkman, 1997; Tolliver, 1997).

Community development can benefit from the knowledge of post-traumatic growth and the factors that contribute to it. Tedeschi (1999) discusses how the impact of violence can change communities. He proposes that societal transformation in the aftermath of violence arises from the changes in individuals, who assist the community in mediating the trauma or the individuals' personal changes galvanize the community to change.

Although there is great controversy surrounding the idea that AIDS has had any positive aspects, there exists the notion that the gay community has been strengthened by the impact of HIV disease.

There are policy implications from this study. HIV disease has a far-reaching impact well beyond those who are HIV-infected. That only 15 percent of this sample of 176 bereaved carers cared for a member of their biological family highlights the importance of recognizing and reflecting diverse caring relationships in medical, legal and hospital policies, and not just those based on blood or marriage.

Social workers are increasingly coming into contact with clients who have been impacted by HIV disease. Social work education could benefit from the introduction of thorough knowledge of AIDS and the impact that it has on every facet of people's lives, even if the clients are not themselves HIV-positive. In addition, the concept of post-traumatic growth could be incorporated into social work education in order that social workers can begin to work with clients' existing resources in order to enhance the possibility of growth.

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Appendix One

Has someone you care about died of HIV or AIDS?

A doctoral student in Social Work at Wilfrid Laurier University is doing a study exploring the experiences of HIV caregivers for whom the care recipient has died.

Would you like to help?

Confidentiality guaranteed
Call toll-free
1-877-673-8371

Appendix Two

Avez-vous perdu quelqu'un atteint du sida ou VIH?

Une étudiante de doctorat en travail social à l'Université Wilfrid Laurier étudie l'expérience collective de personnes ayant donné des soins aux sidéen(ne)s qui par la suite sont décédé(e)s.

Voulez-vous aider?

Confidentialité assurée
Appelez sans frais
1-877-673-8371

Appendix Three

Informed Consent Statement

Exploring the Experience of AIDS Caregivers
Investigator: Susan Cadell
Advisor: Cheryl Regehr

You are invited to participate in a research study. The purpose of this study is to better understand how the lives of bereaved AIDS caregivers are changed by their experiences. For each person who has died there are many left behind to grieve. Caring for or about someone in the context of AIDS is stressful. The stigma associated with AIDS and the common aspect of having lost many friends, acquaintances and family to HIV disease makes the situation traumatic. There are many possible reactions to bereavement, but it is always difficult.

This study is designed to help us understand the experience of bereaved caregivers and what helps them to recover in the best possible way. This knowledge will help us to design better programs to help anyone who has lost someone and others going through similar experiences.

Information

Since you have seen the poster about this study and telephoned, you have received this package. It consists of this information form, a survey asking you questions about your reactions to the death and about your thoughts and feelings in general. If you choose to continue, you are invited to fill in the questionnaire. It should take about 45 minutes to one hour. You can then mail the package back in the stamped envelope provided.

If you are willing to be contacted for a follow-up interview in person, you can indicate your telephone number in the space on the first page of questions. You would be called in several months time. If you agree to this, the interview would be audio-taped. There is no problem if you choose not to.

Risks

As this study asks about a difficult period of your life, you may become upset. If this happens, you can contact Susan Cadell who will provide you with a list of resources available to HIV/AIDS caregivers.

Benefits

This study is designed to increase our understanding of how people recover from the trauma of losing someone that they care for and to help us in planning programs. In this sense, you will not benefit immediately by participating in this study. However you may find that these questions cause you to reflect on a difficult period of your life and realize how this has impacted on you in a positive way.

Confidentiality

The information collected is used only for this research project and your participation is confidential. The information is kept in a locked place at the university and is used only by Susan Cadell. Numerical codes are used in place of names for all information and all identifying information is destroyed when the study is finished in about eight months time. The final report contains no names or other identification.

Compensation

For participating in this study, you will find enclosed a cheque for $20.00. If you decide not to continue with the study, you do not have to return the money.

Contact

If you have any questions at any time about the study or the procedures, or you experience adverse effects as a result of participating in this study, you may contact the researcher, Susan Cadell, at the Faculty of Social Work, Wilfrid Laurier University, 1-877-673-8371 or her advisor, Dr. Cheryl Regehr at (416) 978-6314. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Linda Parker, Assistant Dean of Graduate Studies and Research, Wilfrid Laurier University, 884-0710, extension 3126.

Participation

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed.

If you would like to receive a summary of the final report, please contact Susan Cadell at 1-877-673-8371.

Appendix Four

Déclaration de Consentement Éclairé

Exploration des expériences des soignants de personnes décédées du sida
Investigatrice: Susan Cadell
Directrice: Cheryl Regehr

Vous êtes invité(e) à participer à un projet de recherche. Le but de ce projet est de mieux comprendre comment les vies de ceux qui ont perdu quelqu'un de cher au sida sont changées par leur expérience. Chaque personne qui est décédée a laissé beaucoup d'autres dans le deuil. Prendre soin de quelqu'un dans le contexte du sida est éprouvant. Les stigmates associés au sida, ainsi que, fréquemment, le fait d'avoir perdu de nombreux amis, connaissances et membres de la famille à la maladie du VIH, rendent la situation traumatique. Il y a de nombreuses réactions possibles au deuil, mais aucune n'est facile.

Cette étude est conçue pour nous aider à comprendre les expériences des soignants dans le deuil, ainsi que les facteurs qui les aident à récupérer dans les meilleures conditions possibles. Les résultats de cette étude nous aideront à concevoir de meilleurs programmes pour aider ceux qui ont perdu quelqu'un, ainsi que ceux qui ont fait face à des expériences similaires.

Information

Après avoir vu l'affiche annonçant cette étude et pris contact par téléphone, vous avez reçu cet envoi. Il contient ce formulaire d'information, et un questionnaire vous posant des questions sur votre réaction face au décès et sur vos pensées et sentiments en général. Si vous décidez de continuer, vous êtes invité(e) à remplir le questionnaire. Cela devrait prendre entre 45 minutes et une heure. Vous pouvez ensuite renvoyer le questionnaire au moyen de l'enveloppe affranchie incluse.

Si vous accepteriez d'être contacté(e) pour un entretien individuel complémentaire, vous pouvez indiquer votre numéro de téléphone à l'endroit prévu à cet effet sur la première page de questions. Vous seriez contacté(e) dans plusieurs mois. Si vous optez pour ce choix, l'entretien serait enregistré. Il n'y a aucun problème si vous choisissez de ne pas faire d'entretien.

Risques

Comme elle pose des questions sur une période difficile de votre vie, il se peut que cette étude vous perturbe. Si c'est le cas, vous pouvez contacter

Susan Cadell qui vous pourvoira une liste de resources disponibles pour ceux affectés par une perte au VIH/sida.

Bénéfices

Cette étude est conçue pour nous aider à mieux comprendre comment des personnnes récupèrent du traumatisme de perdre quelqu'un dont elles se sont occupé, et pour nous aider à concevoir des programmes. Dans ce sens, votre participation à cette étude ne vous apportera pas de bénéfice immédiat. Il est cependant possible que ces questions vous amènent à réfléchir à une période difficile de votre vie, et comment celà a eu un effet positif sur votre vie.

Confidentialité

L'information obtenue est utilisée uniquement pour ce projet de recherche et votre participation est confidentielle. L'information est gardée dans un endroit verouillé à l'université, et est utilisée uniquement par Susan Cadell. Des codes numériques sont utilisés à la place de noms pour toutes les informations, et toute information d'identification est détruite quand l'étude se termine dans environ huit mois. Le rapport final ne contient ni nom, ni autre identification.

Indemnité

Pour votre participation à cette étude, vous trouverez ci-joint un chèque de $20.00. Si vous décidez de ne pas continuer avec cette étude, vous n'avez pas à retourner l'argent.

Contact

Pour toute question sur l'étude ou sur les procédures suivies, ou si vous éprouvez des effets néfastes suite à votre participation à cette étude, vous pouvez à tout moment appeler la chercheure, Susan Cadell, à la Faculté de Serice Social de l'Université Wilfrid Laurier, 1-877-673-8371, ou sa directrice, Dr Cheryl Regehr, au (416) 978-6314. Si vous pensez que vous n'avez pas été traité comme décrit dans ce formulaire, ou si vos droits en tant que participant à la recherche ont été violés pendant le cours du projet, vous pouvez contacter Dr. Linda Parker, Doyenne Adjointe des Études de Second Cycle et de la Recherche, Université Wilfrid Laurier, au 884-0710, poste 3126.

Participation

Votre participation à cette étude est volontaire; vous pouvez refuser de particitper sans pénalité. Si vous décidez de participer, vous pouvez vous retirer de l'étude à tout moment, et sans perdre les bénéfices auxquels vous avez autrement droit. Si vous vous retirez de l'étude avant que la collecte de données soit terminée vos données vous seront retournées ou détruites.

Si vous désirez recevoir une copie du rapport final, veuillez contacter Susan Cadell au 1-877-673-8371.

Appendix Five

Caregiving Questionnaire

Present Age: _____

Gender: Male___ Female___ Transgender___

Present Employment:
Not Employed ___ Part-time___ Full-time___

Education:
Less than Grade 12___ Grade 12 or 13 Grad___
College Grad___ University Grad___

Sexual Orientation:
Gay___ Lesbian___ Bisexual___ Heterosexual___

What is your HIV status?
HIV-positive___ HIV-negative___ Unknown___

How many years has it been since the person you cared for died? If there is more than one, please answer for the person to whom you were closest. ______________________

What relationship did you have with the person who died?
Partner___ Friend ___ Family of choice___Family of origin ___
Other (please specify)__________________________________

How many friends and/or family members have you lost to HIV disease?_____

What is your country of birth?_____________________

Some people identify themselves by ethnicity (e.g. French-Canadian, African-Canadian); some people identify themselves by religion (e.g. Jewish, Muslim); some people identify themselves by both. How do you refer to yourself?

____

If you would be willing to be contacted for a follow-up interview, please provide your phone number (with area code) _____________________

CTI

Use the scale below to rate the following statements about feelings, beliefs, and behaviours. Score "1" if the statement is definitely false, "2" if it is mostly false, "4" if it is mostly true, and "5" if it is definitely true. Use "3" only if you cannot decide if the item is mainly true or false.

1	2	3	4	5
Definitely False	Mostly False	Undecided or Equally False and True	Mostly True	Definitely True

_____ 1. When I have a lot of work to do by a deadline, I waste a lot of time worrying about it instead of just doing it.

_____ 2. I tend to classify people as either for me or against me.

_____ 3. When doing unpleasant chores, I make the best of it by thinking pleasant or interesting thoughts.

_____ 4. I don't let little things bother me.

_____ 5. I look at challenges not as something to fear, but as an opportunity to test myself and learn.

_____ 6. I take failure very hard.

_____ 7. I spend much more time mentally rehearsing my failures than remembering successes.

_____ 8. I've learned not to hope too hard, because what I hope for usually doesn't happen.

_____ 9. If I said something foolish when I spoke up in a group, I would chalk it up to experience and not worry about it.

_____ 10. When faced with a large amount of work to complete, I tell myself I can never get it done, and feel like giving up.

_____ 11. The slightest indication of disapproval gets me upset.

_____ 12. I worry a great deal about what other people think of me.

_____ 13. When I am faced with a difficult task, I think encouraging thoughts that help me do my best.

_____ 14. I am the kind of person who takes action rather than just thinks or complains about a situation.

_____ 15. I believe it is best, in most situations, to emphasize the positive side of things.

1	2	3	4	5
Definitely False	Mostly False	Undecided or Equally False and True	Mostly True	Definitely True

_____ 16. If I have something unpleasant to do, I try to make the best of it by thinking in positive terms.

_____ 17. I feel like a total failure if I don't achieve the goals I set for myself.

_____ 18. I am tolerant of my mistakes as I feel they are a necessary part of learning.

_____ 19. I avoid challenges because it hurts too much when I fail.

_____ 20. I spend a lot of time thinking about my mistakes even if there is nothing I can do about them.

_____ 21. I like to succeed, but I don't take failure as a tragedy.

_____ 22. It is foolish to trust anyone completely, as if you do, you are bound to get hurt.

_____ 23. I tend to dwell more on pleasant than unpleasant incidents from the past.

_____ 24. I get so distressed when I notice that I am doing poorly in something that it makes me do worse.

_____ 25. When unpleasant things happen to me, I don't let them prey on my mind.

_____ 26. If I do poorly on a test, I realize it is only a single test, and it doesn't make me feel generally incompetent.

_____ 27. I don't get very distressed over the mistakes of others, but try to deal with them in a constructive way.

_____ 28. I have learned from bitter experience that most people are not trustworthy.

_____ 29. When I am faced with a new situation, I tend to think the worst possible outcome will happen.

ICI

Please read each statement. Where there is a blank, decide what your normal or usual attitude, feeling, or behaviour would be:

A = Rarely (less than 10% of the time)
B = Occasionally (about 30% of the time)
C = Sometimes (about half the time)
D = Frequently (about 70% of the time)
E = Usually (more than 90% of the time)

Of course, there are always unusual situations in which this would not be the case, but think of what you would do or feel in most normal situations.

Write the letter that describes your usual attitude or behaviour in the space provided on the response sheet.

1. When faced with a problem I _____ try to forget it.
2. I _____ need frequent encouragement from others for me to keep working at a difficult task.
3. I _____ like jobs where I can make decisions and be responsible for my own work.
4. I _____ change my opinion when someone I admire disagrees with me.
5. If I want something I ____ work hard to get it.
6. I _____ prefer to learn the facts about something from someone else rather than have to dig them out of myself.
7. I will _____ accept jobs that require me to supervise others.
8. I _____ have a hard time saying "no" when someone tries to sell me something I don't want.
9. I _____ like to have a say in any decision made by any group I'm in.
10. I _____ consider the different sides of an issue before making any decisions.
11. What other people think _____ has a great influence on my behaviour.
12. Whenever something good happens to me I _____ feel it is because I've earned it.
13. I _____ enjoy being in a position of leadership.
14. I _____ need someone else to praise my work before I am satisfied with what I've done.
15. I am _____ sure enough of my opinions to try and influence others.
16. When something is going to affect me I _____ learn as much about it as I can.
17. I _____ decide to do things on the spur of the moment.

A = Rarely (less than 10% of the time)

B = Occasionally (about 30% of the time)
C = Sometimes (about half the time)
D = Frequently (about 70% of the time)
E = Usually (more than 90% of the time)

18. For me, knowing I've done something well is _____ more important than being praised by someone else.
19. I _____ let other people's demands keep me from doing things I want to do.
20. I _____ stick to my opinions when someone disagrees with me.
21. I _____ do what I feel like doing not what other people think I ought to do.
22. I _____ get discouraged when doing something that takes a long time to achieve results.
23. When part of a group I _____ prefer to let other people make all the decisions.
24. When I have a problem I _____ follow the advice of friends or relatives.
25. I _____ enjoy trying to do difficult tasks more than I enjoy trying to do easy tasks.
26. I _____ prefer situations where I can depend on someone else's ability rather than my own.
27. Having someone important to tell me I did a good job is _____ more important to me than feeling I've done a good job.
28. When I'm involved in something I _____ try to find out all I can about what is going on even when someone else is in charge.

SIBS

How strongly do you agree with the following statements? Please circle your response.

	Strongly Agree	Agree	Mildly Agree	Neutral	Mildly Disagree	Disagree	Strongly Disagree
1. I set aside time for meditation and/or self-reflection	7	6	5	4	3	2	1
2. I can find meaning in times of hardship.	7	6	5	4	3	2	1
3. A person can be fulfilled without pursuing an active spiritual life.	7	6	5	4	3	2	1
4. I find serenity by accepting things as they are.	7	6	5	4	3	2	1
5. Some experiences can be understood only through one's spiritual beliefs.	7	6	5	4	3	2	1
6. I do not believe in an afterlife.	7	6	5	4	3	2	1
7. A spiritual force influences the events in my life.	7	6	5	4	3	2	1
8. I have a relationship with someone I can turn to for spiritual guidance.	7	6	5	4	3	2	1
9. Prayers do not really change what happens.	7	6	5	4	3	2	1
10. Participating in spiritual activities helps me forgive other people.	7	6	5	4	3	2	1
11. I find inner peace when I am in harmony with nature.	7	6	5	4	3	2	1
12. Everything happens for a greater purpose.	7	6	5	4	3	2	1
13. I use contemplation to get in touch with my true self.	7	6	5	4	3	2	1
14. My spiritual life fulfills me in ways that material possessions do not.	7	6	5	4	3	2	1

	Strongly Agree	Agree	Mildly Agree	Neutral	Mildly Disagree	Disagree	Strongly Disagree
15. I rarely feel connected to something greater than myself.	7	6	5	4	3	2	1
16. In times of despair, I can find little reason to hope.	7	6	5	4	3	2	1
17. When I am sick, I would like others to pray for me.	7	6	5	4	3	2	1
18. I have a personal relationship with a power greater than myself.	7	6	5	4	3	2	1
19. I have had a spiritual experience that greatly changed my life.	7	6	5	4	3	2	1
20. When I help others, I expect nothing in return.	7	6	5	4	3	2	1
21 I don't take time to appreciate nature.	7	6	5	4	3	2	1
22. I depend on a higher power.	7	6	5	4	3	2	1
23. I have joy in my life because of my spirituality.	7	6	5	4	3	2	1
24. My relationship with a higher power helps me love others more completely.	7	6	5	4	3	2	1
25. Spiritual writings enrich my life.	7	6	5	4	3	2	1
26. I have experienced healing after prayer.	7	6	5	4	3	2	1
27. My spiritual understanding continues to grow.	7	6	5	4	3	2	1
28. I am right more often than most people.	7	6	5	4	3	2	1
29. Many spiritual approaches have little value.	7	6	5	4	3	2	1

	Strongly Agree	Agree	Mildly Agree	Neutral	Mildly Disagree	Disagree	Strongly Disagree
30. Spiritual health contributes to physical health.	7	6	5	4	3	2	1
31. I regularly interact with others for spiritual purposes.	7	6	5	4	3	2	1
32. I focus on what needs to be changed in me, not on what needs to be changed in others.	7	6	5	4	3	2	1
33. In difficult times, I am still grateful.	7	6	5	4	3	2	1
34. I have been through a time of great suffering that led to spiritual growth.	7	6	5	4	3	2	1

Please indicate how often you do the following:

	Always	Almost Always	Usually	Some-times	Not usually	Almost never	Never
35. When I wrong someone, I make an effort to apologize.	7	6	5	4	3	2	1
36. I accept others as they are.	7	6	5	4	3	2	1
37. I solve my problems without using spiritual resources.	7	6	5	4	3	2	1
38. I examine my actions to see if they reflect my values.	7	6	5	4	3	2	1

39. How spiritual a person do you consider yourself? (With “7” being the most spiritual.)

1 2 3 4 5 6 7

SSQ

We would like to know about how things are currently going between you and the people in your personal life – lovers, friends, relatives, etc. Please circle your response to indicate which answer most closely describes how things have been going for you in the past month.

In the past month...

		Never	Rarely	Sometimes	Frequently	All the Time
1.	Did you feel that people in your life let you down by not showing you as much love and concern as you would have liked?	0	1	2	3	4
2.	Have the people in your personal life really gotten on you nerves?	0	1	2	3	4
3.	Did the people in your personal life make you feel respected?	0	1	2	3	4
4.	Have you felt loved and wanted?	0	1	2	3	4
5.	Have you felt isolated from others?	0	1	2	3	4
6.	Have you felt that no one really knows you well?	0	1	2	3	4
7.	Have you felt as though you were part of a group of friends?	0	1	2	3	4
8.	Have you felt tense from arguing or disagreeing with people in your personal life?	0	1	2	3	4
9.	Have you felt irritated or resentful toward people in your personal life?	0	1	2	3	4
10.	Have you wished for more friends?	0	1	2	3	4
11.	Have you kept pretty much to yourself?	0	1	2	3	4
12.	Did you feel misunderstood by the people in your personal life?	0	1	2	3	4

Next are some questions about the extent to which people would be available to help you deal with different problems or situations that might arise.

	Definitely Not	Probably Not	Possibly	Probably	Definitely
13. Is there someone who would help take care of you if you were confined to bed for several weeks?	0	1	2	3	4
14. Is there someone you could turn to if you needed to borrow $10, a ride to the doctor, or some other small, immediate help?	0	1	2	3	4
15. Is there someone you could turn to if you needed to borrow several hundred dollars in an emergency?	0	1	2	3	4
16. Would the people in your personal life give you information, suggestions, or guidance about matters related to HIV or AIDS if you needed it?	0	1	2	3	4
17. Would someone be available to talk to you about HIV or AIDS-related problems if you were upset, nervous, or depressed?	0	1	2	3	4
18. Is there someone you could turn to if you needed advice to help make a decision?	0	1	2	3	4
19. Is there someone you could contact if you wanted to talk about an important personal problem you were having?	0	1	2	3	4
20. Is someone around to confide in or talk to about yourself and your problems related to HIV or AIDS if you want to?	0	1	2	3	4
21. Do the people in your personal life approve of the ways you do things?	0	1	2	3	4
22. Do the people in your personal life give you the idea that it is all right to feel what you are feeling?	0	1	2	3	4
23. Do the people in your personal life tend to size up things and people in the same way you do?	0	1	2	3	4

PSR

We would like to know something about your relationships with other people. Please read each statement below and decide how well the statement describes you. For each statement, show your answer by indicating to the left of the item the number that best describes how you feel. The numbers represent the following answers.

1 = Very much like me
2 = Much like me
3 = Somewhat like me
4 = Not very much like me
5 = Not at all like me

_____ 1. When I'm with my friends, I feel completely able to relax and be myself.

_____ 2. I share the same approach to life that many of my friends do.

_____ 3. People who know me trust me and respect me.

_____ 4. No matter what happens, I know that my family will always be there for me should I need them.

_____ 5. When I want to go out to do things I now that many of my friends would enjoy doing these things with me.

_____ 6. I have at least one friend I could tell anything to.

_____ 7. Sometimes I'm not sure if I can completely rely on my family.

_____ 8. People who know me think I am good at what I do.

_____ 9. I feel very close to some of my friends.

_____ 10. People in my family have confidence in me.

_____ 11. My family lets me know they think I am a worthwhile person.

_____ 12. People in my family provide me with help in finding solutions to my problems.

_____ 13. My friends would take the time to talk over my problems, should I ever want to.

_____ 14. I know my family will always stand by me.

_____ 15. Even when I am with my friends I feel alone.

IES

Below is a list of comments made by people after stressful events. Please read each item, indicating how frequently these comments were true for you **during the last seven days**.

1 = Not at all
2 = Rarely
3 = Sometimes
4 = Frequently

1. I thought about it when I didn't mean to. 1 2 3 4
2. I avoided letting myself get upset when I thought about it or was reminded it. 1 2 3 4
3. I tried to remove it from my memory. 1 2 3 4
4. I had trouble falling asleep or staying asleep. 1 2 3 4
5. I had waves of strong feelings about it. 1 2 3 4
6. I had dreams about it. 1 2 3 4
7. I stayed away from reminders of it. 1 2 3 4
8. I felt as if it hadn't happened or it wasn't real. 1 2 3 4
9. I tried not to talk about it. 1 2 3 4
10. Pictures about it popped into my head. 1 2 3 4
11. Other things kept making me think about it. 1 2 3 4
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them. 1 2 3 4
13. I tried not to think about it. 1 2 3 4
14. Any reminder brought back my feelings about it. 1 2 3 4
15. My feelings about it were kind of numb. 1 2 3 4

Beck Inventory

On this questionnaire are groups of statements. Please read each group of statements carefully. Then pick out the one statement in each group which best describes the way you have been feeling the **PAST WEEK, INCLUDING TODAY.** Circle the number beside the statement you pick. If several statements in the group seem to apply equally well circle each one. Be sure to read all the statements in each group before making your choice.

1 0 I do not feel sad.
1 I feel sad.
2 I am sad all the time and I can't snap out of it.
3 I am so sad or unhappy that I can't stand it.

2 0 I am not particularly discouraged about the future.
1 I feel discouraged about the future.
2 I feel I have nothing to look forward to.
3 I feel that the future is hopeless and things cannot improve.

3 0 I do not feel like a failure.
1 I feel I have failed more than the average person.
2 I feel I have nothing to look forward to.
3 I feel I am a complete failure as a person.

4 0 I get as much satisfaction out of life as I used to.
1 I don't enjoy things the way I used to.
2 I don't get real satisfaction out of anything anymore.
3 I am dissatisfied or bored with everything.

5 0 I don't feel particularly guilty.
1 I feel guilty a good part of the time.
2 I feel quiet guilty most of the time.
3 I feel guilty all of the time.

6 0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

7 0 I don't feel disappointed in myself.
1 I am disappointed in myself.
2 I am disgusted with myself.
3 I hate myself.

8 0 I don't feel I am any worse than anybody else.
1 I am critical of myself for my weaknesses or mistakes.
2 I blame myself all the time for my faults.
3 I blame myself for everything bad that happens.

9 0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself but would not carry them out.
2 I would like to kill myself.
3 I would like to kill myself if I had the chance.

10 0 I don't cry anymore than usual.
1 I cry more now than I used to.
2 I cry all the time now.
3 I used to be able to cry, but now I can't cry even though I want to.

11 0 I am no more irritated now than I ever am.
1 I get annoyed or irritated more easily than I used to.
2 I feel irritated all the time now.
3 I don't get irritated at all by the things that used to irritate me.

12 0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost my interest in other people.
3 I have lost all my interest in other people.

13 0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty making decisions than before.
3 I can't make decisions anymore.

14 0 I don't feel I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel that there are permanent changes in my appearance that make me look unattractive.
3 I believe that I look ugly.

15 0 I can work about as well as before.
1 It takes extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.

16 0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.

17 0 I don't get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.

18 0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.

19 0 I haven't lost much weight lately.
1 I have lost more than 2 kilos (5 pounds)
2 I have lost more than 5 kilos (12 pounds)
3 I have lost more than 7 kilos (15 pounds)
I am purposely trying to lose weight by eating less. Yes ______ No _____

20 0 I am no more worried about my health than usual.
1 I am worried about physical problems such as aches and pains, or upset stomach, or constipation.
2 I am very worried about physical problems and it is hard to think about much else.
3 I am so worried about my physical problems and I cannot think about anything else.

21 0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have loss interest in sex completely.

SRGS

Please use the following scale to answer these questions with regard to death of the person that you care about. Use this scale:

0 = Not at all
1 = A bit
2 = Somewhat
3 = A good deal
4 = A great deal

Because of the death of the person I care about...

_____ 1. I learned to be nicer to others.

_____ 2. I feel freer to make my own decisions.

_____ 3. I learned that I have something of value to teach others about life.

_____ 4. I learned to be myself and not try to be what others want me to be.

_____ 5. I learned to work through problems and not just give up.

_____ 6. I learned to find more meaning in life.

_____ 7. I learned how to reach out and help others.

_____ 8. I learned to be a more confident person.

_____ 9. I learned to listen more carefully when others talk to me.

_____ 10. I learned to be open to new information and ideas.

_____ 11. I learned to communicate more honestly with others.

_____ 12. I learned that I want to have some impact on the world.

_____ 13. I learned that it's OK to ask others for help.

_____ 14. I learned to stand up for my personal rights.

_____ 15. I learned that there are more people who care about me than I thought.

PTGI

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your crisis (the death of the person you care about), using the following scale.

0 = I did not experience this change as a result of my crisis.
1 = I experienced this change to a very small degree as a result of my crisis.
2 = I experienced this change to a small degree as a result of my crisis.
3 = I experienced this change to a moderate degree as a result of my crisis.
4 = I experienced this change to a great degree as a result of my crisis.
5 = I experienced this change to a very great degree as a result of my crisis.

_____ 1. I changed my priorities about what is important in life.
_____ 2. I'm more likely to try to change things which need changing.
_____ 3. I have a greater appreciation for the value of my own life.
_____ 4. I have a greater feeling of self-reliance.
_____ 5. I have a better understanding of spiritual matters.
_____ 6. I more clearly see that I can count on people in times of trouble.
_____ 7. I have a greater sense of closeness with others.
_____ 8. I know better that I can handle difficulties.
_____ 9. I have a greater willingness to express my emotions.
_____ 10. I am better able to accept the way things work out.
_____ 11. I can better appreciate each day.
_____ 12. I have greater compassion for others.
_____ 13. I'm able to do better things with my life.
_____ 14. New opportunities are available which wouldn't have been otherwise.
_____ 15. I put more effort into my relationships.
_____ 16. I have a stronger religious faith.
_____ 17. I discovered that I'm stronger than I thought I was.
_____ 18. I learned a great deal about how wonderful people are.
_____ 19. I developed new interests.
_____ 20. I better accept needing others.
_____ 21. I established a new path for my life.

Appendix Six

Questionnaire

Age: _____

Sexe: Masculin___ Féminin___ Transgenre___

Emploi actuel:
Sans emploi___ Temps partiel___ Plein temps___

Formation:
Inférieure au secondaire 5___ Diplômé(e) d'études secondaires___
Niveau collège/CEGEP___ Niveau universitaire___

Orientation sexuelle:
Homosexuel___ Lesbienne___ Bisexuel(le)___ Hétérosexuel(le)___

Quel est votre état VIH?
VIH-positif(ve)___ VIH-négatif(ve)___ Inconnu___

Combien d'années se sont écoulées depuis la mort de la personne dont vous vous étiez occupé(e)? Si vous vous êtes occupé de plus d'une personne, considérez celle qui vous était la plus proche. _________

Quelle était votre relation avec la personne décédée?
Partenaire___ Ami(e) ___ Famille de choix___ Famille d'origine___
Autre (spécifiez)____

Combien d'ami(e)s et/ou de membres de votre famille sont-ils morts du sida?_____

Quel est votre pays d'origine?______________________________

Certaines personnes s'identifient à un groupe ethnique [ex. Acadien(ne), Africain-Canadien(ne)]; certaines personnes s'identifient à un groupe religieux [ex. juif(ve), musulman(ne)] ; certaines personnes s'identifient aux deux. Que diriez-vous de vous-même? ____

Si vous accepteriez d'être contacté(e) pour un entretien complémentaire, merci d'indiquer votre numéro de téléphone (avec l'indicatif régional).

____

CTI

Utilisez l'échelle ci-dessous afin d'évaluer les assertions suivantes concernant les sentiments, les croyances et les comportements. Mettez 1 si l'assertion est complètement erronée, 2 si elle est plutôt erronée, 4 si elle est vraie la plupart du temps, 5 si elle est tout à fait vraie. Utilisez le 3 si vous ne parvenez pas à décider si elle est surtout vraie ou fausse

1	2	3	4	5
Complètement erronée	Plutôt erronée	Indécis ou aussi bien vraie qu'erronée	Vraie la plupart du temps	Tout à fait vraie

_____ 1. Lorsque j'ai beaucoup de travail à faire pour une date limite, je perds plein de temps à tracasser au lieu tout simplement de le faire.

_____ 2. J'ai tendance à diviser les gens en deux catégories : ceux qui sont pour moi ou contre moi.

_____ 3. Quand je fais des corvées désagréables, je m'en accommode en pensant à des chose agréables, intéressantes.

_____ 4. Je ne me laisse pas embêter par les petites choses.

_____ 5. Les challenges ne me font pas peur, pour moi, ce sont des occasions de me tester et d'apprendre.

_____ 6. Je prends très mal les échecs.

_____ 7. Je passe beaucoup plus de temps à ressasser mes échecs qu'à me souvenir de mes succès.

_____ 8. J'ai appris à modérer mes espoirs parce qu'ils ne se réalisent pas souvent.

_____ 9. Si je dis quelque chose de bête au milieu d'un groupe, je le mets au compte de l'expérience et je ne m'en préoccupe plus.

_____ 10. Lorsque j'ai énormément de travail, je me dis que je n'y arriverai jamais et j'ai envie de laisser tomber.

_____ 11. Le moindre signe de désapprobation me contrarie.

_____ 12. Je me préoccupe énormément de ce que les gens pensent de moi.

_____ 13. Quand je dois faire face à une tâche ardue, je m'encourage intérieurement, ce qui m'ai à faire de mon mieux.

_____ 14. Je fais partie des personnes qui agissent au lieu de se contenter de penser ou de se plaindre.

_____ 15. Dans la plupart des situations, je crois qu'il est préférable de mettre l'accent sur l'aspec positif des choses.

_____ 16. Si j'ai quelque chose de désagréable à faire, j'essaie de le faire au mieux en l'appréhendant de façon positive.

1	2	3	4	5
Complètement erronée	Plutôt erronée	Indécis ou aussi bien vraie qu'erronée	Vraie la plupart du temps	Tout à fait vraie

_____ 17. J'ai un sentiment d'échec total si je n'atteins pas les objectifs que je me fixe.

_____ 18. Je suis tolérant(e) envers mes erreurs car je les considère comme une part nécessaire l'apprentissage.

_____ 19. J'évite les challenges parce que les échecs me sont trop difficiles à supporter.

_____ 20. Je passe beaucoup de temps à penser à mes erreurs même si je ne peux rien faire po remédier.

_____ 21. J'aime réussir mais je ne prends pas les échecs au tragique.

_____ 22. Il est insensé de faire entièrement confiance à quelqu'un, car si vous le faites, vous all inévitablement en souffrir.

_____ 23. J'ai tendance à m'attarder davantage sur les événements agréables que désagréables passé.

_____ 24. Je me sens tellement bouleversé(e) quand je m'aperçois que ce que je suis en train de faire est médiocre que je le fais encore plus mal.

_____ 25. Lorsque quelque chose de désagréable m'arrive, je ne me laisse pas miner.

_____ 26. Si je réussis mal un test, je réalise qu'il s'agit d'un simple test et que cela ne veut pas d que je suis incompétent(e) en tout.

_____ 27. Je ne me sens pas vraiment affligé(e) par les erreurs des autres, j'essaie de les traiter manière constructive.

_____ 28. J'ai appris à mes dépends que la plupart des gens ne sont pas dignes de confiance.

_____ 29. Face à une nouvelle situation, j'ai tendance à penser que cela tournera au plus mal.

ICI

Lisez chaque assertion et indiquez dans l'espace vide ce que serait votre position, sentiment ou comportement normal, habituel :

A = Rarement (dans moins de 10 % des cas)
B = Occasionnellement (dans environ 30% des cas)
C = Quelque fois (presque la moitié du temps)
D = Fréquemment (dans environ 70% des cas)
E = Habituellement (dans plus de 90% des cas)

Il y a, bien entendu, toujours des situations exceptionnelles, où cela ne s'appliquerait pas, mais pensez à ce que vous feriez ou penseriez dans la plupart des cas.
Écrivez la lettre qui décrit votre position ou comportement dans l'espace pourvu à cet effet sur la feuille de réponses.

1. Quand je suis confronté(e) à un problème, j'essaie _____ de l'oublier.
2. J'ai _____ besoin d'être fréquemment encouragé(e) par les autres pour continuer un travail difficile.
3. J'aime _____ le style de travail qui me permet de prendre des décisions et d'être autonome.
4. Je change _____ d'avis quand une personne que j'admire n'est pas d'accord avec moi.
5. Si je veux quelque chose, je travaille ____ dur pour l'obtenir.
6. Je préfère _____ apprendre quelque chose de quelqu'un d'autre plutôt que d'avoir à rechercher l'information par moi-même.
7. Je vais _____ accepter un travail qui me demande de superviser d'autres personnes.
8. J'ai _____ du mal à dire non quand quelqu'un essaie de me vendre quelque chose dont je ne veux pas.
9. J'aime _____ avoir mon mot à dire, quel que soit le groupe dans lequel je me trouve.
10. Je considère _____ les différents aspects d'une question avant de prendre une décision.
11. L'opinion des autres a _____ une grande influence sur mon comportement.
12. Chaque fois que quelque chose de bien m'arrive, j'ai _____ le sentiment de l'avoir mérité.
13. J'aime _____ être en position de leader.
14. J'ai _____ besoin que quelqu'un fasse l'éloge de mon travail avant de pouvoir moi-même en être satisfait(e).

A = Rarement (dans moins de 10 % des cas)
B = Occasionnellement (dans environ 30% des cas)
C = Quelque fois (presque la moitié du temps)
D = Fréquemment (dans environ 70% des cas)
E = Habituellement (dans plus de 90% des cas)

15. Je suis _____ suffisamment sûr(e) de ce que je pense pour pouvoir essayer d'influencer les autres.
16. Quand quelque chose va avoir une incidence sur moi, j' apprends _____ le maximum à ce sujet.
17. Je décide _____ d'agir sur un coup de tête.
18. Pour moi, savoir que j'ai bien fait quelque chose est _____ plus important que de recevoir des éloges de quelqu'un d'autre.
19. Je me laisse _____ déborder par les requêtes des autres, ce qui m'empêche de faire ce que j'ai à faire.
20. Je reste _____ sur mes positions quand quelqu'un n'est pas d'accord avec moi.
21. Je fais _____ ce je que j'ai envie et non ce que les autres pensent que je devrais faire.
22. Je me décourage _____ quand j'entreprends quelque chose de longue haleine.
23. En groupe, je préfère _____ laisser les autres prendre toutes les décisions.
24. Quand j'ai un problème, je suis _____ les conseils de mes amis ou de ma famille.
25. J'ai _____ plus de plaisir à entreprendre quelque chose de difficile que de facile.
26. Je préfère _____ les situations dans lesquelles je dépends des compétences de quelqu'un d'autre.
27. Que quelqu'un d'important me dise que j'ai fait du bon travail est _____ plus important que de le ressentir personnellement.
28. Quand je suis impliqué(e) dans quelque chose, j' essaie _____ d'obtenir le maximum d'informations sur ce qu'il se passe même si une autre personne est responsable du projet.

SIBS

De quelle façon adhérez-vous aux assertions suivantes? Merci d’entourer votre réponse.

	Tout à fait d’accord	**D’accord**	**Moyen-nement d’accord**	**Neutre**	**Pas tout à fait d’accord**	**Pas d’accord**	**Pas du tout d’accord**
1. Je garde du temps pour la méditation et/ou l'introspection.	7	6	5	4	3	2	1
2. Je trouve un sens aux épreuves.	7	6	5	4	3	2	1
3. On peut se réaliser sans avoir de vie spirituelle active.	7	6	5	4	3	2	1
4. Je trouve la sérénité en acceptant les choses telles qu’elles sont.	7	6	5	4	3	2	1
5. Certaines expériences ne peuvent être comprises qu’à travers nos croyances spirituelles.	7	6	5	4	3	2	1
6. Je ne crois pas en une vie post-mortem.	7	6	5	4	3	2	1
7. Une force spirituelle influence les événements de ma vie.	7	6	5	4	3	2	1
8. J’ai une relation avec quelqu'un vers qui je peux me tourner si j’ai besoin de conseil d’ordre spirituel.	7	6	5	4	3	2	1
9. Les prières ne changent pas réellement le cours des événements.	7	6	5	4	3	2	1
10. Participer à des événements d’ordre spirituel m’aident à pardonner les autres.	7	6	5	4	3	2	1
11. Je trouve la paix intérieure quand je suis en harmonie avec la nature.	7	6	5	4	3	2	1
12. Tous les événements ont un but plus élevé.	7	6	5	4	3	2	1
13. La contemplation me sert à me relier à mon être véritable.	7	6	5	4	3	2	1

	Tout à fait d'accord	D'accord	Moyennement d'accord	Neutre	Pas tout à fait d'accord	Pas d'accord	Pas du tout d'accord
14. Les possessions matérielles ne m'apportent pas ce que m'apporte ma vie spirituelle .	7	6	5	4	3	2	1
15. Je me sens rarement en connexion avec quelque chose qui m'est supérieur.	7	6	5	4	3	2	1
16. Quand je suis désespéré(e), je trouve peu de raisons d'espérer.	7	6	5	4	3	2	1
17. Quand je suis malade, je voudrais que les autres prient pour moi.	7	6	5	4	3	2	1
18. J'ai une relation personnelle avec une puissance qui m'est supérieure.	7	6	5	4	3	2	1
19. J'ai fait une expérience spirituelle qui a considérablement transformé ma vie.	7	6	5	4	3	2	1
20. Quand j'aide les autres, je n'attends rien en retour.	7	6	5	4	3	2	1
21. Je ne prends pas le temps d'apprécier la nature.	7	6	5	4	3	2	1
22. Je dépends d'une puissance supérieure.	7	6	5	4	3	2	1
23. J'ai de la joie dans ma vie grâce à ma spiritualité.	7	6	5	4	3	2	1
24. Ma relation avec une puissance supérieure m'aide à aimer les autres de façon plus complète.	7	6	5	4	3	2	1
25. Les écrits d'ordre spirituel enrichissent ma vie.	7	6	5	4	3	2	1
26. J'ai expérimenté l'apaisement après la prière.	7	6	5	4	3	2	1
27. Ma compréhension spirituelle continue à se développer.	7	6	5	4	3	2	1
28. J'ai plus souvent raison que la	7	6	5	4	3	2	1

plupart des gens.

	Tout à fait d'accord	D'accord	Moyen-nement d'accord	Neutre	Pas tout à fait d'accord	Pas d'accord	Pas du tout d'accord
29. Nombre d'approches spirituelles ont peu de valeur.	7	6	5	4	3	2	1
30. La santé spirituelle contribue à la santé physique.	7	6	5	4	3	2	1
31. J'interviens régulièrement avec d'autres à des fins spirituelles.	7	6	5	4	3	2	1
32. Je focalise sur ce qui doit être changé en moi et non sur ce qui doit être changé chez les autres.	7	6	5	4	3	2	1
33. Dans les moments difficiles, je continue à être reconnaissant(e).	7	6	5	4	3	2	1
34. J'ai traversé une période d'intense souffrance qui a accentué ma spiritualité.	7	6	5	4	3	2	1

Indiquez à quelle fréquence vous faites ce qui suit :

	Toujours	Presque toujours	Géné-ralement	Parfois	Généra-lement pas	Presque jamais	Jamais
35. Quand je fais du tort à quelqu'un, je fais l'effort de m'excuser.	7	6	5	4	3	2	1
36. J'accepte les autres tels qu'ils sont.	7	6	5	4	3	2	1
37. Je résous mes problèmes sans avoir recours à la spiritualité.	7	6	5	4	3	2	1
38. J'examine mes actes pour voir s'ils sont en accord avec mes valeurs.	7	6	5	4	3	2	1

39. Quel degré de spiritualité vous attribuez-vous? (Le chiffre 7 représente le degré de spiritualité le plus élevé.)

1 2 3 4 5 6 7

SSQ

Nous aimerions connaître l'état de vos relations, en ce moment, entre les personnes qui vous entourent - amants, amis, membres de votre famille... - et vous. Entourez votre réponse pour indiquer la réponse qui décrit au mieux le climat de vos relations au cours du mois dernier.

Le mois dernier...

	Jamais	Rarement	Parfois	Fréquemment	Tout le temps
1. Avez-vous eu le sentiment que les personnes qui vous entourent vous ont déçu en ne vous témoignant pas autant d'amour et d'attention que vous auriez aimé?	0	1	2	3	4
2. Les personnes qui vous entourent vous ont-elles vraiment tapé sur les nerfs?	0	1	2	3	4
3. Les personnes qui vous entourent vous ont-elles donné le sentiment de vous respecter?	0	1	2	3	4
4. Avez-vous eu le sentiment d'être aimé(e) et désiré(e)?	0	1	2	3	4
5. Vous êtes-vous senti(e) isolé(e)?	0	1	2	3	4
6. Avez-vous eu le sentiment que personne ne vous connaissait vraiment bien?	0	1	2	3	4
7. Avez-vous eu le sentiment de faire partie d'un groupe d'amis?	0	1	2	3	4
8. Vous êtes-vous senti tendu(e) à la suite de disputes ou de désaccords avec les personnes qui vous entourent?	0	1	2	3	4
9. Avez-vous éprouvé de l'irritation ou de la rancune envers les personnes qui vous entourent?	0	1	2	3	4
10. Avez-vous souhaité avoir davantage d'amis?	0	1	2	3	4
11. Avez-vous fait bande à part?	0	1	2	3	4
12. Avez-vous eu le sentiment que les personnes qui vous entourent ne vous comprenaient pas?	0	1	2	3	4

Viennent maintenant des questions pour évaluer dans quelle mesure les gens seraient disposés à vous aider à faire face à des problèmes ou des situations potentiels.

	Absolument pas	Probablement pas	Peut-être	Probablement	Absolument
13. Y aurait-il quelqu'un pour vous aider à vous occuper de vous si vous étiez cloué(e) au lit plusieurs semaines?	0	1	2	3	4
14. Y a-t-il quelqu'un vers qui vous pourriez vous tourner pour emprunter 10 $, vous emmener chez le médecin ou pour vous rendre un petit service tout de suite?	0	1	2	3	4
15. Y a-t-il quelqu'un vers qui vous pourriez vous tourner pour emprunter de toute urgence quelques centaines de dollars?	0	1	2	3	4
16. Les personnes qui vous entourent auraient-elles des renseignements, des suggestions, des conseils pour vous concernant ce qui tourne autour du VIH, du sida, si vous en aviez besoin?	0	1	2	3	4
17. Y aurait-il quelqu'un de prêt à vous parler des problèmes liés au VIH ou au sida si vous étiez en colère, nerveux(se) ou déprimé(e)?	0	1	2	3	4
18. Auriez-vous quelqu'un vers qui vous tourner si vous aviez besoin de conseils pour vous aider à prendre une décision?	0	1	2	3	4
19. Pourriez-vous contacter quelqu'un si vous vouliez parler d'un problème important vous concernant?	0	1	2	3	4
20. Y a-t-il quelqu'un dans votre entourage à qui vous pouvez vous confier ou parler de vous ou des problèmes liés au VIH ou au sida, si vous le voulez?	0	1	2	3	4
21. Les personnes qui vous entourent approuvent-elles votre façon d'agir?	0	1	2	3	4
22. Les personnes qui vous entourent vous donnent-elles l'impression qu'il est normal de ressentir ce que vous ressentez?	0	1	2	3	4
23. Les personnes qui vous entourent ont-elles tendance à appréhender les choses et les gens de la même façon que vous?	0	1	2	3	4

PSR

Nous aimerions avoir des renseignements sur vos relations avec les autres personnes. Lisez chaque assertion ci-dessous et indiquez de quelle façon elle vous décrit. Pour chaque assertion, mettez à gauche le chiffre qui décrit le mieux vos sentiments. Les chiffres représentent les réponses suivantes:

1 = Me correspond très bien
2 = Me correspond bien
3 = Me correspond quelque peu
4 = Ne me correspond pas beaucoup
5 = Ne me correspond pas du tout

_____ 1. Quand je suis avec mes amis, je me sens tout à fait capable de me détendre et d'être moi-même.

_____ 2. J'ai la même approche de la vie que bon nombre de mes amis.

_____ 3. Les personnes qui me connaissent me font confiance et me respectent.

_____ 4. Quoi qu'il arrive, je sais que ma famille sera toujours là pour moi si j'ai besoin d'elle.

_____ 5. Quand je veux sortir faire quelque chose, je sais que bon nombre de mes amis seront contents de se joindre à moi.

_____ 6. J'ai au moins un ami à qui je pourrais tout dire.

_____ 7. Parfois, je ne suis pas sûr(e) de pouvoir entièrement compter sur ma famille.

_____ 8. Les personnes qui me connaissent pensent que je suis compétent(e) dans mon domaine.

_____ 9. Je me sens très proche de certains amis.

_____ 10. Les membres de ma famille ont confiance en moi.

_____ 11. Ma famille me fait savoir que je suis une personne digne d'intérêt.

_____ 12. Les membres de ma famille m'aident à résoudre mes problèmes.

_____ 13. Mes amis prendraient le temps de discuter de mes problèmes si je le souhaitais.

_____ 14. Je sais que ma famille sera toujours à mes côtés.

_____ 15. Je me sens seul(e), même en compagnie de mes amis.

IES

La liste ci-dessous contient des commentaires faits par des gens aprés des événements traumatisants. Pour chaque énoncé, veuillez encercler le chiffre qui décrit le mieux la fréquence à laquelle vous avez vécu chacune de ces réactions au cours des **7 DERNIERS JOURS.**

1 = Jamais
2 = Rarement
3 = Quelques fois
4 = Souvent

1.	J'ai pensé à cet événement lorsque je ne le voulais pas.	1	2	3	4
2.	J'ai évité de devenir troublé(e) lorsque j'ai pensé à cet événement ou lorsque quelque chose me le rappelait.	1	2	3	4
3.	J'ai tenté de sortir cet événement de ma mémoire.	1	2	3	4
4.	J'ai eu de la difficulté à m'endormir ou à demeurer endormi(e).	1	2	3	4
5.	J'ai eu des sentiments intenses face à cet événement.	1	2	3	4
6.	J'ai rêvé à cet événement.	1	2	3	4
7.	Je suis demeuré(e) à l'écart de ce qui pouvait me rappeler cet événement.	1	2	3	4
8.	J'ai eu l'impression que cet événement n'était jamais arrivé ou n'était pas réel.	1	2	3	4
9.	J'ai essayé de ne pas parler de cet événement.	1	2	3	4
10.	Des images de cet événement se sont imposées à mon esprit.	1	2	3	4
11.	D'autres choses continuaient à me faire penser à cet événement.	1	2	3	4
12.	J'étais conscient(e) que j'avais beaucoup d'émotions par rapport à cet événement, mais je ne m'en suis pas occupé(e).	1	2	3	4
13.	J'ai essayé de ne pas penser à cet événement.	1	2	3	4
14.	Tout ce qui me rappelait cet événement a suscité chez moi des émotions face à cet événement.	1	2	3	4
15.	Mes émotions par rapport à cet événement étaient comme engourdies.	1	2	3	4

Inventaire de Beck

Ceci est un questionnaire contenant plusieurs groupes de phrases. Pour chacun de ces groupes lisez attentivement **TOUTES** les phrases. Choisissez la phrase qui décrit le mieux comment vous vous sentez **CETTE SEMAINE, Y COMPRIS AUJOURD'HUI.** Encerclez le numéro à côté de la phrase choisie. Si plusieurs phrases conviennent aussi bien, encerclez chaque phrase qui convient. Prenez soin de lire toutes les phrases dans chaque groupe avant de choisir.

1 0 Je ne me sens pas triste.
1 Je me sens morose ou triste.
2 Je suis morose ou triste tout le temps et je ne peux pas me remettre d'aplomb
3 Je suis tellement triste ou malheureux(se) que je ne peux plus le supporter.

2 0 Je ne suis pas particulièrement pessimiste ou découragé(e) à propos du futur.
1 Je me sens découragé(e) à propos du futur.
2 Je sens que je n'ai rien à attendre du futur.
3 Je sens que le futur est sans espoir et que les choses ne peuvent pas s'améliorer.

3 0 Je ne sens pas que je suis un échec.
1 Je sens que j'ai échoué plus que la moyenne des gens.
2 Quand je pense à ma vie passée, je ne peux voir rien d'autre qu'un grand nombre d'échecs.
3 Je sens que je suis un échec complet en tant que personne (parent, conjoint(e)).

4 0 Je ne suis pas particulièrement mécontent(e).
1 Je ne prends pas plaisir aux choses comme auparavant.
2 Je n'obtiens plus de satisfaction de quoi que ce soit.
3 Je suis mécontent(e) de tout.

5 0 Je ne me sens pas particulièrement coupable.
1 Je me sens souvent coupable.
2 Je me sens coupable presque tout le temps.
3 Je me sens coupable tout le temps.

6 0 Je n'ai pas l'impression d'être puni(e).
1 J'ai l'impression que quelque chose de malheureux peut m'arriver.
2 Je sens que je suis ou serai puni(e).
3 Je sens que je mérite d'être puni(e).

7 0 Je ne me sens pas déçu(e) de moi-même.
1 Je suis déçu(e) de moi-même.
2 Je suis dégoûté(e) de moi-même.
3 Je me hais.

8 0 Je ne sens pas que je suis pire que les autres.
1 Je me critique pour mes faiblesses et mes erreurs.
2 Je me blâme pour mes fautes.
3 Je me blâme pour tout ce qui arrive de mal.

9 0 Je n'ai aucune idée de me faire du mal.
1 J'ai des idées de me faire du mal mais je ne les mettrais pas à exécution.
2 Je sens que je serais mieux mort(e).
3 Je me tuerais si je le pouvais.

10 0 Je ne pleure pas plus que d'habitude.
1 Je pleure plus maintenant qu'auparavant.
2 Je pleure tout le temps, maintenant. Je ne peux pas m'arrêter.
3 Auparavant, j'étais capable de pleurer mais maintenant je ne peux pas pleurer du tout, même si je le veux.

11 0 Je ne suis pas plus irrité(e) maintenant que je le suis d'habitude.
1 Je deviens contrarié(e) ou irrité(e) plus facilement maintenant qu'en temps ordinaire.
2 Je me sens irrité(e) tout le temps.
3 Je ne suis plus irrité(e) du tout par les choses qui m'irritent habituellement.

12 0 Je n'ai pas perdu intérêt aux autres.
1 Je suis moins intéressé(e) aux autres maintenant qu'auparavant.
2 J'ai perdu la plupart de mon intérêt pour les autres et j'ai peu de sentiment pour eux.
3 J'ai perdu tout mon intérêt pour les autres et je ne me soucie pas du tout d'eux.

13 0 Je prends des décisions aussi bien que jamais.
1 J'essaie de remettre à plus tard mes décisions.
2 J'ai beaucoup de difficultés à prendre des décisions.
3 Je ne suis pas du tout capable de prendre des décisions.

14 0 Je n'ai pas l'impression de paraître pire qu'auparavant.
1 Je m'inquiète de paraître vieux (vieille) et sans attrait.
2 Je sens qu'il y a des changements permanents dans mon apparence et que ces changements me font paraître sans attraits.
3 Je me sens laid(e) et répugnant(e).

15 0 Je peux travailler pratiquement aussi bien qu'avant.
1 J'ai besoin de faire des effort supplémentaires pour commencer à faire quelque chose.
2 J'ai besoin de me pousser très fort pour faire quoi que ce soit.
3 Je ne peux faire aucun travail.

16 0 Je peux dormir aussi bien que d'habitude.
1 Je me réveille plus fatigué(e) le matin que d'habitude.
2 Je me réveille 1-2 heures plus tôt que d'habitude et j'ai de la difficulté à me rendormir.
3 Je me réveille tôt chaque jour et je ne peux dormir plus de 5 heures.

17 0 Je ne suis pas plus fatigué(e) que d'habitude.
1 Je me fatigue plus facilement qu'avant.
2 Je me fatigue à faire quoi que ce soit.
3 Je suis trop fatigué(e) pour faire quoi que ce soit

18 0 Mon appétit est aussi bon que d'habitude
1 Mon appétit n'est pas aussi bon que d'habitude
2 Mon appétit est beaucoup moins bon maintenant.
3 Je n'ai plus d'appétit du tout.

19 0 Je n'ai pas perdu beaucoup de poids (si j'en ai vraiment perdu) dernièrement.
1 J'ai perdu plus de 5 livres.
2 J'ai perdu plus de 10 livres.
3 J'ai perdu plus de 15 livres.

20 0 Je ne suis pas plus préoccupé(e) de ma santé que d'habitude.
1 Je suis préoccupé(e) par des maux et des douleurs, ou des problèmes de digestion ou de constipation.
2 Je suis tellement préoccupé(e) par ce que je ressens ou comment je me sens qu'il est difficile pour moi de penser à autre chose.
3 Je pense seulement à ce que je ressens ou comment je me sens.

21 0 Je n'ai noté aucun changement récent dans mon intérêt pour le sexe.
1 Je suis moins intéressé(e) par le sexe qu'auparavant.
2 Je suis beaucoup moins intéressé(e) par le sexe maintenant.
3 J'ai complètement perdu mon intérêt pour le sexe.

SRGS

Utilisez l'échelle suivante pour répondre aux questions concernant la mort d'un être cher:

0 = Pas du tout
1 = Un peu
2 = Dans une certaine mesure
3 = Beaucoup
4 = Énormément

En raison de la mort d'un être cher...

_____ 1. J'ai appris à être plus gentil(le) avec les autres.

_____ 2. Je me sens plus libre de prendre mes propres décisions.

_____ 3. J'ai appris que je possédais un élément de valeur à apporter aux autres concernant la vie.

_____ 4. J'ai appris à être moi-même et non celui (celle) que les autres veulent que je sois.

_____ 5. J'ai appris à affronter les problèmes au lieu d'abandonner.

_____ 6. J'ai appris à trouver plus de sens à la vie.

_____ 7. J'ai appris à tendre la main et à aider les autres.

_____ 8. J'ai appris à avoir davantage confiance en moi.

_____ 9. J'ai appris à mieux écouter les autres.

_____ 10. J'ai appris à être ouvert(e) aux nouvelles idées et informations.

_____ 11. J'ai appris à communiquer plus honnêtement avec les autres.

_____ 12. J'ai appris que je voulais avoir de l'impact sur le monde.

_____ 13. J'ai appris que c'était une bonne chose de demander de l'aide.

_____ 14. J'ai appris à défendre mes droits.

_____ 15. J'ai appris qu'il y avait davantage de personnes qui se souciaient de moi que je ne le pensais.

PTGI

Pour chacune des assertions ci-dessous, indiquez de quelle façon le changement intervenu dans votre vie est dû à la crise que vous avez traversée (la mort d'un être cher), en utilisant l'échelle suivante:

0 = Ce changement n'est pas dû à la crise que j'ai traversée.
1 = Ce changement n'est dû à la crise que j'ai traversée que dans <u>une très faible mesure</u>.
2 = Ce changement n'est que <u>faiblement</u> dû à la crise que j'ai traversée.
3 = Ce changement n'est dû que <u>modérément</u> à la crise que j'ai traversée.
4 = Ce changement est dû <u>en grande partie</u> à la crise que j'ai traversée.
5 = Ce changement est <u>très largement</u> dû à la crise que j'ai traversée.

_____ 1. Mes priorités ont changé.
_____ 2. Je suis plus enclin(e) à changer ce qui doit l'être.
_____ 3. J'apprécie mieux la valeur de ma vie.
_____ 4. Je compte davantage sur moi.
_____ 5. Je comprends mieux ce qui a trait à la spiritualité.
_____ 6. Je me rends mieux compte que je peux compter sur les autres en cas de problème.
_____ 7. Je me sens plus proche des autres.
_____ 8. Je sais davantage que je peux faire face aux difficultés.
_____ 9. J'exprime plus volontiers mes émotions.
_____ 10. J'accepte plus facilement la tournure que prennent les événements.
_____ 11. J'apprécie davantage le présent.
_____ 12. J'ai davantage de compassion pour les autres.
_____ 13. Je suis capable de faire de meilleures choses dans ma vie.
_____ 14. De nouvelles opportunités sont apparues, ce qui n'aurait pas été le cas auparavant.
_____ 15. Je fais davantage d'efforts dans mes relations.
_____ 16. Ma foi s'est renforcée.
_____ 17. J'ai découvert que j'étais plus fort(e) que je ne le pensais.
_____ 18. J'ai appris à quel point les gens peuvent être merveilleux.
_____ 19. J'ai de nouveaux centres d'intérêt.
_____ 20. J'accepte mieux d'avoir besoin des autres.
_____ 21. J'ai donné une nouvelle orientation à ma vie.

Appendix Seven

Interview Schedule

Demographic Information
- age
- employment
- education
- sexual orientation
- HIV-status
- How many friends and family have they lost to HIV/AIDS?

Description of Caregiving Experience
- relationship to the deceased person
- Would you tell me about [care recipient]?

How have you been changed by the experience of caregiving and bereavement?
What has helped you to recover?
What has not helped?
Did you and do you have support from family and friends?
Does spirituality help you in any way?
Is there anything about yourself that you believe helped or hindered the process?

Appendix Eight

Wilfrid Laurier University
Informed Consent Statement

Exploring the Experience of AIDS Caregivers
Investigator: Susan Cadell
Advisor: Cheryl Regehr

You are invited to participate in a research study. The purpose of this study is to better understand how the lives of bereaved AIDS caregivers are changed by their experiences. For each person who has died there are many left behind to grieve. Caring for or about someone in the context of AIDS is stressful. The stigma associated with AIDS and the common aspect of having lost many friends, acquaintances and family to HIV disease makes the situation traumatic. There are many possible reactions to bereavement, but it is always difficult.

This study is designed to help us understand the experience of bereaved caregivers and what helps them to recover in the best possible way. This knowledge will help us to design better programs to help anyone who has lost someone and others going through similar experiences.

Information

Since you indicated on the earlier questionnaire that you were willing to be contacted for a follow-up interview in person, you are now invited to be interviewed. If you agree to this, an interview of approximately two hours with Susan Cadell will be audio-taped.

Risks

As this study asks about a difficult period of my life, you may become upset. If this happens, you can contact Susan Cadell who will provide you with a list of resources available to HIV/AIDS caregivers.

Benefits

This study is designed to increase our understanding of how people recover from the trauma of losing someone that they care for and to help us in

____
participant's initials

planning programs. In this sense, you will not benefit immediately by participating in this study. However you may find that these questions cause you to reflect on a difficult period of your life and realize how this has impacted on you in a positive way.

Confidentiality

The information collected is used only for this research project and your participation is confidential. The tapes are kept in a locked place at the university and are used only by Susan Cadell. The final report contains no names or other identification.

Compensation

For participating in this study, you will find enclosed a cheque for $20.00. If you decide not to continue with the study, you do not have to return the money.

Contact

If you have any questions at any time about the study or the procedures, or you experience adverse effects as a result of participating in this study, you may contact the researcher, Susan Cadell, at the Faculty of Social Work, Wilfrid Laurier University, and 1-877-673-8371 or her advisor, Dr. Cheryl Regehr at (416) 978-6314. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Linda Parker, Assistant Dean of Graduate Studies and Research, Wilfrid Laurier University, 884-0710, extension 3126.

Participation

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw form the study before data collection is completed the tape will be returned to you or destroyed.

Consent

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature__________________________Date____________

Investigator's signature__________________________Date____________